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## STRUCTURAL ANALYSIS OF SOCIAL REPRESENTATIONS ON AIDS AMONG PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS

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### ABSTRACT

**Objective:** was to identify the social representations structure about AIDS among people with Human Immunodeficiency virus.

**Method:** this is a descriptive research, based on the Central Core Theory of social representations. A free association test of words among 231 adults in antiretroviral therapy was applied. *Software Ensemble de programmes permettant l'analyse des evocations* – EVOC2000® processed the evocations, generating a chart corresponding to the probable representation structure.

**Results:** the elements disease, sadness, fear, death and transmission integrated the central nucleus. The peripheral system constituted itself more frequently by: prejudice, medicine and treatment, in the first periphery; difficult, preservative and healing, in the second periphery; bad, prevention and normal in the contrast zone. The central perceptions revealed shared elements since the onset of the infection.

**Conclusion:** the peripheral system pointed to the need for continuous effort to coping with society and negative feelings, until they reach a cure.

**DESCRIPTORS:** Acquired immunodeficiency syndrome. HIV. Knowledge, attitudes and practices in health. Perception. Nursing.

## ANÁLISE ESTRUTURAL DAS REPRESENTAÇÕES SOCIAIS SOBRE A AIDS ENTRE PESSOAS QUE VIVEM COM VÍRUS DA IMUNODEFICIÊNCIA HUMANA

### RESUMO

**Objetivo:** identificar a estrutura das representações sociais sobre a aids entre pessoas com Vírus da Imunodeficiência Humana.

**Método:** pesquisa descritiva, fundamentada pela Teoria do Núcleo Central das representações sociais. Aplicou-se um teste de associação livre de palavras com, entre 231 adultos em terapia antirretroviral. As evocações foram processadas com o *software Ensemble de programmes permettant l'analyse des evocations* – EVOC2000®, que gerou um quadro correspondente à provável estrutura da representação.

**Resultados:** o núcleo central foi integrado pelos elementos doença, tristeza, medo, morte e transmissão. O sistema periférico constituiu-se em maior frequência por: preconceito, remédio e tratamento, na primeira periferia; difícil, preservativo e cura, na segunda periferia; ruim, prevenção e normal, na zona de contraste.

**Conclusão:** as percepções centrais revelaram elementos compartilhados desde o surgimento da infecção. O sistema periférico apontou a necessidade de esforço contínuo para o enfrentamento da sociedade e sentimentos negativos, até que alcancem a cura.

**DESCRIPTORIOS:** Síndrome de imunodeficiência adquirida. HIV. Conhecimentos, atitudes e práticas em saúde. Percepção. Enfermagem.

# ANÁLISIS ESTRUCTURAL DE LAS REPRESENTACIONES SOCIALES SOBRE EL SIDA ENTRE PERSONAS QUE VIVEN CON VIRUS DE LA INMUNODEFICIENCIA HUMANA

## RESUMEN

**Objetivo:** identificar la estructura de las representaciones sociales sobre el SIDA entre personas con Virus de la inmunodeficiencia humana.

**Método:** investigación descriptiva, fundamentada en la Teoría del Núcleo Central de las representaciones sociales. Se aplicó un test de asociación libre de palabras entre 231 adultos en terapia antiretroviral. Las evocaciones fueron procesadas en el software *Ensemble de programmes permettant l'analyse des evocations* - EVOC2000® que generó un cuadro correspondiente a la probable estructura de la representación.

**Resultados:** el núcleo central fue integrado por los elementos enfermedad, tristeza, miedo, muerte y transmisión. El sistema periférico se constituyó en mayor frecuencia por prejuicio, remedio y tratamiento, en la primera periferia: difícil, preservativo y cura, en la segunda periferia: malo, prevención y normal, en la zona de contraste.

**Conclusión:** las percepciones centrales revelaron elementos compartido desde el surgimiento de la infección. El sistema periférico apuntó la necesidad de esfuerzo continuo para el enfrentamiento de la sociedad y sentimientos negativos, hasta que alcancen la cura.

**DESCRIPTORES:** Síndrome de inmunodeficiencia adquirido. VIH. Conocimientos, actitudes y práctica en salud. Percepción. Enfermería.

## INTRODUCTION

Human Immunodeficiency Virus (HIV) infection and Acquired Immunodeficiency Syndrome (AIDS) are clinical conditions that generate multidimensional impacts on the lives of those affected because they involve social stigma, no cure and require lifelong treatment. They are often in a context permeated by uncertainties regarding the infection dynamics, the diagnosis impact and therapy in everyday life, with repercussions that constitute a privileged space for the elaboration of representations.<sup>1</sup>

In Brazil, AIDS was initially characterized as a disease infiltrated in big cities, which mainly affected people of higher socioeconomic classes, belonging to the cultural milieu or restricted to neglected and excluded social groups such as homosexuals, sex workers and injecting drug users. Between 2000 and 2012, there was a change of paradigm and distinct peculiarities, in view of its internalization, pauperization, feminization and heterosexualization, starting to affect people not considered belonging to vulnerable groups such as monogamous women, children and the elderly.<sup>2-3</sup>

These epidemiological and social changes of epidemic show their strong dynamism and the vulnerability of the population to the disease. Together with the advances in treatment, significant improvement in quality and life expectancy of those infected, these issues contributed to new perceptions of society about pathology over time<sup>4-5</sup>. In this context of constructing meanings, opinions, beliefs and attitudes as to the seropositivity, it is relevant to understand the social representations about the disease, as well as their influence on the daily experiences of infected individuals.

Social representations work as a system of interpretation of reality that establishes the relations of individuals with their physical and social environment, determining their behaviors and practices, as well as a set of anticipations and expectations. They are part of the system of ordinary knowledge of individuals, understood by a set of beliefs, images, metaphors and symbols, with their own cultural significance surviving independently from individual experiences.<sup>6-7</sup> Thus, this study aimed to identify the elements and structure of social representations about AIDS among people living with HIV.

## METHODS

This is a descriptive study, with a qualitative approach, which had as theoretical-methodological support the Central Core Theory, considering that the simple content determination is not enough for the recognition and specification of a representation; it is essential the identification of its organization and evidence of structures for a better understanding of social representations.<sup>6</sup>

It is a cut of the research entitled "Social representations on antiretroviral therapy and its repercussions on the therapeutic adherence of people with HIV/AIDS", developed by the Postgraduate Program in Clinical Care in Nursing and Health of the State University of Ceará (UECE), approved by the Research Ethics Committee of the UECE, number 630,908.

Data collection occurred from July to December 2014, at the Specialized Ambulatory Service of a reference hospital in infectious diseases in Fortaleza, Ceará, and 231 adults diagnosed with HIV/AIDS on antiretroviral therapy for at least six months participated in the study.

An interview was conducted for initial application of a Free Association Test (FAT), with inducer stimulus "HIV/AIDS", seeking to obtain up to four evocations of each participant. The importance of each word was in accordance with the order of evocation, and so the first readily mentioned word was considered the most significant for the structure of social representations, in comparison to the terms mentioned later. Then, a semi-structured form investigated the socioeconomic and clinical profile. Eight individuals interviewed who were unable to respond to FAT due to lack of understanding of the technique were excluded.

For the structural analysis of the free evocations a table was elaborated, using the *software Ensemble de programm permettant l'analyse des evocations - EVOC2000®*. This software organizes the representational elements into a four-box chart, according to the frequency of the mentioned terms and the average order of evocations (AOE), graphically demonstrating the words belonging to the central nucleus and the peripheral system of social representations<sup>8</sup>. Table 1 describes the prototypical structure of the social representations and organization of the elements in the four-box frame, in the central and peripheral system (contrast zone, first and second peripheries).

**Table 1 - Description<sup>9</sup> and organization of the structural components of social representation in the four-box chart**

<p style="text-align: center;"><b>Central core</b></p> <p>It includes the evocations that had high frequency and low average order of evocations (AOE), that is, a greater number of subjects and in the first positions mentioned them. It presents the important function of providing organization and meaning to the representation.</p>	<p style="text-align: center;"><b>First periphery</b></p> <p>Terms with high frequency evocations, but which are shown in the last positions (high AOE).</p>
<p style="text-align: center;"><b>Contrast zone</b></p> <p>Consisting of low frequency evocations, but which are shown in the first positions (low AOE). It may suggest one or more subgroups and the existence of contrast of ideas between small and large group.</p>	<p style="text-align: center;"><b>Second periphery</b></p> <p>Formed by terms mentioned by a small number of subjects and still in the last positions (high AOE).</p>

The evocations were further processed with the *software IRAMUTEQ® (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires)*, version 0.7 alpha 2, which allowed similarity analysis and maximum tree construction, showing how the elements that make up social representations about HIV/AIDS infection are interconnected.

## RESULTS

Among the 231 participants, there was predominance of individuals: male (131; 56.7%); self-declared mulatto (152; 65.8%); of Catholic religion (128; 55.4%); residents of Fortaleza (171; 74.0); with individual income of up to one minimum wage (166; 71.8%); who had been living with HIV/AIDS for at

least 10 years (114; 49.3%). Age ranged from 18 to 59 years, with a mean of 41.4 years (SD=±8.7), with a large sample proportion concentrated in the 40-49 age group (96; 41.6%).

The inducer stimulus "HIV/AIDS" originated a universe of 906 evocations that, after being treated and analyzed, constituted 167 different terms. The minimum frequency of evocation calculated by the *software EVOC®* for the appearance of terms in the four-box chart was seven evocations, the intermediate frequency was 19 and the average general rang was 2.5. Only 34 terms were part of the social representation structure about the HIV infection and AIDS of the interviewed individuals, generating the four-box chart illustrated in table 2.

**Table 2 - Social representation structure of HIV/AIDS of people with HIV. Fortaleza, CE, Brazil, 2014**

Central core			First periphery		
Frequency $\geq 19$		Rang $< 2.5$	Frequency $\geq 19$		Rang $\geq 2.5$
Words	Freq.	Rang	Words	Freq.	Rang
Disease	86	1.291	Care	27	2.630
Fear	23	2.435	Discrimination	22	3.136
Death	44	2.341	Prejudice	43	2.535
Transmission	29	2.414	Medicine	40	2.875
Sadness	29	2.138	No cure	19	2.526
			Treatment	42	2.548
			Living	22	3.318
Contrast zone			Second periphery		
Frequency $\geq 19$		Rang $< 2.5$	Frequency $\geq 19$		Rang $\geq 2.5$
Words	Freq.	Rang	Words	Freq.	Rang
Struggle	7	2.000	Distress	7	2.571
Normal	11	2.273	Cure	12	3.917
Other-people	7	2.286	Depression	10	2.900
Dangerous	8	2.250	Difficult	15	2.600
Concern	7	1.857	Hope	12	2.917
Prevention	13	2.385	Strength	7	2.571
Problem	7	2.286	Limitation	8	2.750
Bad	17	2.118	Preservative	14	2.714
Symptoms	8	2.000	Loneliness	7	3.143
Suffering	9	2.333	Trauma	7	2.857
Overcoming	8	2.375			
Virus	9	1.556			

The upper left quarter suggests a central core composed of negative elements, defining AIDS as a "disease" that generates feelings of "sadness" and "fear," closeness to "death" and that can be transmitted to other people ("transmission"), becoming the guiding principles of the whole representation.<sup>6</sup>

Close to the central core, protecting it from changes, are the elements of the first periphery, bringing terms such as "prejudice", "discrimination" and "no cure", which strengthen the aforementioned main feelings that arise in the face of the disease, in addition to the perception of scientific advances and available technologies, such as treat-

ment, medicine and care, which make "living" possible, despite the discomfort brought by the disease.

In the second periphery were the weakest elements for the organization of social representations, determination of attitudes and behaviors in the face of HIV/AIDS, being more easily demonstrated for adaptations to common situations, interfering with less strength than the other structural zones. The most frequently mentioned elements referred to the difficulty of living with the infection ("difficult", "preservative", "depression", "limitation", "distress", "loneliness", "trauma"), which coexist with feeling of "hope" and the possibility of the outbreak of "cure".



Another element of the central core within the four-box chart was “fear”, which was linked, as evidenced in the maximum tree, to the possibility of experiencing “prejudice”, to the “doubts” regarding the “consequences” and prognosis of infection, but faced by “faith” and “hope” of overcoming adversities.

The second term with the highest number of connections (nine) was “prejudice”. In the structural analysis, it appeared in the first periphery of the representation, being the more mentioned third term. Therefore, it is a probable centralizing and organizing character of HIV/AIDS representation. It was associated with feelings of “fear” and “sadness”, strengthening the concepts of a “difficult” and “bad” disease, and the need to “hide” the diagnosis as a way to avoid experiencing social “prejudice”. The “lack of knowledge” about HIV/AIDS was a strengthening aspect of persistent prejudice in society.

“Treatment” was the fourth term in frequency of evocations and the third in number of co-occurrences, obtaining seven connections, which point to AIDS as a “disease” that has “treatment” and requires greater “care”, requiring regularity in “consultations” and “feeding” to improve and maintain “health”.

The term “medicine” was the fourth in frequency of evocations, with four co-occurrences, indicating the possibility of life (“living”), even in the face of diagnosis, through the need for daily “struggle” and “strength” to overcome side effects and changes in routine, resulting from an Infection that still has no cure.

## DISCUSSION

The representations about AIDS that this study revealed have subtle differences constructed by the participants, through the coping with their health context, as a carrier of a chronic disease, which makes it possible to approach them as protagonists in their therapeutic course and as a center of nursing care. Looking at the problem under the structural approach of social representations,<sup>6</sup> it implies recognizing the diversity of factors that influence living with HIV/AIDS, considering the importance that the involved subjects attribute to these factors, to the point that they interfere in decisions about their health.

Based on the central core theory assumptions, the centrality of the terms “disease”, “fear”, “death” and “sadness” was observed in the analysis of the

social representations, which are coexistent both in prototypical and similarity analysis. However, the maximum tree still points as central terms the words “prejudice”, “treatment”, and “medicine” which, in turn, are part of the first periphery zone of the four-box chart.

It was found that the constituent terms of the central core have an affective dimension,<sup>10</sup> such as “fear” and “sadness”, and linked to the information dimension<sup>11</sup> as “disease”, “transmission” and “death”. These dimensions unfold in the other quarters of the four-box chart. Accordingly, terms such as “suffering”, “distress”, “depression”, “hope” and “loneliness” embody the affective dimension, while “medicine”, “treatment”, “virus” and “preservative” translate the information dimension. In addition, attitudes and behaviors were identified, translated only by contrast or peripheral elements, such as “struggle”, “care” and “prevention”.

The information dimension portrays the social representations formed from the knowledge acquired over time, by the individual, on a given subject, since it is a form of socially elaborated knowledge, shared, and that assists in the construction of a common reality.<sup>11</sup>

It should be noted that representations are understood as variants of social thought, which is also mediated by an “affective” dimension. Thus, affection is not restricted to subjective private life, since the emotions experienced during collective interaction also influence the construction of representations.<sup>10</sup> For example, the central term “disease”, even though based on the knowledge acquired by the individual about the pathology, in the similarity analysis, is strongly connected with elements connected in affective dimensions, such as “depression”, “anger”, “shame” and “trauma”.

The continuous experience of a whirlwind of contradictory emotions is very common among individuals living with AIDS, interfering with their worldview from the moment of diagnosis and, consequently, their representations about the pathology.<sup>12</sup> In this perspective, a significant portion of people living with AIDS presents depressive symptomatology, characterized by profound “sadness”, and this condition interferes with treatment and is more prevalent and severe among women<sup>13</sup>. Feelings of “anger” may be related to guilt felt by the individual to have contracted a disease characterized by being avoidable and often resulting from deviant sexual behavior, causing “shame” before

their closest people and even regret of impulsive and unthinking acts.<sup>12,14</sup>

There was negativism in the terms that make up the central core in common to the representations generated by the analyzes. In the context of structural analysis, "disease" stood out as the lowest order term of evocation and highest frequency, demonstrating its strong salience in the context of this analysis. Moreover, it has a connection with several other terms in the similarity analysis, making it the most central element of the representation and, therefore, organizes a significant part of the cognitive elements related to AIDS.

The direct connection of the term "disease" with words such as "virus", "treatment", "medicine", "preservative" and "no cure" evidences connection in two fundamental aspects of the pathology. Firstly, in the biomedical aspect, given that AIDS is a type of pathology transmitted by the HIV virus that attacks the body's immune system. Thus, people living with AIDS demand continuous "treatment" with specific antiretroviral "medicine" that reduce morbidity and mortality, improve quality and life expectancy without, however, eradicating the infection, since it has no cure.<sup>15</sup> Its connection with the term "preservative" shows anchorage in preventive aspects of representation, since this barrier method is one of the main ways of preventing HIV virus transmission and other sexually transmitted infections.<sup>16</sup>

"Death", the second most mentioned word, presented in the analysis of similarity, connection with the terms "disease", "suffering", "hospitalization", "fragility" and "child". Such a representation shows that AIDS is a "disease" that causes intense physical and psychological "suffering" to the individual who lives with it, leading to their "hospitalization" because of the opportunistic diseases installed in the body and that attack their immune system, leaving him fragile.<sup>15,17</sup>

Although deaths caused by AIDS have declined in 2013, 1.5 million people have died worldwide due to this pathology,<sup>18</sup> which may contribute to the representation of AIDS as a synonym for "death." This is a good fact illustration, since most of the participants, when they became aware of the diagnosis, referred to great "suffering" and negative feelings of accelerated closeness of finitude because of the representation of "death", intrinsically linked to HIV infection.<sup>12</sup>

It should be noted that "death" also presented a connection with the term "child", evidencing that the fear of dying is associated not only with its

symbolic proximity, but also with the family and children's helplessness, which are the targets of significant concern. Thus, the seropositive individuals see in their offspring a reason to continue living and a source of strengths for such an attempt, even if upon receiving the diagnosis they feel like surrendering to the disease<sup>12</sup>. Thus, the representation of "death" is overcome to emphasize the representation of life and survival.<sup>19</sup>

"Fear" and "sadness", elements that are part of the central core of the structural analysis of evocations and similarity, had a strong connection with the term "prejudice". This demonstrates the fear that individuals have to be discriminated because of their seropositivity, which can cause significant distress.<sup>20-21</sup> A research has shown that fear of rejection was a strong feeling among participants when they referred to AIDS, since the disease is still considered as threatening, worrying and frightening due to its incurable nature.<sup>22</sup>

In turn, "prejudice" had connection with the lexicon "difficult," "did not want," "hide" and "lack of knowledge." Experiencing an incurable disease is already understood as an arduous and painful process, since maintaining life depends on the use of various medications that have significant side effects.<sup>19</sup> When society "prejudice" joins the painful disease daily life experience, facing it becomes even more "difficult" and fatiguing.<sup>20</sup>

The study found that HIV-positive people do not feel fully accepted by society because AIDS is often anchored in the perception of at-risk social groups, among them homosexuals, drug users and promiscuous people. Thus, society can perceive AIDS as a "punishment that the person deserved," because of their deviant behavior, morally unacceptable<sup>22</sup>. This stigmatizing view may be the result of "lack of knowledge" or insufficient knowledge about the pathology transmission, in view of the fact that there is other forms of contamination other than sexual contamination.<sup>16</sup>

Because of "prejudice," people living with HIV eventually "hide" the diagnosis as a means of social survival in order to live a normal life and even maintain their friendships and jobs without being discriminated.<sup>19</sup> In a research on the experiences of men living with HIV/AIDS in the workplace, some of the respondents resigned for fear of having their seropositivity discovered and others were fired due to prejudice or gave up looking for work for fear of being submitted to HIV testing at the time of admission. The authors also concluded that the participants strongly feared the possibility of suf-

fering prejudice from colleagues if the disease were discovered.<sup>21-22</sup>

The lexicon "treatment" was linked to the terms "consultation", "care", "cohabiting", "feeding" and "conforming", once again showing the "attitude/behavior" dimension to therapy. After HIV diagnosis, the individual needs to adapt to a new lifestyle and adhere to antiretroviral therapy on an ongoing basis, with the aim of avoiding illness that, in turn, can lead to death. For this, attitudes of commitment, willingness and interest in caring for oneself, regular consultation with the multidisciplinary health team as well as physical exercises and eating well are essential<sup>15</sup>. The connection with "cohabiting" and "conforming" demonstrates attitudes of resignation, in which the seropositive people are lead to accept their condition so that they can "cohabit" with the disease and its consequent "treatment", for the rest of their life or until the cure is discovered.

The structural configuration of the social representation of AIDS is also characterized by the vision of the chronicity of the disease<sup>23</sup>, and includes, in the first periphery zone, positive meanings and normative elements of coping with the pathology, such as "care", "treatment", "medicine" and "living". These symbolic constructions reaffirmed the contrast zone by the lexicons "struggle", "prevention" and "overcoming". It is also worth noting the consolidated displacement of the positive symbolism of the disease to the second periphery of representation, with the incorporation of elements related to optimistic feelings of "cure", "hope" and "strength".

This configuration demonstrates the coexistence of contradictory representational perspectives on AIDS, since for some it may be synonymous of "death", "distress", and "sadness", whereas for other individuals, there can be an optimistic and "overcoming" view faced with the adversities imposed by the disease.<sup>24</sup> The positive perception of AIDS can be explained by the fact that the seropositive person perceives, in a progressive way, that death is not imminent; however, it becomes inevitable to live with a disease with no cure. After a first moment of distress with the impact of the diagnosis news, life can then be resignified and begin to acquire some sense capable of transforming the hitherto pessimistic feelings towards themselves and the people around.<sup>12</sup>

Another contradictory aspect found relates to the connection of the central element "disease" with the terms "no cure" and "cure". The link sug-

gests that the participants have relative knowledge about the pathology and understand AIDS in a realistic way, as a disease that can be controlled with treatment, however, without promoting full recovery. On the other hand, the weaker connection with the word "cure" evidences the expectation of some subjects about a possible discovery of the cure of AIDS, strengthened by the current scientific advances. It should also be pointed out that in the four-box chart context, the term "no cure" lies in the first periphery zone, with a median border (2.53), while "cure" is in the area of the second periphery, therefore, the most significant representation of the first element.

## CONCLUSION

The limitations of the study originate from the research be developed in a single reference care center for people with HIV/AIDS, among others that exist in the city of the study, which expresses a reality based on the subjectivity of a delimited group, making it impossible to generalize the data.

The representational elements involved contents related to descriptive conceptions, linked to AIDS, to the biological, psychological and social impacts of the infection, to acquired knowledge and ways of coping with health, demonstrating the complexity of factors that permeate living with this infection.

The probable centrality of the terms "disease", "fear", "death" and "sadness" was observed, both coexisting in structural analysis and similarity analysis. Although participants consider the possibility of life through antiretroviral treatment, these main conceptions about infection refer to common sense, shared since the epidemic began, evidencing the stable representation character over the years.

However, the similarity analysis also showed the terms "prejudice", "treatment" and "medicine" as central terms, which in turn are part of the first periphery zone of the four-box chart. Treatment as a whole and medication are essential for the quality of life and the attainment of a life expectancy similar to that of the general population; however, they make visible a disease impregnated with strong social prejudice. The peripheral system, by emphasizing terms such as "cohabiting", "conforming", "care", "cure", "struggle", "overcoming" and "strength" suggested that living with infection requires continuous effort to coping with society and various negative personal feelings, which is difficult for



many, but makes life possible in an optimistic way, until healing is achieved.

The social representations of AIDS are fundamental for the planning of alternative care forms that extend beyond the biomedical dimension, covering the psychosocial aspects that constitute the being. In this context, specialized and continuous nursing care, inserted in a multidisciplinary team, becomes essential for the strengthening of more elaborate coping mechanisms among people living with HIV.

The research points to the need for clarification on issues that involve social prejudice in the face of HIV infection and AIDS, since the combat remains a necessity that must be included in the planning of health services activities.

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