

## Social representations of death held by people living with HIV/AIDS

*Representações sociais da morte para pessoas que vivem com HIV/AIDS*

*Representaciones sociales de la muerte para personas que viven con VIH/SIDA*

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### ABSTRACT

**Objective:** to describe the content and organization of social representations of death in people living with HIV/AIDS. **Method:** in this qualitative, descriptive study based on Social Representation Theory, the participants were 165 people living with HIV/AIDS, in treatment at a referral outpatient clinic in Rio de Janeiro city. The research ethics committee approved the study. A four-box chart was set up using Evoc software. **Results:** indicate an emotional dimension and knowledge of representations of death as a multifaceted object with diverse meanings and varied feelings, pointing to a naturalization of death. **Conclusion:** even though death does contain negative representations for people with HIV/AIDS, due to feelings of sadness, fear and pain, government policy strategies and prevention and treatment measures for controlling the disease point in new directions, in view of the syndrome's timeframe, resulting in representations that overlap in the meaning of life, of living and of dying as a natural process.

**Descriptors:** Nursing; HIV; acquired immunodeficiency syndrome; death.

### RESUMO

**Objetivo:** descrever os conteúdos e a organização das representações sociais da morte para pessoas que vivem com HIV/AIDS. **Método:** estudo descritivo, de abordagem qualitativa, e delineado por meio da Teoria das Representações Sociais. Participaram 165 pessoas vivendo com HIV/AIDS, em tratamento no ambulatório de referência na cidade do Rio de Janeiro. Projeto aprovado por Comitê de Ética em Pesquisa. Utilizou-se o *software* Evoc, ao final construiu-se o quadro de quatro casas. **Resultados:** abalizam uma dimensão emocional e do conhecimento das representações da morte, como um objeto multifacetado com diversos significados e variados sentimentos, apontando para a naturalização da morte. **Conclusão:** ainda que a morte contenha uma representação negativa, em pessoas com HIV/AIDS, pelos sentimentos ligados à tristeza, medo e dor, as estratégias políticas e governamentais, medidas de prevenção e tratamento no controle da doença delineiam uma nova direção, diante da cronicidade da síndrome, resultando em representações imbricadas no sentido da vida, do viver e do morrer como processo natural.

**Descritores:** Enfermagem; HIV; síndrome da imunodeficiência adquirida; morte.

### RESUMEN

**Objetivo:** describir los contenidos y la organización de las representaciones sociales de la muerte respecto a las personas que viven con VIH-SIDA. **Método:** estudio descriptivo, con enfoque cualitativo, basado en la teoría de las representaciones sociales. Participaron 165 personas, que viven con VIH-SIDA, en tratamiento en una clínica ambulatoria de referencia en Río de Janeiro. El proyecto fue aprobado por el Comité de Ética. Usando el *software* Evoc, se construyó un marco de cuatro elementos. **Resultados:** indican una dimensión emocional y el conocimiento de las representaciones de la muerte como un objeto multifacético con varios significados y sentimientos, que apuntan hacia la naturalización de la muerte. **Conclusión:** aunque la muerte contenga una representación negativa para las personas con VIH-SIDA, debido a sentimientos relacionados con la tristeza, el miedo y el dolor, las estrategias políticas y gubernamentales, medidas de prevención y tratamiento en el control de la enfermedad delinean una nueva dirección, ante la cronicidad del síndrome, que condujo a representaciones imbricadas en el sentido de la vida, de vivir y de morir como un proceso natural.

**Descritores:** Enfermería; VIH; síndrome de inmunodeficiencia adquirida; muerte.

## INTRODUCTION

Death is part of human development, signifying and re-signifying life<sup>1</sup>. People living with human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) have for a long time presented their representations based on the collective imaginary of AIDS as a death sentence. The structure of the representations is based on beliefs pointing out the negative aspects and feelings for the syndrome that had repercussions as a synonym of death<sup>2</sup>.

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<sup>VI</sup>Thanks to the Nurse Doctor Érick Igor dos Santos, *in memoriam*, for his collaboration in this research and for his brief and intense life dedicated to nursing.

However, advances in the treatment of infection with the incorporation of antiretroviral therapy in association with prevention have resulted in important improvements in the survival of people living with HIV, resulting in the reduction of morbidity and mortality<sup>2-4</sup>.

The reduction of AIDS mortality in the country, with rates that are evenly balanced nationally, shows important progress in some Brazilian states. In the last 10 years in Brazil, it has gone from 6.0 deaths per 100,000 inhabitants in 2005 to 5.7 in 2014, representing a decrease of 5%<sup>5</sup>. And although it is a global health problem, in many countries the number of new HIV infections continues to decline, with a decline of 75% in 10 countries and by over 50% in 27 countries; in Latin America there was a decline in new infections of 3% between 2005 and 2013<sup>6</sup>. The decline in mortality favors the transference of negative expectations to positive, as AIDS changes from the condition of acute and fatal disease, synonymous with death and becomes a chronic disease, and as such evolves as a natural process<sup>7</sup>.

In view of the foregoing, the purpose of this study was to describe the contents and organization of social representations of death for people living with HIV.

## LITERATURE REVIEW

Death is a biological phenomenon that integrates the natural cycle of life, and points to the finitude of the human being, which marks the intrapsychic aspects<sup>1</sup>. For death is a question only for the human, so it has been the object of artistic production, of poets, musicians, romanticized with great works; in the production of the illustrious painters who left their records on the way to see the death<sup>1,8</sup>. It is important to consider it as a phenomenon not only biological but also individual, as well as social, whose psychological, philosophical, religious, ethical, historical, cultural and juridical aspects must be considered insofar as they are fundamental for human being to face with dignity its distressing limit<sup>2</sup>.

To die, as well as to be born, is a natural consequence of life, for which all human beings will have to spend one day<sup>8</sup>. And, even for man, it is very difficult to internalize and coexist with the feeling of the finitude itself<sup>8,9</sup>. And looking at AIDS leads you to reflect on death, and this can shape your impotence in the control of your life<sup>1</sup>, putting it before the incomplete and the unfinished.

In Western society, not only is it avoided to speak, to live and to think of death as a natural thing, but, above all, to avoid talking about the process of dying and the causes of death<sup>1,2,8-10</sup>. Therefore, one can consider the fear of death as the fear of the unknown and the helplessness at the end of life<sup>11</sup>. The consciousness of death makes life matter; therefore, its possibility transforms the way one lives life<sup>12</sup>. Thus, he walks, accepting death as the natural process of existence.

## METHOD

This is a descriptive study, with a qualitative approach and delineated through the Theory of Social Representations in its structural approach<sup>3,7,13-17</sup>. The research was carried out between March and October 2015 in a public institution, reference for outpatient treatment to people living with HIV, located in the city of Rio de Janeiro, Brazil.

The sociodemographic data for characterization of the group were collected by questionnaire and the contents of the representation through the technique of free evocations to the term inductor death. It is worth noting that the sociodemographic characterization of the participants is not analyzed in the present study.

The sample for convenience was defined considering all the users served in said unit, without losing sight of the minimum number of subjects necessary for the retrieval of representations in the structural approach of the theory<sup>3,7,13-15</sup>. Thus, 165 people living with HIV were effectively enrolled, with criteria for inclusion - age greater than 18 years, with no borderline age group and at least 6 months of diagnosis. The proposed exclusion criterion considered the presence of cognitive or communication limitations that made the data collection unfeasible.

In compliance with the provisions of Resolution No. 466 of December 12, 2012, of the National Health Council / Ministry of Health, the study project was submitted to the Human Research Ethics Committee (CEPq) of the State University of Rio de Janeiro of January (UERJ), and was approved by opinion no. 699,220.

The data coming from the questionnaire were recorded in an *Excel worksheet* and analyzed by descriptive statistics. The contents of the free evocation were analyzed by the technique of the Four Sports Square, using the *Ensemble des programmes permettant l'analyse de evocations* (EVOC), version 2005 software. The *software* calculated

and reported the simple occurrence frequency of each evoked word, the mean occurrence of each word in evocation order, and the mean weighted average order of the set of terms evoked<sup>3,7,16</sup>.

At the end, a four-frame picture was produced where the terms located in the upper left quadrant correspond to the possible central elements of the representation, comprising the contents probably more significant from the perspective of the study participants. The elements located in the lower left quadrant constitute the contrast zone of the representation, which are elements of low frequency and low mean order of recall, i.e., are readily evoked. Already in the upper right quadrant are the elements that have high frequency, although they are less readily evoked. In the lower right quadrant are the less frequent and less readily evoked second-periphery elements, which are the most peripheral and farthest elements of the representation nucleus<sup>3,7</sup>.

According to the Central Nucleus Theory (TNC), the four-house framework is divided into two distinct systems: one central and the other peripheral. The former attributes stability, organization and meaning to the identified representation and the peripheral system is flexible, integrates new information into the structure of representation, protects the central core, and is more focused on practice and concrete situations. The terms that meet at the same time the criteria of more frequent and more readily evoked ones have greater importance in the social thought of the participants, being the probable members of the central nucleus of the representation<sup>3</sup>.

After the completion of this technique, we analyzed the contents of four houses in order to identify the degree of connectivity between them in order to give an indication of the centrality of certain elements.

## RESULTS

### The representational structure of death for people living with HIV

For the term *death* 645 words were invoked, among which 244 were different. The minimum frequency defined was 8, with words less frequent than this being excluded. The calculated average frequency of the remaining terms was 14, based on Zipf's Law. The mean recall order (OME) was 2.6 on a scale of 1 to 5. From these parameters, the four-house framework was established, as shown in Figure 1.

O.M.E.		< 2.6		≥ 2.6		
Average frequency	Evoked term	Freq.	O.M.E.	Evoked term	Freq.	O.M.E.
≥ 14	sadness	32	2.563	another life	21	2.667
	fear	28	1.929	rest	20	2.600
	end	21	2.333			
< 14	natural	13	1.846	God	13	3.308
	no fear	13	1.769	missing	13	2.846
	passage	13	2.154	pain	12	2.917
	loss	12	2.167	peace	11	2.727
	suffering	10	2.500	fresh start	10	2.900
	mission	8	2.500	ended	10	2.700
				acceptance	10	3.100

FIGURE 1: Frame of four houses at the term inductor death. Municipality of Rio de Janeiro, Brazil, 2015.

The upper left quadrant is formed by possibly central elements, which in this study are: *sadness*, *fear* and *end*, which indicate a strong emotional and knowledge dimension, and, therefore, presents a normative character. In the context of the TNC, the normative character is linked to the value system of the investigated group; functional character already favors in the representation and constitution of the central nucleus more important elements for the accomplishment and justification of a task, that is, elements linked to an action, which are not evidenced in this quadrant<sup>7,15</sup>.

The words *sadness* and *fear* are possibly from the morbid entity of AIDS in its most extreme physical repercussions, namely death. Death, in the context of AIDS, is threatening and, therefore, arouses negative feelings in the social group.

Thus, despite the negative attitude of the group towards the death object, the word *end* enunciates an attempt of conceptual approximation to the object of representation to incorporate it into the psycho-social universe of the participants. This emotional dimension, therefore, aims to rationalize the emotional dimension pointed out previously to establish it in the subjectivity of the social group, thus provoking a tension between the two representational dimensions.

It is important to note that the words that compose the probable central nucleus have a frequency much higher than the calculated cutoff point, which is 14. This characteristic points to a high recurrence of these words among the members of the group when requested to evoke the first five words or expressions that occurred to them after hearing the term inducer death. It reinforces the idea of emotional dimension present in the depiction of death for people living with HIV. In this context, the term fear is what has the smallest OME standing out as one of the most readily evoked words in the entire representational structure.

The lower left quadrant, also called the contrast zone, is the second most important in the structure of representation according to the TNC, reinforcing the central elements or indicating the presence of a subgroup. In this quadrant were identified the words *natural, non-fear, passage, loss, suffering* and *mission*. The terms *loss* and *suffering* seem to reinforce the emotional dimension of representation in its probable core. On the other hand, the terms *natural, passage* and *mission* suggest the reinforcement of the dimension of knowledge previously highlighted in the probable central nucleus of representation and the existence of a group psychosocial effort to appropriate a highly abstract object such as death. In this sense, faced with the threat of death in their daily living with seropositivity or the development of the syndrome, the study participants are pressured to inference, perceiving themselves in the task of re-signifying death to better coexist with the idea of their proximity.

Still in the contrast zone, the expression *non-fear* may be tied to a possible subgroup whose representation of death does not belong to the general group.

In the first periphery, located in the upper right quadrant, are the evocations *other-life* and *rest*, which reinforce the inference of a certain rationality in the representational structure. It is observed that the meaning of death for the investigated group may be linked to another existence beyond the present life, existence capable of promoting resting to the tribulations of living with HIV. This inference gains strength by virtue of the evocation *passage* in the contrast zone, which reiterates the procedural character of death for the investigated group.

In the lower right quadrant, or second periphery, are the words or expressions not so important to the group about the object of representation or are reflecting the life context of that group. In it are the terms *God, missing, pain, peace, restart, finish* and *acceptance*. The term *God* expresses an imaginary dimension of representation based on the divine figure. The terms *longing* and *pain* reinforce the affectivity of the probable central nucleus, justifying the evocation of the terms *fear* and *sadness* in the upper left quadrant. *Peace, restart* and *finish* express the products of finitude of life for the group and are imbricated in the rationalization of the process of dying. *Acceptance* enunciates a practical dimension of representation that, even if it is situated more peripherally in the representational structure, leads one to believe that the participants are, in fact, under strong pressure to inference and thus feel obliged to accept the future process of death in view of its inevitability.

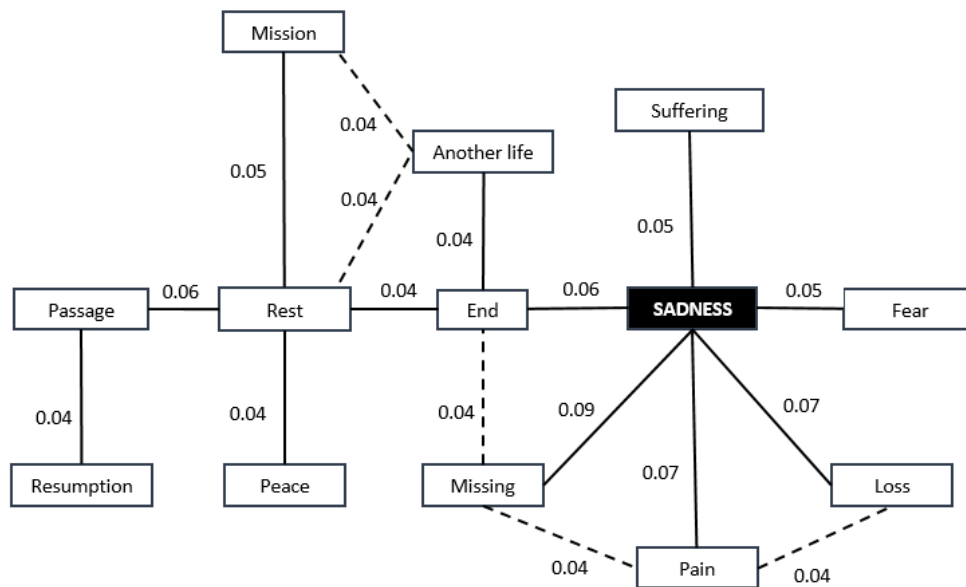
It can be seen in the representational structure that the central system has a higher negative content while the existing positive content elements make up the peripheral system of representation.

### **Analysis of the connectivity of elements of social representation of death for people living with HIV / AIDS**

In certain contexts, some of the elements that make up the peripheral system may have centrality because of their high frequencies. To refute or reiterate this hypothesis, we proceeded to the analysis of similarity of the terms that composed the representational structure, as shown in Figure 2.

The cognition that most established connections in the maximal tree was *sadness*, already indicated as central in the frame of four houses, followed by *rest*, which, in the structural analysis, is in the first periphery. In view of the possibility that connectivity may be considered as a criterion for the indication of centrality<sup>16</sup>, these lexicons can be considered, by hypothesis, as belonging to the central nucleus of the representation.

It is noted that cognition *sadness* maintains connection with more negative elements, such as *fear, loss, pain, missing, end* and *suffering*, a characteristic that confirms the negative content of the representation. *Rest*, on the other hand, shows a high index of similarity with the *passage* cognitions *mission, peace* and *end*, which indicates that this is the meaning attributed to death by people living with HIV in the knowledge dimension of representation.



**FIGURE 2:** Maximum tree of the similarity analysis of social representations of death for people living with HIV/AIDS. Rio de Janeiro, Brazil, 2015.

## DISCUSSION

The study points out as the probable cognitions that are part of the central nucleus of representation, the terms *sadness* and *rest* which, respectively, constitute an emotional dimension and knowledge, reflected in all quarters. Participants construct representations and concept of death through the experience lived and shared throughout their lives. For those living with HIV, even with scientific progress in the battle against the virus, the appearance of symptoms and worsening of the disease, added to the prospect of death, reflect intensely on their expectations of life<sup>1-2</sup>.

The words *rest* and *end* expressing the same meanings, from the structural analysis, and in an attempt to conceptual approximation of the group investigated here, are conditioned by the social representations historically anchored in the social construction of AIDS, which has, since its origin, the relationship with suffering and the finitude<sup>18</sup>.

Death, in this study, is represented as a strong and intense multifaceted object that needs several definitions and, thus, is tied to several emotions. And although it has a predominantly negative representation, the evocation of the terms *non-fear* and *natural*, in this study, point to the naturalization of the process of death as something proper to the human being, also represented in a positive way to signify the phenomenon. These findings also allow us to infer the occurrence of a process of change in the representation of AIDS, for the more positive sense brought about by the displacement of this element from its centrality. HIV infection no longer represents a death sentence, since it is now possible to live healthy and asymptomatic for many years<sup>2,3</sup>.

From this perspective, from death as a multifaceted object, the dimension of knowledge in the terms *natural*, *passage* and *mission*; their generating potential and organizer in representation, described around this highly abstract. Death is an occurrence not easily described and depends on how each one apprehends it. Because the question transcends natural and biological aspects, which makes a single term difficult to translate, and is implicated in the experiences / experiences of each individual<sup>2,9</sup>.

The elements that present themselves are anchored with the belief linked to the conception of AIDS that, previously, in the collective popular imagination, was associated with death. Representations on AIDS are reproduced throughout the socio-historical process of these more than 30 years of illness and perpetuated through communication in the daily lives of individuals.

Cognitions *rest*, *another life* and *passage*, which are at the periphery of the structure of representation, reinforce the term, *end* present in the probable central core, evidencing more positive ways of signifying death, reflecting a more spiritual dimension, and in turn qualifying it as a *natural*, therefore, without provoking fear (non-fear), but rather the *restart*, which point to the belief of death as *mission*, in the sense of translating life as a learning to live<sup>19</sup>.

The change in the coping way of death, evoked as *natural* and it seems to be one of the elements that, although it is established in the peripheral system of these representations, already directs towards the structuring of death in people with HIV, in the very evocation of *acceptance* of the biological finitude of human existence. Death is no longer considered failure, because it is part of life, it is an event that has to live<sup>20</sup>.

These findings also allow us to infer the occurrence of a process of change in the representation of AIDS in the most positive sense brought about by the displacement of this probable element of its centrality<sup>3</sup>. Such a change would occur, above all, by the alignment of the cognition death of the organizing elements of these social representations in the daily life of the participants of this study, in which the peripheral systems emerge for the introduction of other representation of death, revealed by stability and better control gives disease that goes from its acute and fatal condition to the chronic and, as such, naturalized with the follow-up of life<sup>14</sup>. It is presented, then, in its multifaceted nomads like *restart, peace and passage*.

The emotional dimension was present in all quarters, and in feelings about death, cognition *sadness* is the one that maintains more connections with other terms, all of which are negative, such as *fear, loss, pain, suffering* and *missing*, configuring in this particular part of the negative content of the representation. Being sick with AIDS can bring to man the awareness of his finitude, generating suffering and pain. However, these feelings of suffering and loss are attributed to the fact that man does not accept death his challenge is to try to overcome it, seeking immortality<sup>1,9,20</sup>.

Death is seen as impregnated with emotions linked to sadness, loneliness and pain<sup>1,2,4,21</sup>, represents an element loaded with psychic suffering, of the person living with HIV, especially by the chronological aspect.

In addition to antiretroviral treatment, today's society has been developing strategies for coping, bringing together not only people living with HIV, but civil society in its various representations that mobilize and are represented for universal access to prevention, treatment, attention and support in the fight against HIV<sup>22</sup>.

Men's attitudes towards death are reflections of society, temporality and culture of which they are a part<sup>22</sup>. In this sense, the negative feelings about death presented by men may be imbricated by the cultural system in which they are inserted<sup>10</sup>.

In Western society, not only does one avoid talking, living and thinking about death as a natural thing, but above all, one avoids talking about the process of dying and the causes of death<sup>1,2,8,10-12</sup>.

The fear of death, although it is a common feeling in people, is accentuated in some individuals when faced with the disease. There is a kind of anguish about the certainty of death, a fear of dying when faced with the disease and its consequences<sup>2,23</sup>.

The relationship between these terms suggests that the death element of the person living with HIV would be related to the *end* and resigns it, as the clarity of the finitude of man, at the close of life, for all will die. Then, to die is the indisputable fact of every human being, meaning death as the final stage of human growth<sup>21</sup>, bringing representations in which the spiritual or philosophical conception signifies death as part of the existence of man<sup>14</sup>.

The facing of death, which mobilizes so many affections and meanings, refers to the understanding of the elements that define it. From the social representations of the participants of this research, with their various meanings and varied feelings, linked to sadness suffering, pain and fear, although they present the idea of an end, in the description in *rest, passage, peace, non-fear and natural*, point to the naturalization of death in people with HIV and, as a human being, who is going to die, resigning life from the awareness of his death<sup>24</sup>.

There is a need for group and individual dialogical approaches in the promotion and transformation of negative representational facets related to AIDS and in the approach of death as a natural process, re-signifying the existence itself from its representations, given their function as a guide for the action<sup>7,14,21,25,26</sup>.

## CONCLUSION

This study aimed to describe the contents and organization of social representations of death for people living with HIV. It was characterized as probable central system for the social representations of death the cognitions *sadness and rest*. The emotional dimension and knowledge, present in all the quadrants, have brought to the surface representations of death, presenting itself as a multifaceted object, which by its reflective character has several denominations, anchored in the meanings historically constructed by the normative elements that determine the taking position of this group. The cognitions *peace, restart and acceptance* express the fruits of finitude of life for the group and are imbricated in the rationalization of the process of dying. It expresses a practical dimension of representation to accept the future process of death in the face of its inevitability.

The process of death and dying, like other phenomena of social and public life, can be lived in different ways, according to the historical moment and the sociocultural contexts. Death, the companion of man through all phases of life, becomes implied with the way of seeing and living in the world. And, the world of people living with HIV, in this study points a new direction, facing the chronicity of the syndrome, resulting in imbricated representations in the sense of life, living and dying as a natural process.

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