66 - THE EVENT OF AIDS AS A DISEASE AND THE BELIEFS SYSTEM: A LOOK THROUGH SOCIAL REPRESENTATIONS

REJANE MILLIONS VIANA MENESES;
FRANCISCO ARNOLDO NUNES DE MIRANDA;
CLÉLIA ALBINO SIMPSON;
RAPHAEL NEPOMUCENO GALVÃO SANTOS.
Universidade Federal do Rio Grande do Norte-Natal/Rn-Brasil
rejmillions@hotmail.com

INTRODUCTION:

Since its discovery in 1981, the Acquired Immunodeficiency Syndrome (AIDS) had incorporated itself to the landscape, as anyone who has access to any means of communication, certainly has heard about this disease. Despite the knowledge produced and distributed on AIDS and the information about its transmission forms, the collective fear is still beyond rationality, showing the danger that comes from the culture symbolic power.

The AIDS had triggered such strong reactions of fear of contagion, that in the beginning of epidemic, the most part of those sick patients were excluded from the social and family relationships. The fear of contagion had also affected healthcare professionals. Several are the studies published concerning the panic created among healthcare professionals about the contagion of fear of the unknown, which can be quoted those from Parker (1994), Galvão (1985) and others.

The emotional investment that the disease mobilizes, demonstrates how extremely useful is to understand how are built the social representations of AIDS, drove to a better and more interactive treatment. It's known that the study of social representations shows that subjects contradictorily coexists to the knowledge and beliefs that had stored about the disease and to what was being socially built as its representation.

On this perspective, Marková (2006) states that social representations always involve the knowledge and beliefs about a subject of interest and that is unlikely to find a thought system that could be based purely on one or another, whether its science or religion. Continuing, says that the representations based on beliefs may inspire social categorization and exclusion of groups and individuals.

Through this study, we aimed to understand and reflect the symbolic content and the beliefs system involving the therapeutic routine of individuals with the Human Immunodeficiency Virus (HIV), as well as show their biological and social aspects.

METHODOLOGY:

The study of social representations aims understanding the complexity of the object in question. Aware that a social representation involves several mental and cultural products - such as beliefs, perceptions, opinions, images, concepts and many others, we will adopt a plurimethodological approach, using for this, different methodological techniques and strategies in order to understand the different dimensions of representation (JODELET, 1994; SÁ, 1996).

Following this, the methodology adopted for this study seeks exploring qualitative aspects of phenomenon, guiding itself both by assumptions of the Social Representation Theory, proposed by Serge Moscovici (1987), as well as the contributions from the Central Nucleus Theory, by Jean-Claude Abric (1994).

In the period from May 1999 to June 2000, the study was conducted in Natal, capital of the state of Rio Grande do Norte, in Giselda Trigueiro Hospital, from the state healthcare network. The population of the study included patients hospitalized, the ambulatory registered bearers and their families.

The sample was composed by 13 patients - 06 being sick, who were hospitalized during the research, and 07 being HIV bearers, who had received ambulatory healthcare during this time - and their families, totalizing 28 respondents.

It was used, primarily, the participant observation, once we believe that this technique offers greater chance of understanding the problem under study. So, in a first moment, we took the records from our observation, since it was taken into account the professional experience along these years with the hospitalized patients and their families.

In a second stage, aware that the social representations, as a social and group culture manifestation is manifested not only in terms of the speech, but also in practices, we tried to observe, through visits to the patients' homes, the evidence that could be found in the domestic environment, or how the family members reorganize themselves, facing the disease.

For the deepening of the most relevant issues collected, we perform semi-structured interviews that had meant to expand access to the representational content under study.

The interviews were built on two times. First, we use the technique of free association on the word “AIDS”, where we questioned “What is AIDS for you?”; and in second time, were put thematic questions on the subject under study, such as: “How do you knew that you were with the AIDS virus?”, “How did you reacted?”, “How did you get yourself contaminated?”, “Who was the first person to be notified?”, “Did you received any orientations on the treatment to be followed?”, “How was your relationship with your family?”, “And now, how is this relation?”, “How is your life after the disease?”; and in relation to interview relatives and friends: “How did you reacted after knowing that your relative was with the AIDS virus?”, “And how the friends reacted?”, “You talk about the disease or treatment?”.

The register techniques were the field notes and the tape-recording, which were transcribed and, after, analyzed, based on the categorical content analysis method proposed by Bardin (1973) and Michelat (1982). We also used as a resource to facilitate the development of the analysis categories, a software that supports the qualitative analysis, LOGOS version 1.4, created by Prof. Kenneth Rochel de Camargo Jr. (IMS / UERJ), which had been very useful in the organization, classification, categorization and systematization of the information obtained through interviews and participant observation.

RESULTS:

Starting from the Social Representation Theory, we aimed to understand and reflect the content of the AIDS social representation made by the individuals and, in particular, highlighted by the central nucleus element of this representation, whether is the sense of DEATH. This element, which predominantly attracts all elements, is called peripherals by Abric (1994). Therefore, if the central element is one that emphasizes the more socialized content (macro) of the representation, the peripheral elements are those that allow individuals to maintain its meaning variations or "readings" more detailed about the object. Thus, in representing AIDS as DEATH, the study subjects seem to share, at the same time, a collective and an individual sense, showing

that these dimensions of the real does not oppose.

"To me it already was a skull, it was the death, but not today. At my home, I have not spoken before to anyone that I am a bearer, because it will have a look and I am afraid of glance that they will pass to me. Nobody knows that I carry it, but they know that I am gay." (S9, M, 54 years);

"At first, we don't want to tell anyone. (...) It means to me ... death. But at the beginning, as I told you, I was very afraid. "(S13, F, 26 years).

Marková (2006, p.231) explaining the belief issue says that AIDS is taken as a dirty disease, or that AIDS is associated with a punishment of a disseminator and that the punishment is linked to death. Such beliefs can implicitly survive in a community for generations, which can be transmitted through collective memory, implicit communication and traditions.

If AIDS social representation appears to be extremely useful for understanding the features of the meaning that each patient builds for this disease, that importance stands out even more when seeking to understand how social representation anchored to DEATH interfere in reactions and behaviors of patient.

The social representations, while pre-conceptions 'systems' of images and values, have their own cultural significance and survive regardless of individual experiences. Its multiple dimensions are such that the disease can not be seized only by the biomedical paradigm narrow. Therefore, the relation of healthcare professional-patients/relatives requires the plurality incorporation of directions present in these representations, which will facilitate the compliance with treatment.

"People do not know the disease, think just that the fact of sitting next to a bearer will contaminate them... Even shaking the hand of a positive serum person will contaminate, and yet it is not ... Even me, when I discovered that I was positive HIV, and had a boy who was also, but he was in a terminal state, and when he sat by my side, gave me determination to stand away, because I thought that would became the same as him, just by the fact of being close. "(S5, M, 32 years).

As told by healthcare professionals, the disease works as production and transmission of medical knowledge, which gives a sense of direction for their practical activities in their own *modus operandi* performance. Therefore, the communication quality will depend on the familiarity of professionals with the illness narratives of their patients and how the patient will experience the information offered by professionals.

The physician should be alert to their patients' reports in order to not only make a correct diagnosis, but also propose a treatment program that is accepted by the patient, so that he can help in the treatment applied.

Thus, the patient disease perception creates something new, not showing only the pathological, scientific side of the disease, but transforming symptoms and events in a whole with meaning, thus creating a world of the disease, where the social representations have an important role. To Moscovici and Marková (2000), the beliefs can be efficiently replaced only by another belief. And to deny a belief, we need to present another powerful image, which demands commitment with the passions.

The event of a disease makes us question the existence of a connection between it and the moral values or how the person lived his/her own live, in order to see what kind of circumstances, actions and personal attitudes may have influenced or generated the disease.

Similar to religious explanations along the Middle Age, when facing the general feeling of powerlessness, the scourges signs of divine anger, thereby announcing the end of times, this imaginary resurfaces in the content of the representations of some subjects which share an AIDS explanation as a punishment from God.

"I wanted and I ask God every day when I go sleep, that if it has happened, that one day or two more days... to me repeat the exam again. That on the day that I would go, it was a laboratory mistake, and I would hug everyone in the lab... "(S7, F, 26 years).

AIDS is also instigating the redesigning process of old and modern representations about sexuality, articulated with the possibility of death before an sexual transmissible disease, because being with AIDS means not only see the body disappearing or to feel useless for work, but still, be private for leisure, for sex and for love. The subjects fear to be unable to go out, date, live, fearing infect others.

The combination disease-death, whose strength is present in epidemics of once, resurfaces with AIDS so intensely, when it was believed in the control of transmissible and contagious diseases. In addition to its lethality, as in the case of cancer, AIDS encourages the reminder of the fragility and human finitude, at a time when there is credibility in the scientific-technical progress in human life to enable its maximum potential length.

The patient with AIDS challenges the scientific knowledge, as the disease diagnosis does not guarantee the necessary therapy, and in these patients, diseases once taken as easily curable, will present surprising incidence, as in the case of tuberculosis. Other more rare, such as Kaposi Sarcoma, become frequent, making its investigation and treatments physical and economically expensive.

"At first it was difficult to take 14, 15, 16 pills per day ... There I was outraged, but now I will take, only feel pain in the stomach, but I drink milk, liquids..."(S1, F, 28 years);

"(...) I am very comfortable today, nowadays it amazes me no more, I have no fear of it, in any way it haunts me ... "(S13, F, 26 years).

Treatment with anti-retroviral drugs has shown very positive results in all countries, causing a significant decrease in the numbers of deaths caused by AIDS, as well as a reduction in the occurrence of events associated with this pathology, increasing, also, the survival and improving the life quality of infected patients.

AIDS walks to be a chronic and manageable disease and it is hoped its reconstruction in the popular imagination. That has been done with several writers, who were AIDS bearers, which seek ways to demystify the construction of AIDS-death association in life. But in the universe of this research, where all patients were on anti-retroviral therapy, this representation remains strong.

The risk of HIV transmission between homosexual and bisexual population in Brazil remains significant, regardless of the important behavioral changes already reported, the high-risk behavior continues to be part of the sexual repertoire of a significant percentage of the sample.

"Just as I do not have to face AIDS, because AIDS has no face, so did not him. He had no symptoms or anything, it was not thin, nor anemic, it was a beautiful man, a perfect man, handsome... I never imagined... "(S7, F, 26 years);

"Because I thought he was so elegant, so handsome, and thought it only gave in poor people, but, actually, I am also poor." (S8, F, 58 years).

Indeed, it seems that many individuals who reported changes in behavior continue to pursue a several high-risk behaviors, although it's quite clear that there is already a level of knowledge and information about the means of transmission. The reduction in the risk appears contrast directly with a series of sexual values, deeply rooted not only in the homosexual subculture, but in Brazilian sexual culture, mainly in the Northeast region, associated with erotic pleasure and sexual satisfaction, where the practice of risk behavior is still relatively frequent and the use of condom is still relatively limited.

These patterns of risk behavior can be observed both in relation to men as women and even more significant levels of risk feature, apparently, heterosexual relations, especially the less frequent use of condoms, independent of the knowledge and information levels available.

So, it is not so simple "wear a condom" or asks to wear it. Before requiring changes in sexual behavior and social-cultural deeply present in culture, we need to scale the symbolic reach that this measures may have, considering, therefore, different social representations of the subject, the intervention of important variables, such as the genre.

I spent two days using, and then, as a constant partner, you consider me and I believe him. But after it ... I have created more judgment, prevent me more. It is so that will make 01 year that I have this boy and we always use "condom." (Francinete, friend of S13, F, 26 years);

In a heterosexual relationship, is not the woman who "wears a condom," but the man. And if this initiative comes from the women, mainly in the monogamous model, she will have to ask for partner to consent, that in general, is against the use (in addition to calling into question the relationship confidence and monogamy).

Contacted the great problem issue triggered from the social representation of AIDS in society, the nursing professionals also came to get worried because they feel a huge responsibility on the bearers, patients and their families in compliance to appropriate therapy of this health-disease process.

About infectious and contagious diseases, the nursing and healthcare professionals were already used to live with the infection, without the fear of dying, but the emergence of AIDS has imposed this fear of death again, because at the beginning of that pathology ,the transmission ways had not been well clarified. The nursing professionals, by examining AIDS the problematic through the factors that determine their occurrence, must understand that this process should not be seen only by the intention of material life, although it predominantly determinate.

AIDS itinerary, from the point of view of family, emphasizes the complexity that surrounds the health-disease process about various aspects here discussed, as the weaknesses in communication of healthcare professional-patient, the relationship between biological/cultural aspects of the disease, and the AIDS only helps to highlight them.

"I was in a desperate way." (Margarida, S3 sister, F, 22 years); [1]

"We became desperate , no one wanted to accept. I was one of them, I did not want to accept it any way. "(Mary, S8 daughter, F, 58 years);

"My grandmother was a little sad… My father cried a lot and said: What did you do with your life?" (S3, F, 22 years);

"We never expected that any person in the family will have a virus like this, but I was very sorry of him." (Denise, S6's niece, M, 44 years).

Therefore, certain types of social representations, according to Marková (2006, p.230), are predominantly based on beliefs. In Social Representation Theory, the beliefs are considered mental states with considerable length of time. Rooted in the culture, in tradition and in language, are characterized by strength and rigidity of convictions and are, often, full of passions. It means that the believer does not seek proofs or evidences related to the object.

FINAL CONSIDERATIONS:

Although healthcare professionals say, daily, that the individual with AIDS is a patient like any other, we know that it is not like this. The AIDS bearer is a unique patient, because no other disease had resulted in so many contradictory acts in society.

In leprosy case, although having a discriminatory and deadly connotation, it did not had the sexual connotation of AIDS. Tuberculosis, for being associated with promiscuous and bohemian behavior, has raised its threat to a romantic death. AIDS, however, seems to had succeeded in joining in one disease, all stigmata and disasters related to others, because of its characteristics - which had been mentioned previously, making people continue to communicate by the invisible, believing they know how to recognize the AIDS patient.

AIDS is a complainant of socially recriminatory conducts, and there is an almost crucial curiosity in knowing how that patient got the AIDS virus. Since is a slow, but progressive disease, it can take the patient and their families to extreme situations: from the hope of healing to the despair. It is deadly, and the mortality here has its largest weight, the body vanishing along to the suffering and slow and gradual depletion. These features had helped transforming a person with AIDS in a "living-dead", since the diagnosis confirmation.

AIDS brings with it a hidden face that is expressed with extreme force, taking us to the awareness of human being finitude. Thus, it configures a fatality that confuses the existential dramas with the fear of social, and with the discrimination on the part of family and friends. And from the imaginary symbolic of these subjects, resurfaces an assignment that being with AIDS is a punishment from God.

The religious explanations, almost always present in situations that put the subjects and their families facing the death imminence, seem to be a cultural issue more present on the formation of Brazil's Northeast people, as shown by the recurrence on speeches and objects present in the hospital and residence environments.

It becomes extremely relevant the subjective dimension that AIDS representations sublimates. It emphasizes the need for incorporation of death as a part of life for both patient and family members who live disease and pass to coexist with death, as well as for healthcare professionals, for politics and for society in general. These are, thus, suggestions that can contribute in our knowledge, beyond the biomedical paradigm, of this object/disease that comes challenging the scientific knowledge, particularly in healthcare field.

REFERENCES

ABRIC, J.C. L'organisation interne des représentations sociales: système central et système périphérique. In: GUIMELLI, C. Structures et transformations des représentations sociales. Textes de Base en sciences sociales. Paris: TDF/Delachaux et Niestlé, p. 73-83, 1994.

BARDIN, L. Análise de conteúdo. Rio de Janeiro: Edições 70, 1977.

BRASIL, Ministério da Saúde. Programa Nacional de DST/AIDS. Boletim Epidemiológico: transmissão vertical do HIV, ano XII. n.3; Semana Epidemiológica 22 a 34, Brasília, jun./ago., 1999.

HUNGLER, B. P.; POLIT, D. F. Fundamentos de Pesquisa em Enfermagem. 3.ed., Porto Alegre: Artes Médicas,1991.

JODELET, D. Representações Sociais: um domínio em expansão. Presses Universitaires de France, 1994.

JOVCHELOVITH, S.; GUARESCHI, P. (org.) Textos em representações sociais. Petrópolis: Vozes, 1994.

MARKOVÁ, I. Dialogicidade e representações sociais - as dinâmicas da mente. Petrópolis: Vozes, 2006.

MOÑIVAS, A. Epistemologia y representaciones sociales: concepto y teoría. Madrid: Rev. de Psicol. Gerale y Aplic. ,v.47, n.4, p.409-419, 1994.

MICHELAT, GUY. Sobre a utilização da entrevista não-diretiva em Sociologia. In: THIOLLENT, Michel. Crítica

metodológica, investigação e enquete operária. 3.ed., São Paulo: Polis, 1982.
MOREIRA, A.S.P.; OLIVEIRA, D. C. (orgs). Estudos interdisciplinares de representação social. Goiânia: AB Editora, 1998.
MOSCOVICI, S. A representação social da psicanálise. Rio de Janeiro: Zahar, 1978.
MOSKOVICI, S., MARKOVÁ, I. Ideas and their development: a dialogue between Serge Moscovici and Ivana Marková. In: MOSCOVICI, S. Social representation. Londres: Polity Press, p.224-286.
PARKER, R. Corpos, prazeres e paixões: a cultura sexual no Brasil contemporâneo, São Paulo, Best Seller, 1991
SÁ, C.P. Representações Sociais: o conceito e o estado atual da teoria. In: SPINK, M.J. O conhecimento no cotidiano: as representações sociais na perspectiva da psicologia social. São Paulo: Brasiliense, 1993. p.19-45.

THE EVENT OF A DESEASE SUCH AIDS AND THE BELIEF´S SYSTEM: A LOOK FROM SOCIAL REPRESENTATIONS

ABSTRACT:

This study aimed to understand and reflect symbolic contents and beliefs involving therapeutic routine of individuals with Human Immunodeficiency Virus (HIV). We took the assumptions from Social Representations Theory proposed by Serge Moscovici (1987) and contributions of Central Core Theory, by Jean-Claude Abric (1994). The sample was composed by 13 patients - 06 sick and 07 HIV bearers - and their families, totalizing 28 respondents, respecting the ethical precepts from Res. 196/CNS/1996. When representing AIDS as DEATH, subjects seem to share, at same time, a collective and individual sense, showing that these real dimensions doesn't oppose since are anchored in beliefs system.

KEY WORDS: Social representations, AIDS, Beliefs

LE CAS DE LA MALADIE DU SIDA ET LE SYSTÈME DE CROYANCES: UNE ÉTUDE DES REPRÉSENTATIONS SOCIALES

RESUME:

Cette étude visait à comprendre et à refléchir le contenu symbolique et thérapeutique de routine concernant les croyances des individus avec l'Immunodeficiency Virus (VIH). Nous avons pris les hypothèses de la théorie des représentations sociales proposée par Serge Moscovici (1987) et les contributions théoriques de Jean Claude Abric (1994). L'échantillon était composé de 13 malades - 06 malades et 07 porteurs du VIH et de leurs familles, totalisant 28 répondants, dans les préceptes de l'éthique Res. 196 / CNS/1996. Lorsque le SIDA en tant que représentant MORT, les sujets semblent partager, en même temps, un sens collectif et individuel, ce qui montre que ces dimensions réelles ne sont pas opposés car ancré dans les croyances.

MOTS CLES: Représentations sociales, le SIDA, Croyances

EL EVENTO DE UMA ENFERMEDAD COMO EL SIDA Y EL SISTEMA DE CREENCIAS: UNA MIRADA A PARTIR DE LA REPRESENTACIONES SOCIALES.

RESUMEN:

El presente estudio tuvo como objetivo comprender y refletir los contenidos simbólicos y las creencias que envolucran el intinerário terapeutico del portador del Human iminnedeficiency Vírus (HIV). Adoptamos los presupuestos de la teoria de las representaciones sociales elaborada por Serge Moscovici(1987) y las contribuiciones de la teoria del Núcleo central propuesta por Jen-Claude Abric (1994). La muestra se contituyo de 13 pacientes, siendo 06 enfermos, que en el momento del pesquisaje estaban ingresados, y 07 portadores del HIV, que recibieron atencion ambulatorial en el decursar de la pesquisa, y de sus familiares, haciendo um total de 28 entrevistados, respetados los preceptos éticos de la Res. Nº 196/CNS/1996. Al representar el SIDA como MUERTE los sujetos de la pesquisa demuestran, al mismo tiempo, dividir un sentido colectivo y individualizado, enseñando que esas dimensiones del real no se oponen, pues estan ancladas en el sistema de creencias.

PALABRAS-CLAVE: Representaciones sociales, SIDA, crencias.

O EVENTO DE UMA DOENÇA COMO A AIDS E O SISTEMA DE CRENÇAS: UM OLHAR A PARTIR DAS REPRESENTAÇÕES SOCIAIS

RESUMO:

O presente estudo teve como objetivo compreender e refletir os conteúdos simbólicos e as crenças que envolvem o itinerário terapêutico do portador do Human Imunnedeficiency Vírus (HIV). Adotamos os pressupostos da Teoria das Representações Sociais elaborada por Serge Moscovici(1987) e as contribuições da Teoria do Núcleo Central proposta por Jen-Claude Abric (1994). A amostra constituiu-se de 13 pacientes, sendo 06 doentes, que no momento da pesquisa estavam internados, e 07 portadores do HIV, que receberam atendimento ambulatorial no decorrer da pesquisa, e de seus familiares, perfazendo um total de 28 entrevistados, respeitados os preceitos éticos da Res, nº 196/CNS/1996. Ao representar a Aids como MORTE os sujeitos da pesquisa demonstram, ao mesmo tempo, partilhar um sentido coletivo e individualizado, mostrando que essas dimensões do real não se opõem, pois estão ancoradas no sistema de crenças.

PALAVRAS-CHAVES: Representações sociais, AIDS, Crenças.