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DEATH/DYING OF PEOPLE WITH HIV: FROM THE NURSING POINT OF VIEW

MORTE/MORRER DE PESSOAS COM HIV: O OLHAR DA ENFERMAGEM

MUERTE /EL MORIR DE PERSONAS CON VIH: LA MIRADA DE LA ENFERMERÍA

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ABSTRACT

Objective: to describe the representational contents of Nursing professionals about the death and dying of people living with HIV. **Method:** this is a qualitative, field-based, descriptive and exploratory study, based on the Theory of Social Representations, carried out in seven Specialized Assistance Services (SAS) in HIV/AIDS and a Testing and Counseling Center (TCC) with 20 nursing professionals, through a semi-structured interview. The speeches were analyzed by the technique of Content Analysis in the Categorical Analysis modality. **Results:** four thematic categories were chosen from the analysis of the lines: "The diagnosis"; "The meanings of death and dying"; "The confrontation of nursing professionals before death and die of PLHIV" and "Death giving way to the possibility of life". **Conclusion:** the focus was on the representational contents on health and nursing practices from the symbolic construction of illness to the possibility of death related to HIV and the new perspectives of treatment and health promotion, being possible to highlight the advance of the scientific knowledge of nursing professionals, which contributes to their health care to PLHIV. **Descriptors:** Nursing; Death; HIV; Acquired Immunodeficiency Syndrome; Social Perception; Health Promotion.

RESUMO

Objetivo: descrever os conteúdos representacionais de profissionais da Enfermagem sobre a morte e o morrer de pessoas vivendo com HIV. **Método:** trata-se de estudo qualitativo, de campo, descritivo e exploratório, fundamentado na Teoria das Representações Sociais, realizado em sete Serviços de Assistência Especializada (SAE) em HIV/AIDS e um Centro de Testagem e Aconselhamento (CTA, com 20 profissionais de enfermagem, por meio de entrevista semiestruturada. Analisaram-se as falas pela técnica de Análise de Conteúdo na modalidade Análise Categorical. **Resultados:** elegeram-se quatro categorias temáticas a partir da análise das falas: "O diagnóstico"; "Os significados da morte e do morrer"; "O enfrentamento dos profissionais da Enfermagem perante a morte e morrer de PVHIV" e "A morte dando lugar à possibilidade de vida". **Conclusão:** incidem-se os conteúdos representacionais nas práticas em saúde e enfermagem desde a construção simbólica do adoecimento perante a possibilidade de morte relacionada ao HIV e às novas perspectivas de tratamento e promoção da saúde, sendo possível destacar o avanço do conhecimento científico dos profissionais de enfermagem, o que contribui para a sua assistência em saúde às PVHIV. **Descritores:** Enfermagem; Morte; HIV; Síndrome de Imunodeficiência Adquirida; Percepção Social; Promoção da Saúde.

RESUMEN

Objetivo: describir los contenidos representacionales de profesionales de Enfermería sobre la muerte y el morir de personas viviendo con VIH. **Método:** se trata de un estudio cualitativo, de campo, descriptivo y exploratorio, fundamentado en la Teoría de las Representaciones Sociales, realizado en siete Servicios de Asistencia Especializada (SAE) en VIH/SIDA y un Centro de Pruebas y Asesoramiento (CTA, con 20 profesionales de enfermería, por medio de una entrevista semiestructurada. Se analizaron las hablas por la técnica de Análisis de Contenido en la modalidad Análisis Categorical. **Resultados:** se elejieron cuatro categorías temáticas a partir del análisis de las hablas: "El diagnóstico"; "El significado de la muerte y del morir"; "El enfrentamiento de los profesionales de la enfermería ante la muerte y morir de PVHIV" y "La muerte dando lugar a la posibilidad de vida". **Conclusión:** se inciden los contenidos representacionales en las prácticas en salud y enfermería desde la construcción simbólica de la enfermedad ante la posibilidad de muerte relacionada al VIH y las nuevas perspectivas de tratamiento y promoción de la salud, siendo posible destacar el avance del conocimiento científico de los profesionales de enfermería, lo que contribuye a su asistencia en salud a las PVVIH. **Descriptor:** Enfermería; Muerte; VIH; Síndrome de Inmunodeficiencia Adquirida; Percepción Social; Promoción de la Salud.

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INTRODUCTION

At the beginning of the epidemic of Acquired Immunodeficiency Syndrome (AIDS), in the 1980s, concepts related to the emotional and psychological aspects related to illness and biological death, considering death and dying as a process which contemplates five stages: denial, depression, anger, bargaining and acceptance.¹⁻²

In this scenario, sickness and mortality in the representational contents of health and nursing professionals on Human Immunodeficiency Virus (HIV) are found in several studies, linking the process of death and dying to professional practice.³⁻⁴

They are thus called to explore professional practices in the face of the evident complexity of the death and dying object of People Living with HIV (PLHIV) in a set of limits and contradictions, usually not highlighted, although present in the set of institutionalized practices of the health care and professional practice, as in the questions that involve the transformations related to the concepts of groups at risk to the vulnerability to infection after changes in paradigms and conceptions.⁵⁻⁸

It is considered in this research, in view of what has already been pointed out in some studies,^{2-3,9} that, even though death is understood as a common event, which is repeated in the work environment of health and nursing professionals, particularly in relation to each patient, reflecting the anguish and fear of their own end, which can impact their practice, interfering with the care.

It is intended, therefore, in view of the increase in the number of HIV/AIDS-related deaths described by the Ministry of Health for some regions of Brazil (as is the case in the Northeast region), to reveal, in this research, the impacts of this phenomenon on representational contents of professionals reflected in their practices.¹⁰

With this study, we hope to contribute to the identification of fragilities and sufferings that lead to exhaustion and exhaustion, in critical situations related to the subjectivity of the process of death and death of PLHIV in the course of the transformations of the representations of the epidemic,² which place the professional in high demand of the physical, emotional and spiritual capacities in their practice, as well as collaborate to confront this condition by professionals and users of the attention network.¹⁰

OBJECTIVE

- To describe the representational content of Nursing professionals about the death and dying of people living with HIV.

METHOD

This is a qualitative, descriptive and exploratory field study, based on the Theory of Social Representations, in seven Specialized Assistance Services (SAS) in HIV/AIDS and a Testing and Counseling Center (TCC) located in the city of Recife/Pernambuco.

Data was collected from December 2014 to May 2015, with a total of 20 Nursing professionals, of which 14 were Nursing technicians and six were nurses. It was listed as an inclusion criterion: they were nurses or nursing technicians who worked in the services selected for the proposed research for at least one year. Professionals who were on leave or vacations during the period of data collection were excluded. The sample was selected by the data saturation criterion.

The collection was carried out by graduate students in Nursing (academic master's degree) and by students of the research group, using the technique of the in-depth interview from a semi-structured script developed for the exploration of representational contents about HIV/AIDS and the practices developed since the beginning of the epidemic by Nursing.

The interviews were recorded in audio format, in digital equipment, transcribing them integrally afterwards and only making adjustments to the standard cultured standard of the language.

QSR NVivo9.0 software continued to be used as support for the stage of organization of the collected data (pre-analysis), considering, as a technique, the Thematic-Categorical Content Analysis, which consists of a set of analysis techniques of communication, which uses systematic procedures and objectives to describe the content of verbal and nonverbal messages, revealing the importance of semantics and inference.¹¹⁻²

It was followed, after the pre-analysis (by means of the floating reading of the corpus), for the exploration of the material by means of several readings, in order to apprehend the main ideas and the general meanings. The results were then treated (inference and interpretation),⁸ allowing the selection of the units of meaning or analysis.

Four classes emerged from the Thematic Analysis. The sentences, phrases or

paragraphs pertinent to each class identified by the professional category (nurse or nursing technician) and a number following the order of their execution (example: Nursing 03) were found, in order to preserve the confidentiality of the identity of professionals.

It should be noted that the study respected the ethical observances recommended for research involving human beings, and was approved by the Research Ethics Committee of the University of Pernambuco under CAAE number: 01080.0.097.000-11 and Opinion no. 125-A/11.

RESULTS

1,234 Record Units were identified based on the analysis of data from the interviews, which are distributed in four categories representing 100% of the corpus analyzed. The categories are described: 1) The diagnosis; 2) The meanings of death and dying; 3) The confrontation of nursing professionals before death and death of PLHIV; 4) Death giving rise to the possibility of life.

◆ The diagnosis

In this category, we discuss the moment of communication of the HIV diagnosis, highlighting it as an object of representation in the professional practice in Nursing, in which the professionals perceived, in the patients, attitudes of revenge, behavior change and loss of will to live.

It is demonstrated, with the registration unit to follow, how Nursing professionals perceive the revenge attitude of the patient before the diagnosis.

The father, when he discovered that he had HIV, said that he did not want to see his mother any more, he did not want to see his son and that he would not die alone, so he went to a party. (Nurse 03)

On the other hand, it should be emphasized that there were also cases of patients who do not become angry or revolt, but elaborate a different coping strategy, leading to changes in their behavior, which symbolize the desire of PLHIV to adopt practices that are considered healthy or that make them a better person, morally and/or spiritually, in an attempt to redeem themselves against the stigmata of infection.

I already received here, a crack and marijuana user and drinker. When he got the result, the person seems to have stopped everything, improved on everything. I already received a mother who said to me like this: "My son, after he discovered that he has AIDS, was the best thing in the world. He got off drugs and now, after he knows he has AIDS and that he

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can die, he's feeding himself, he's staying at home, he's not leaving, he's going with me to the church. " (Nursing 06)

However, the social actors in the study also stated that often when behavioral change does not deliver the expected result and the process of biological or social death progresses (due to clinical complications or marginalization and prejudice), the loss of the will to live in PLHIV occurs.

People even lost this stimulus of fighting, of running after them, because they knew they had AIDS and would die. (Nursing Technician 08)

I met many people who did not want to live again after discovering the disease. (Nursing Technician 12)

◆ The meanings of death and dying

From the analysis of this category, it was possible to discuss the meanings of death and dying, and professionals emphasized that HIV often represents not only a biological but also a psychological and social death.

It is observed in this context that the holistic compression of the human being allows us to glimpse that not only the biological theories of the representation of the virus can allow their understanding in the social reality, which reveals the psychological suffering caused to the patients as well as the professionals.

And they died consciously, asking, embracing us, not to die. So for me, this experience was very depressing. (Nurse 20)

In relation to the so-called social death, elements and processes that generate HIV-related death to life, in which the PLHIV is forgotten or abandoned by the society or the actors that form part of its social network after the revelation of the diagnosis.

In the great majority, lacking financial situation, lacking the history of the disease, they have many that the family leaves, even because of this. There are others who do not even tell the family or the family does not want to know. (Nursing 06)

◆ The confrontation of Nursing professionals before the death and dying of PVIHV

In this category, there were marked experiences of professionals related to the care of PLHIV, showing how they faced these experiences.

It is seen that, faced with the imminence of death, Nursing professionals are confronted with conflict in their practice of daily care in which, even struggling for the health of the patient, they consider that some efforts are in vain.

I began to see him thinning and dying slowly. As much as I struggled with him, with his antiretrovirals, with a doctor, with everyone, I did not see him improve and, rather, die. (Nursing Technician 12)

Memories of the beginning of the epidemic, in which death was still a verdict for people with the virus, aroused memories and sad feelings evoked by professionals, as shown in the following speech.

I was a nurse in the first AIDS case of the State by vertical transmission. The death of the first child. We did not have many alternatives to take care of. So the sad reminder is the death of the patients. (Nurse 27)

It is mentioned, in the face of this evidence, that the scientific and medical society at the beginning of the epidemic did not have the tools to assist PLHIV facing the death process. It turns out that, at that time, within the biomedical model, focused only on the curative issue, professionals were powerless in the face of the phenomenon and the failures in the distribution of health resources.

The patients die without having a respirator, without being able to do much. It was putting on a mask of oxygen and watching him die without being able to do much. It was as if we were powerless, incapable of nursing care. (Nursing Technician 12)

It is also possible to observe that, without the necessary tools to provide care, in addition to the lack of technical-scientific knowledge at the beginning of the epidemic, it was common for professionals to be afraid of physical contact with the patient, which is related to a social representation that HIV was something cruel and lethal.

So he had to take everything from him to incinerate, throw away. [...] there was that fear: "Is it that you lean on it, catch it, do you catch it in the air?" (Nursing 01)

Death giving rise to the possibility of life

This category was constructed from the exploration of the empirical material from which emerged talks focused on living in the face of the possibility of treatment and the question of the chronification of the disease.

It should be noted that, since the implementation of policies to increase the supply of antiretroviral drugs, the social representation of HIV-related death has been slowed down, and is now seen as something that is possible to coexist with and the reorganization of the way of thinking about the disease.

[...] the most modern antiretroviral drugs came together with more than one drug and

this made immunity, rescue of immunity more effective and patients had a very good recovery and a satisfactory response, where they can live with AIDS, without presenting great difficulties in their daily lives. Just take the antiretrovirals and adhere to the treatment. (Nursing 01)

Other aspects discussed by some professionals are related to the understanding that, after technological advances in treatment, PLHIV have time to grow old, which is characterized as a chronic health condition, as demonstrated by the following speech.

It has become a chronic disease like any other, such as hypertension, such as diabetes. There is no difference, they deal like any other chronic illness. (Nursing 04)

DISCUSSION

Different attitudes towards the diagnosis of HIV/AIDS by the PLHIV were identified, based on reports from health professionals. It is noted that feelings of revolt may be present, reflecting the desire to intentionally transmit the virus to others,¹³ with unprotected sexual activities or the abuse of substances such as alcohol and drugs.¹⁴

It is noted that other PLHIV, in turn, develop a posture of imprisonment because, due to the stigma and prejudice rooted in HIV/AIDS and so present to this day, they may lose the will to live or to fight for their life and treatment, which can have negative social consequences.¹⁵

It is also acknowledged that it is also common for certain PLHIV to adopt different positions, oriented towards a more regulated and responsible lifestyle, reflecting on a greater concern for their health, adhering to treatment and abandoning old habits that they consider harmful for a lifetime healthy.¹⁶

It is emphasized that, in the context of the meaning of death and dying, the different concepts of death attributed by health professionals to HIV were evidenced. It is known that, at the beginning of the epidemic, there was insufficient technical and scientific knowledge about the disease, and treatment appeared later. It is reported that, currently, with antiretroviral therapy (ART), the life expectancy of PLHIV has increased; Thus, biological death, caused by the deterioration of the immune system, is becoming less frequent.

It is considered, however, that HIV diagnosis can generate other impacts on the lives of PLHIV, highlighted in the registry units analyzed in this study and reaffirmed in the literature, such as problems to obtain

employment, difficulties in marital relations and, mainly, lack family support and other social networks. It is inferred that such problems have a negative effect on the lives of these people, characterizing a social death.¹⁷

It is also admitted that social stigma and fear of rejection make PLHIV tend to isolate themselves and feel frustrated with their life situation, which influences the desire to conceal the diagnosis and to be afraid of possible reaction of people, which can lead to develop psychoemotional problems, characterizing psychological death.¹⁸

Feelings of frustration about the way the Nursing team faces the death/dying process of PLHIV are identified, because although living with death is something inherent in their profession, it does its best to provide the best patients.

It is emphasized that, in the face of the imminence of death, even in the struggle for the health of the patient, professionals feel powerless in the face of loss, which can lead to sad memories regarding their care,¹⁹ as if their care had been sufficient to save the life of the individual, triggering in these professionals, sadness and the idea of failure.²⁰

It was also observed in the registry units the contents that refer to the care provided at the beginning of the HIV epidemic, where, in the midst of the various doubts and questions about the disease, professionals adopted attitudes of fear during patient care, characterized by fear of being contaminated by air or physical contact.

It is evident from this perspective that the lack of knowledge about the forms of HIV transmission generated misconceptions among health professionals at the beginning of the epidemic, which reflected negatively on their practices, often permeated by rejection of the patient due to the significance of the HIV as a synonym of danger and death.^{8,21}

In view of this circumstance, it was necessary to investigate and produce knowledge in the area, with a view to enabling and equipping professionals to offer safe care, free from uncertainties and common-sense opinions.⁸

It is added that, even before HIV was considered a death sentence, today, despite continuing to be something without cure, it already has advances in its prevention and treatment, giving hope of longevity to PLHIV. This is justified by the chronification of HIV and a new way of facing the disease.²²

It is thus argued that the possibility of living with HIV leads to a representation of the disease dissociated from death and dying, based on the current tendency to naturalize it.²³

It becomes commonplace, when naturalizing HIV, that it ceases to be viewed as a threat and compared to any other chronic illness, both by health professionals and patients. The challenge of death is thus overcome and it becomes much more of a managerial order, in which one must invest in guidance, prevention of new cases and maintenance of the well-being of PLHIV.²⁴

It is seen that Nursing practice and care integrate elements of the representational field built by them and that they are inseparable from the professional as a social being and in their role in health and nursing.

CONCLUSION

In this study, we find findings that show that the representational contents of nurses and nursing technicians influence the processes of social interaction and stigmatization, as well as the symbolic construction of the disease in view of the possibility of HIV-related death.

In the results, the complexity of the representations is also demonstrated, and the contribution of this study to the nursing aggrandizement as a science and profession is highlighted, contributing to the advancement of knowledge in this area, since it was possible to identify the reconstruction of the imaginary of the nursing professionals in the face of the transformations arising from the scientific positioning on the infection, allowing the re-presentation of the concept of death and giving rise to the knowledge about the possibility of life after the diagnosis, which demands even more complex demands for care.

It is admitted that this study presents, as a limitation, the fact that it was performed in only seven services and encompassed only two professions (Nursing technicians and nurses), not representing all the multiprofessional team involved in the care of PLHIV. It is therefore suggested that new studies on the subject be carried out in more services and include other health professionals in order to deepen the findings.

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