

## HEALTH PROFESSIONALS TALK MORE ABOUT CARE THAN ABOUT ACQUIRED IMMUNODEFICIENCY SYNDROME\*

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**ABSTRACT:** This study aimed to apprehend the social representations elaborated by health professionals on the acquired immunodeficiency syndrome and care to people living with the human immunodeficiency virus through comparison of the diversity and rarity indexes. This is a multi-method study, based on the Theory of Social Representations, involving 73 health professionals, in four specialized services units, in the city of Salvador, Bahia, in 2015. Data was collected with the use of the free word association test (processing was made with EVOC software) and calculation of centrality degrees. 'Prejudice and death "are the nucleus of the representation of the acquired immunodeficiency syndrome, and "advice and care" constitute the nucleus of Care. It is concluded that the structuring elements of social representation denote the presence of value judgments, and the calculation of diversity and rarity indexes revealed that there was less sharing of evocations about the disease than about Care. **DESCRIPTORS:** Care; Acquired Immunodeficiency Syndrome; Health worker; Nursing; Semantics.

### PROFISSIONAIS DE SAÚDE FALAM MAIS SOBRE CUIDADO E MENOS SOBRE SÍNDROME DA IMUNODEFICIÊNCIA ADQUIRIDA

**RESUMO:** Objetivou-se apreender as representações sociais de profissionais de saúde sobre a síndrome da imunodeficiência adquirida e o cuidado às pessoas que vivem com vírus da imunodeficiência humana, comparando os índices de diversidade e de raridade. Trata-se de estudo multimétodos, aportado na Teoria das Representações Sociais, envolvendo 73 profissionais de saúde, em quatro unidades de serviços especializados, na cidade de Salvador-Bahia, em 2015. Os dados foram coletados mediante a aplicação da técnica de associação livre de palavras processadas no *software* EVOC e calculando os índices de centralidade. 'Preconceito e morte' constituem o núcleo central da representação da Síndrome da imunodeficiência adquirida, e 'aconselhamento e acolhimento' o de Cuidado. Conclui-se que os elementos estruturantes da representação social denotam a presença de juízos de valor, e o cálculo dos índices de diversidade e raridade revelou menor compartilhamento das evocações sobre a doença do que sobre o Cuidado. **DESCRIPTORIOS:** Assistência; Síndrome da Imunodeficiência Adquirida; Trabalhador da saúde; Enfermagem; Semântica.

### PROFESIONALES DE SALUD HABLAN MÁS ACERCA DEL CUIDADO Y MENOS ACERCA DEL SÍNDROME DE LA INMUNODEFICIENCIA ADQUIRIDA

**RESUMEN:** Estudio cuya finalidad fue apreender las representaciones sociales de profesionales de salud acerca del síndrome de la inmunodeficiencia adquirida y el cuidado con las personas que viven con el virus de la inmunodeficiencia humana, comparando los índices de diversidad y de raridad. Es un estudio multimétodos, con base en la Teoría de las Representaciones Sociales, de lo cual participaron 73 profesionales de salud, en cuatro unidades de servicios especializados, en la ciudad de Salvador, Bahia, en 2015. Los datos fueron obtenidos por medio de aplicación de la técnica de asociación libre de palabras procesadas en el *software* EVOC y calculándose los índices de centralidad. 'Prejuicio y muerte' constituyen el núcleo central de la representación del Síndrome de la inmunodeficiencia adquirida, y 'aconsejar y acoger', el de Cuidado. Se constata que los elementos estructurantes de la representación social apuntan la presencia de juicios de valor; el cálculo de los índices de diversidad y raridad reveló que se comparten menos informaciones y experiencias sobre la enfermedad que sobre el Cuidado. **DESCRIPTORIOS:** Asistencia; Síndrome de la Inmunodeficiencia Adquirida; Trabajador de la salud; Enfermería; Semántica.

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## ● INTRODUCTION

The Acquired Immunodeficiency Syndrome (AIDS), caused by the Human Immunodeficiency Virus (HIV), which emerged in the early 1980s, has been considered a unique epidemic, particularly because it did not follow normal patterns of disease and infection <sup>(1)</sup>.

Thirty years after the beginning of the epidemic and its impact on the world, AIDS is now characterized as a chronic disease <sup>(2)</sup>. This new view is justified by lower mortality rates and the higher survival rates of people living with HIV/AIDS (PLWHA), although dependence of antiretrovirals and their adverse effects may confer physical and psychological limitations. However, since interpretations of diseases are influenced by the time period and context, the concepts and meanings assigned to AIDS can change overtime.

Different periods in the history of HIV/AIDS in Brazil are interconnected with the broader history of the political life of the country <sup>(3)</sup>. In the beginning of the epidemic, in the 1980's, health professionals experienced a unique moment, in an atmosphere pervaded by fear, scientific ignorance and the omission of governmental authorities.

Contrasting with this initial phase, there was a second moment in the nursing care practice, when, in addition to the development of scientific knowledge and the active participation of Non-Governmental Organizations (NGOs), Brazil takes a leading political position, notably regarding coping with the epidemic: the enactment of Law 9.313/96 <sup>(4)</sup>, that ensured free and universal access to antiretroviral drugs to treat HIV/AIDS.

In the third decade of the epidemic, AIDS is characterized as a chronic disease, which requires a reformulation of the healthcare structure <sup>(5)</sup>. Health professionals need to discuss and attempt to provide answers to previously unexplored issues in health care, such as sexuality, loss, and death.

In this regard, since this approach provides the recognition of the intersubjective dimension, health clients should be perceived again in their integrality, as active subjects that participate in health actions. Therefore, the care environment should ensure active listening without value judgments about the clients.

The presumed visibility of the study objects - AIDS and Care - through the interpretation of social discourses becomes viable with the Theory of Social Representations (TSR), which allows understanding and discussing the underlying intentions of individual and collective actors, as well as beliefs, feelings and thoughts expressed by rational discourses <sup>(6)</sup>.

The TRS is considered a fertile field for studies related to the health-disease process, as it demonstrates the complexity of the relations between biological and psychosocial factors, by exploring the relationship between the reified and consensual universes. The reified universe is composed of scientific knowledge expressed by objectivity and logical and methodological rigor, and the second universe consists of consensual knowledge that emphasizes the activities of common sense. In this regard, it is important to investigate the social representations of health professionals who experienced care in specialized care units due to the high prevalence of AIDS in the world scenario, as well as the repercussions of specialized care on the quality of life of people living with HIV/AIDS.

The present study aimed to gain insight on the social representations of health professionals about the acquired immunodeficiency syndrome and the care provided to people living with the human immunodeficiency virus, by comparing diversity and rarity indexes.

## ● METHODOLOGY

It is a descriptive and analytical study, with a multi-methodological approach, based on the Theory of Social Representations. Social representation is a sort of "preparation for action" as it guides behaviors, remodels and reconstructs aspects of the environment, by providing the individuals with the necessary elements for their relationships <sup>(7)</sup>.

The TRS is defined as a set of coordinated concepts, arising from social practices and group differences, aimed to give meaning to social reality, produce identities, organize communications and guide conducts<sup>(8)</sup>. The representations consist in “a set of information, beliefs, opinions and attitudes related to a given social object”<sup>(9:13)</sup>.

In this study, the structural approach of social representations or Central Nucleus Theory (CNT) was used to provide insight not only on the representation of the content, but also on its structure and internal organization. This approach assumes that the elements of social representation are more prototypical, i.e. more accessible to consciousness<sup>(10)</sup>.

The Free Word Association Test (TALP) was used in data production based on the following inducing stimuli: HIV/AIDS and Care for individuals with HIV/AIDS. This test allows that the expressions of the subjects are construed not merely in terms of their intended meanings, but also in terms of a pre-established psychological concept<sup>(11)</sup>.

Seventy-three (73) health professionals (nurses, doctors, dentists, pharmacists, social workers, psychologists and occupational therapists) of the public health care network of four health services in Salvador, Bahia, participated in the study from December 2014 to March 2015. The health services selected are reference services in care for people living with HIV/AIDS.

The inclusion criteria were permanent attachment to the institution; health professional performing care activities in the period of data collection who has been working in the institution for at least one year to be able to elaborate social representations. The exclusion criterion was health professional on vacation/leave. The study was approved by the Research Ethics Committee of UFBA School of Nursing, under no 874,468, on November, 17, 2014.

The variables profession, training time and time of professional activity were used to characterize the participants for the creation of a database. The EVOC 2005 software was used to process the data of each corpus composed of the evocations of the subjects. This tool increases the validity of the study, as it allows transferring the results obtained to other studies, in the case of lexical analysis and similarities. It also allows the calculation of means and co-occurrence and construction of the box with 4 positions of evocations of the inducing terms, through which it is possible to discriminate the core and peripheral elements of the representation<sup>(12)</sup>.

The evoked responses grouped by semantic criteria, i.e. classified according to a common meaning were processed<sup>(11,13)</sup>. Subsequently, analysis with EVOC 2005 software was used to calculate the frequency and order of evocation of the words obtained. The average order of evocations (AOE) is the average of the order of the weighted averages of the set of evoked words. Thus, there is an AOE for each evocation shown in the box with four positions, in the representation of health professionals for the objects HIV/AIDS and Care.

In the third step, calculations and analysis of the diversity and rarity indexes were performed. The procedures were developed in France by Flament and Rouquette, for a general approach of evocations under the TRS<sup>(14)</sup>. These indices are based on three basic categories of data provided by the software RANGMOT EVOC: number of evocations (N), types (T) and Hepax (M), and allow performing the calculation of the significance test. Student t test was used for the stimuli ‘HIV/AIDS’ and ‘Care’.

The following information must be obtained with the RANGMOT software to perform the calculations: number (N) that refers to the total amount of information; Types (T) corresponding to the number of different evoked words; Hepax(H) that means words with frequency one<sup>(1)</sup> that increase the likelihood of heterogeneity of representation. Based on the indicators of rarity and diversity “information on the degree of social sharing of each object, its level of idiosyncrasy and community proportion between two corpora” is obtained<sup>(15:119)</sup>. This information contributes to a better understanding of the relationship professionals-object.

## ● RESULTS

Of all the professionals who participated in the research, 66 were female (90.4%), 58 were over 35 years of age (79.5%) and 13 were over 55 years of age. Regarding the time of participation in the AIDS

program, 29(39.5%) have been joining the program for five years; 30 (41.1%), between six and fifteen years and 14 (19.4 per cent) have been participating in the AIDS program for more than sixteen years, i.e. professionals with considerable experience in providing care to people living with HIV/AIDS.

The first analysis resulted in the formation of a corpus composed of the evocations of the 73 participants in response to the inducing term "HIV/AIDS". It revealed that 355 words were evoked, and there were 128 different words, with an AOE of 2.9 in a 1-5 scale, that is, each participant, was free to evoke a minimum of one word and a maximum of five words. Disregarding evocations with frequency equal to or less than 2, the average evocation frequency was equal to 8 and the cumulative frequency was 56.6%. Therefore, of the total number of different words evoked (128), the software considered 23 based on the average frequency of 8. Combined analysis of these data resulted in the box with four positions, Figure 1.

Average frequency	AOE < 2.9			AOE ≥ 2.9		
	Evoked term	Freq.	AOE	Evoked term	Freq.	AOE
≥ 8	<b>Prejudice</b>	52	2.308	<b>disease</b>	14	2.929
	death	43	2.209	personal isolation	10	3.800
	fear	36	2.361	social isolation	9	3.778
	ignorance	20	2.500	suffering	9	3.333
	promiscuity	9	2.556	despair	8	3
< 8	End	3	1.667	Hopelessness	6	4.167
	Loss	3	2.333	abandonment	5	3.200
	worry	3	2.333	distress	4	3.750
	transmission	3	2.333	Lack of care	4	3
				homosexuality	4	4
				condom	3	4
				punishment	3	3.333
				commitment	3	3
				guilt	3	3

Figure 1 – Box with four positions, inducing term HIV/AIDS in direct order, for the whole set of participants of the study. Salvador, BA, Brazil, 2015

The upper left quadrant of the box is composed of the words evoked with greater frequency (above the established frequency) and low order of evocation, that is, words that were more readily evoked. They are, in order of frequency: prejudice (52), death (43), fear (36), ignorance (20) and promiscuity (9).

The most significant words for the group, considering the AOE value, are death (2.209), prejudice (2.308) and fear (2.361). In the context of the Central Nucleus Theory (CNT) it is important to identify both the elements and dimensions of the central nucleus related to the object, and the relationship of the subject or group with the object. Thus, the words prejudice, death and fear describe the relationship of professionals with the inducing term AIDS. On the other hand, the elements of ignorance and promiscuity are less expressive in the set of words and reveal an evaluation dimension.

The other words shown in the second quadrant (despair, illness, personal isolation, social isolation and suffering) reveal a negative view of the AIDS phenomenon.

The words 'abandonment, distress, punishment, guilt, physical degradation, hopelessness, lack of care and homosexuality' appear in the fourth quadrant, were evoked by few participants and form the central nucleus with value judgments and negative aspects of the representation. However, they are opposed to the words 'commitment and condom', which are somehow consistent with the current discourse on AIDS.

The second analysis resulted in the formation of a corpus, also composed of the evocations of the 73 participants in response to the inducing term "Care of people with HIV/AIDS." Three-hundred and forty-two (342) words were evoked, with 102 (T) different terms, and an AOE of 2.9. An average frequency of 9 and a cumulative frequency of 64.6% were obtained. Of the total number of different words (102), the software retained 25 (Figure 2).

Average frequency	AOE < 2.9			AOE ≥ 2.9		
	Evoked word	Freq.	AOE	Evoked word	Freq.	AOE
≥ 9	Advice	24	2.750	help	13	3.615
	welcoming	20	2.875	love	12	2.917
	Training	16	2.600	care	11	3.455
	Health education	14	2.714	commitment	9	3.222
< 9	Humanized assistance	8	2.250	acceptance	7	3.286
	patience	8	2.571	solidarity	7	3
	attention	7	2	treatment	6	3
	recognition	7	2.250	prevention	6	3.167
	respect	7	2.143	empathy	5	3.400
	care-protection	6	2.667	treatment adherence	4	3.286
	Availability	4	2.750	psychological support	4	3.250
				confidence	4	3.250
				non-discrimination	4	3.500
				responsibility	4	3

Figure 2 – Box with four positions, inducing term Care for people with HIV/AIDS in direct order, considering the whole set of participants. Salvador, BA, Brazil, 2015

In this corpus, the most important component according to the hierarchy, comprised the words ‘advice’ and ‘welcoming’ which possibly form the Central Nucleus (CN) for the stimulus caring for people with HIV/AIDS. The words have also been confirmed by their saliences - words evoked more readily because they are more strongly related to the stimulus - and are accompanied by the words ‘empowerment’ and ‘health education’.

The element ‘attention’ is the most significant of the representation of Care, with an AOE of 2.000, and appears in the contrast zone. The fourth quadrant, where the evoked words (humanized assistance, patience, respect, acceptance and solidarity) have low and high frequencies of AOE, depicts a reified knowledge, based on public policies that support the representation of these workers about care for people with HIV/AIDS.

Finally, based on the responses to the inducing terms obtained through the application of the Free Word Association Test (TALP) regarding the two investigated objects - HIV/ AIDS and Care - we expose the appreciation of the representational structure, through the calculation of the indices of diversity of the evoked words and the level of sharing or index of rarity, Table 1.

Table 1 – Characteristics of the corpora of evocations per object. Salvador, BA, Brazil, 2015

Indicators	HIV/AIDS	Care
Number of evocations (N)	355	341
Number of Types (T)	128	103
Number of Hepax (H)	68	48
Average frequency of evocations of Types (N/T)	2.77	3.31
Diversity index (T/N)	0.36	0.30
Rarity index (H/T)	0.53	0.46

The HIV/AIDS object had a larger number of types of Hepax (68), a result that translates into higher indices of diversity and rarity. The diversity index of the ‘Care’ object (0.30) is lower than that of the ‘HIV/AIDS’ object (0.36).

The object ‘HIV/AIDS’ with a greater variety of evocations (128), includes words generally evoked 2.77 times. As for the rarity index, it can be seen that the percentage of Hepax – words evoked only

once - on the Types is also higher for the object 'HIV/AIDS', which translates into a greater abundance of responses with characteristics that differ from the others for this inducing term, compared to the inducing term 'Care'. A value of 0.025 was obtained with Student-t-test, which indicates that the chance this result could be random is small. Therefore, the value obtained is statistically relevant.

## ● DISCUSSION

The upper left quadrant is composed of words that are most likely to have a greater impact on the cognitive scheme of the participants, and are considered the possible core elements of the representation<sup>(16)</sup>. However, although they meet the two criteria: frequency and AOE, some words of this group are not considered central elements in the representation, because "it is not the massive presence of an element that defines its centrality, but the meaning that it gives to the representation"<sup>(9:47)</sup>.

Identification of the elements and dimensions of the central nucleus in relation to the object and of the relationship of the subject or group with the object is required according to the theory of the central nucleus (TCN). As soon as these elements are identified, their different meanings are shown. These elements can be classified as functional or pragmatic elements, which are related to the accomplishment of the task and determine the behaviors related to the object, and as normative or evaluation elements, focused on stereotypes and attitudes, originated from the system of values of the individuals<sup>(16)</sup>.

Thus, the first aspect observed in the set of elements of the Central Nucleus (CN), core of the representation of the group (Figure 1), is a predominantly normative dimension (prejudice, death and fear), given the presence of socioaffective, image and attitudinal and value nature elements. The CN is the result of the collective memory and the standards system to which a particular group alludes, and consists in absolute rules<sup>(17)</sup>.

AIDS is the first disease whose historical evolution showed consistency between the social and medical aspects, allowing a social representation of the disease (cancer gay, gay syndrome) (18-19). From this point of view, the prejudice and the consequent discrimination of AIDS sufferers that followed the emergence of the epidemic has triggered a need that persists today, which is to provide an effective response to the so-called second epidemic: a moral epidemic<sup>(19)</sup>.

The elements of the central nucleus (CN) characterize social representation as a meaning assigned to a given object by the subject, based on information that arise continuously from its practice and its relationships<sup>(7)</sup>. Prejudice and death may be reflections of the daily experiences of these professionals in their care practice. People living with HIV/AIDS not rarely mention lack of social support and feel vulnerable as a result of prejudice (real or perceived), which limits their lives and contributes to social exclusion<sup>(19-20)</sup>. In addition to facing the risk of death, AIDS sufferers are also at risk of a social death, as a result of prejudice, stigma and discrimination that followed the appearance of the HIV. Both words (prejudice and death) are related to personal isolation, social isolation and abandonment, shown in the second and fourth quadrants of Figure 1.

The CN elements also reveal that prejudice, death, fear, ignorance and promiscuity reproduce the representation of HIV/AIDS since the beginning of the epidemic. The sample of this study was mostly composed of professionals aged 35 years or more (79.5%), so that a significant number of them experienced the history of AIDS from its earliest days.

The strong presence of the words 'prejudice' (52) and 'death' (43), evoked by health professionals that perform their activities in reference services for AIDS reveals the negative and historical meaning of the representation of the investigated group.

Fear is another expressive, normative element, a feeling experienced by some participants. The word was found in studies of health professionals<sup>(19-21)</sup> and expresses their emotion once faced with a possible exposure to the virus in their health practices with infected patients. On the one hand, these individuals fear the risks they are exposed to in their daily lives, despite the availability of protective equipment. On the other hand, this kind of feeling sometimes determines the practices of personal

and professional self-protection adopted by these health workers <sup>(21)</sup>.

These words express factors that contribute to the vulnerability of people living with HIV/AIDS. They are blamed on promiscuous, uninformed and guilty for the transmission of the virus. The small frequency of these words in the central nucleus may indicate a change in the social representation of this group. These elements were usually not mentioned in more recent studies <sup>(19-20)</sup> and, when mentioned, they were placed in the periphery of the structure of the representation.

This analysis, based on Figure 1, shows that the elements that integrate the social representations of these professionals are similar to the elements in social representations elaborated in the 1980s and early 1990s, reflecting a prototypical configuration characterized by the association AIDS/death, AIDS/fear and AIDS/contagion, typical of that period <sup>(19)</sup>.

Corroborating a study with health professionals in the Northeastern region of Brazil, in 2004, the representation of AIDS does not reveal nuances of a modern epidemic supported by the reified universe, with predominance of clinical rationality. On the contrary, it reproduces a reality with deeply-rooted prejudice, promiscuity and death <sup>(22)</sup>.

Regarding stimulus 2, the content in the central nucleus (CN) is consistent with the current standardization (advice, welcoming). Another important aspect of the CN content in the representation of care in HIV/AIDS by health professionals is the predominance of the affective dimension. The evoked words suggest "instruments" (training and health education) as possible ways to cope with the AIDS phenomenon. Since health professionals are responsible for providing assistance to sick or healthy persons, family members and community, when performing activities of promotion, maintenance and recovery of health, the revelation of this meaning may interfere positively in the adoption of clinical conducts and/or care practices targeted to the users of specialized health services.

Health education and training appear in this representation as elements that value communicative skills, which are crucial to the care process, being closely related to the need for technical competence involving specialized knowledge.

The other words that appear in the second quadrant or first periphery (help, love, commitment and care) reveal a positive position in relation to the AIDS phenomenon in the care process. The words connote aspects of solidarity and empathy expressed by health professionals directly involved in care and who have scientific knowledge of the disease. This is consistent with the current context of AIDS: the disease has become more socially acceptable, as a reified knowledge.

In Table 1, comparison between the investigated objects shows that for health professionals in specialized services, "Care" provides proportionally fewer types of evocations than "HIV/AIDS".

With the use of calculation of indices, the two objects can be compared, and it was found that the "HIV/AIDS" inducing term activates more idiosyncratic words, and hence its evocations are less shared than those of the inducing term "Care" ( $p < 0.003$ ). This may indicate less social elaboration <sup>(17)</sup> in this group of the "HIV/AIDS object".

Although 97% of the total number of professionals working in the selected units participated in the study, one limitation concerns the fact that it was conducted in only one city, which does not allow generalizations regarding the topic addressed. It should be stressed that the data shown are attached to a multicenter survey. Therefore, the results can be used in theoretical comparisons related to the subject.

## ● CONCLUSIONS

"Prejudice and death" constitute the central nucleus of the social representation of HIV/AIDS supported by "fear, ignorance and promiscuity", with "death" being the most significant element of the representation. The stimulus "care" has a central nucleus formed by the words "advice and welcoming" followed by the words "training and health education".

The structuring elements of the social representation of AIDS connote the presence of value

judgments and negative aspects that characterized the early days of the epidemic. In contrast, the representation of care reinforces theoretical aspects incorporated by the health policies implemented in Brazil, although that requires cautiousness by health professionals.

Quantitative processing of results and calculation of diversity and rarity indices revealed less sharing of evocations regarding the object HIV/AIDS than about the object Care among the participants.

Both the content and the structure of representation for Care revealed that, according to health professionals, this object is contextualized in the field of reified knowledge. Moreover, such representation of Care by health professionals is similar to the society's representation of Care, indicating that caring for people living with HIV/AIDS is associated with the normative aspect and the attitudes accepted as typical of health professionals.

## ● FUNDING

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