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SOCIAL REPRESENTATIONS ON PALLIATIVE CARE BETWEEN NURSING PROFESSIONALS

REPRESENTAÇÕES SOCIAIS SOBRE O CUIDADO PALIATIVO ENTRE PROFISSIONAIS DE ENFERMAGEM

REPRESENTACIONES SOCIALES SOBRE ATENCIÓN PALIATIVA ENTRE PROFESIONALES DE ENFERMERÍA

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ABSTRACT

Objective: to understand the social representations about palliative care among Nursing professionals. ***Method:*** an exploratory-descriptive study, with a qualitative approach, based on the Theory of Social Representations, based on the theoretical-methodological approach of Central Nucleus Theory. The subjects of the survey were 103 Nursing professionals from a reference hospital in Oncology. The data collection was performed by the Free Evocation Technique of Words (FETW) and its analysis, by EVOC 2003 software. ***Results:*** the results showed that palliative care is represented as a permeated care of love, whose objective is to alleviate suffering and patient's pain. ***Conclusion:*** this understanding demonstrates an increasingly humanized and emotional Nursing practice, breaking the stigma of the gap between professional and patient. ***Descriptors*:** Palliative care; Nursing; Social Psyschology.

RESUMO

Objetivo: apreender as representações sociais sobre cuidados paliativos entre profissionais de Enfermagem. ***Método:*** estudo exploratório-descritivo, com abordagem qualitativa, fundamentada na Teoria das Representações Sociais, a partir do enfoque teórico-metodológico da Teoria do Núcleo Central. Os sujeitos da pesquisa foram 103 profissionais de Enfermagem de um hospital de referência em Oncologia. A coleta de dados foi realizada pela Técnica de Evocação Livre das Palavras (TELP) e sua análise, pelo software EVOC 2003. ***Resultados:*** os resultados mostraram que os cuidados paliativos são representados como um cuidado permeado de amor, cujo objetivo é aliviar o sofrimento e a dor do paciente. ***Conclusão:*** essa compreensão demonstra uma prática de Enfermagem cada vez mais humanizada e emocional, quebrando o estigma do distanciamento entre profissional e paciente. ***Descritores:*** Cuidados Paliativos; Enfermagem; Psicologia Social.

RESUMEN

Objetivo: captar las representaciones sociales sobre atención paliativa entre los profesionales de Enfermería. ***Método:*** estudio descriptivo exploratorio con un enfoque cualitativo, basado en la teoría de las representaciones sociales, desde el enfoque teórico y metodológico de la teoría del núcleo Central. Los sujetos de la investigación fueron 103 profesionales de Enfermería de un hospital de referencia en oncología. Los datos fueron recogidos mediante la técnica de la libre evocación de palabras (TELP) y su análisis, por software EVOC 2003. ***Resultados:*** los resultados demostraron que los cuidados paliativos se representan como una precaución impregnada de amor, cuyo objetivo es aliviar el sufrimiento y el dolor del paciente. ***Conclusión:*** esta comprensión demuestra una práctica de enfermería cada vez más humana y emotiva, rompiendo el estigma de la diferencia entre profesional y paciente. ***Descriptores:*** Cuidados Paliativos; Enfermería; Psicología Social.

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INTRODUCTION

In the last decades, scientific and technological advances in the health area have shown a progress in the curative practices, contributing to a change in the age pyramid, which points to a progressive aging of the population with the increase of the rate of survival.[1] However, Longevity results in an increase in chronic diseases, such as, cancer (CA) .[2]

Because it is a disease often out of therapeutic possibilities, people with CA need, more and more, of an assistance that goes beyond that offered by the most modern therapeutic apparatuses. These individuals constitute a group that we call Patients Out of Healing Therapeutic Possibilities and the care provided to them has been called Palliative Care.

Palliative care emerged through a movement entitled Modern Hospice, led by the nurse, physician and social worker Cicely Sunders who, in the course of their formations, realized what few at the time had the insight to perceive: the need to return the dignity of life to the patients in the eminence of death. Thus, in 1967, in the United Kingdom, was created the first institution dedicated to the comfort of the patients, St.Christopher's Hospice, thus, giving rise to a distinct practice in the area of health.[3]

The term Palliative Care refers, therefore, for historical reasons, to another term, the Hospice (which were hostels intended for the care of pilgrims and travelers). However, due to linguistic problems (for, in many languages, a reliable translation was not Term), this has been replaced by Palliative Care. "Palliare", which comes from Latin and means mantle used to protect pilgrims in travel to shrines. Similarly, when the disease cannot be cured, what remains is to cover it with care Palliatives.[2,4-5]

In retrospecting the Nursing genesis, it can be seen that palliative care is inherent to the practice of this area, and has been present since its beginnings, when Nursing elders, Florence Nigthtingale and Ana Nery, have abdicated their luxurious lives to serve in the Crimea and Paraguay Wars, respectively, assisting the soldiers who were on the verge of death. Thus, they were practicing the "empirical" practice of palliative care, while giving a more dignified death to people who had no chance of surviving because of the conditions of medicine at that time.[6]

Palliatively care for a patient does not mean trying to cure him, slow down or reverse his health condition, since these patients are deprived of possibilities of cure. It is therefore a question of providing the best way to die, bringing the family closer to the patient, making them aware of their real condition, including their participation in the decision-making process relevant to their life and death.[7]

Palliative care is configured as a service modality that is possible, through the endless organization of a team that in essence, needs, to have multidisciplinarity and interdisciplinarity. It is worth mentioning that all the professionals involved, such as nurses, doctors, nutritionists, physiotherapists, social workers, speech therapists, spiritual assistants, among others, have their practice based on palliative care principles that are pain treatment, and other symptoms present and supply of their bio-psycho-social and spiritual needs.[4]

The participation of each member of the team is unique and inseparable for the provision of palliative care. However, for the nurse, performing "palliative Nursing" is not an easy task and, although care permeates all of its routine, this modality demands the generalized approach in a specialized practice, requiring nurses to have an insight to articulate not only with the patient, but also with their relatives, which should be considered a unit of care.[4,8]

Such a feat being achieved, what is established is a warm care for that patient, because the nurse stays with them for a lot more time than any other professional and, therefore knows his limitations and especially their demands. In this way, this professional can do vale Is one of the most beautiful resources in his area, systematized and individualized assistance, where they plan and implement actions that result in a greater autonomy for the patient over their own life and illness.[3-4]

Helping an individual to achieve a dignified death is not an easy task, especially, if the team that watches it is unaware of its importance or lacks the appropriate technical and scientific knowledge. The nurse, along with their team, has tried, through palliative care, to find a way to provide their care associated with the best care for these patients, using, for that purpose the knowledge that is inherent in their practice, since, the specific ones for patients often neglected during their academic training.

In this context, it is worth to add that the interest in the subject under study resulted from the experience of an academic practice in an oncology hospital, where the fear of death and the dying process was observed, in

patients, and how difficult it is for the professionals in the team, especially in Nursing, to work with the precepts of palliative care, which consists of mitigating this fear, offering comfort and providing quality the life that remains for the patient.

Thus, the objective of the research was to know the social representations that the Nursing team has about palliative care, based on the assumption that these representations influence the conception of care and the assistance provided by these professionals to the patient outside curative therapeutic possibilities. To reveal the meaning of palliative care for the Nursing Team, we sought to use the Theory of Social Representations.

The choice of this theory was due to the vast field of health that the field of study provides for the study of social representations, since this area represents one of the sciences that most undergoes transformations, since the events are uncontrollable and, are often, beyond the comprehension of the man, which creates fear and anxiety in people. Therefore, it is of great value to apply this method in this area, since the domains of the health-disease process constitute one of the most diversified knowledge, allowing to understand how the cognitive and cultural act in an area where the evidence stands out to the detriment of the belief systems of society.[10]

METHOD

Based on the theoretical-methodological approach of the structural approach of the Central Nucleus Theory, proposed by Jean-Claude Abric, in 1976. The TRS has based numerous researches in the field of Nursing. It can be defined as a set of concepts, affirmations and explanations originated in everyday and interindividual communications.[11]

The methodological design involved a reference institution in Oncology located in the city of São Luís, Maranhão, which serves clinical and surgical patients from the capital of Maranhão and its surroundings.

The institution has a Palliative Care Committee chaired by a doctor, counting on the performance of other professionals such as nurse, psychologist, nutritionist, physiotherapist and social worker. However, the institution does not have a physical palliative care unit, and the patients who are in this modality of care are hospitalized in the medical clinic sector.

Data collection took place from December 2013 to January 2014. The hospital has, a staff of 35 nurses and 250 Nursing technicians. The quantitative of subjects was defined during the research, until a sufficient population was obtained to define the object under study. Thus, the population surveyed was 103 professionals, among nurses and Nursing technicians. The research subjects were chosen according to the following inclusion criteria: to have experience with palliative care and the desire and willingness to participate in the research voluntarily, by signing the Informed Consent Term (TCLE).

The data were produced by means of an individual instrument containing a stimulus question, answered by the use of the Speech-Free Evocation Technique (TELP), developed by Carl Gustav Jung, in 1905. Each participant received a data collection form containing Questions related to its socio-economic characterization and, then, a stimulus question, whose chosen inducer term was "Palliative Care". Each subject was asked, to evoke at most, five words or expressions that came to mind when listening to the term "Palliative Care." Then he was asked to organize the words or expressions evoked in order of importance, numbering them from one to five, that is, from the most important to the least important.

The compilation of the collected data was done with the aid of a software called EVOC (version 2003) - Ensemble of Permettant Programs L'analyze des Evocations. The analysis process began with the preparation of the dictionary of words produced by the subjects of the research, where they were typed alphabetically in the Microsoft Office Word program. Subsequently, the grouping of the words according to the semantics occurred. Shortly after a second file was created in Microsoft Office Excel, the corpus, which was introduced in the EVOC 2003 software.

Thus, the EVOC-2003 software established the Mean Order of Evocation (OME) and the Intermediate Frequency (FI) of the evoked words, which, were then, grouped into categories. The identification of the structure of the representation was obtained from the use of the technique of the four - house table, through a figurative scheme that allows the distribution of the evoked terms according to the two criteria mentioned above.

Regarding ethical aspects, this study was supported by the National Commission for Research Ethics (CONEP), inserte in the resolution in Resolution No. 466/2012, which regulates studies involving human beings and

their annexes. The project was approved by the research ethics committee of Ceuma University under protocol CAAE 27566314.3.0000.5084.

RESULTS

The research population consisted of 103 Nursing professionals: 27 were nurses and 76 were Nursing technicians, 93 were female and ten were male. This fact reveals that, despite the increasing insertion of the man in Nursing, the profile of the class is still constituted with the same characteristics of its genesis, that is, the predominance of women in the field of work.

In relation to the age group, the most prevalent with the highest prevalence was the one between 21 and 30 years old, with a percentage of 54.36%, followed by the age groups between 31 and 40 years, and, finally, among professionals who present between 41 And 50 years. These data characterize the subjects studied as "young" team members, which may explain the higher percentage of recent work time with palliative care, since 45.63% of the institution's Nursing professionals had between one and five years of work in this area.

Table 1. Distribution of Nursing professionals studied (n = 103) according to socio-demographic variables. São Luís (MA), Brazil, 2014.

Variables	n	%
Sex		
Female	93	**90.30**
Male	10	**9.70**
Age		
21 to 30 years old	56	**54.36**
31 to 40 years old	24	**23.31**
41 to 50 years old	23	**22.33**
Cargo		
Nurse	27	**26**
Nursing Technician	76	**74**
Time of qualification		
< 1 year	3	**2.93**
1 to 5 years	50	**48.54**
6 to 10 years	26	**25.24**
11 to 15 years	5	**4.85**
>16 years	19	**18.44**
Time of work with paliative care		
< 1 year	17	**16.50**
1 to 5 years	58	**56.32**
6 to 10 years	11	**10.67**
11 to 15 years	5	**4.86**
>16 years	**12**	**11.65**

After the formation of the corpus, the lexicographic analysis of the stimulus-inducer, palliative care, resulted in a total of 515 words, which, after the semantic standardization, resulted in 134 different words.

Regarding the treatment of these evocations by EVOC software, used, as a cutoff, a frequency of at least ten was used, indicating that evocations below this value were eliminated from the table. The Intermediate Frequency (FI) was 17 and the Average Order of General (OME) of evocation was 3.0, on a scale of one to five, according to the following table:

Number of evocations	**515**
Total number of different evocations	134
Minimum frequency	10
Intermediate frequency	17
Average of evocations by subject	3,0
Mean of the average orders of evocations (*Rang*/OME)	?

Source: *Software* EVOC 2003.

Figure 2. Description of the evocations about the term inducer "palliative care". São Luís (MA), Brazil, 2014.

Based on the above data, the four-house panel on palliative care, obtained through EVOC 2003 software, was structured so that each quadrant provides information about the representation. The evocations present in the upper left quadrant are those that are possibly part of the central nucleus. Those in the lower right quadrant belong to the peripheral system, while the others are considered intermediate elements. In this way, it presents the following figurative scheme:

1st QUADRANT Possible elements of the central nucleus			2nd QUADRANT Elements of the 1st periphery		
Frequency >= 17	Range < 3		Frequência >= 17	Rang >= 3	
Evoked term	Freq.	Rang	Evoked term	Freq.	Rang
Love	32	1.938	Attention	29	3.034
Care	36	2.611	Death	29	3.517
Pain	18	2.667			
4th QUADRANT Elements of contrast			3rd QUADRANT Elements of the 2nd periphery		
Frequency < 17	Range < 3		Frequência < 17	Rang >= 3	
Evoked term	Freq.	Rang	Evoked term	Freq.	Rang
Comfort	14	2.857	Caressing	13	3.000
Dedication	14	2.929	Comprehenson	11	3.818
God	11	2.545	Patience	10	3.800
Family	13	2.231	Suffering	15	3.267
Humanization	13	1.692	Terminal	15	4.000
Quality of life	13	2.462	Sadness	14	3.429
Respect	12	2.583			

Figure 2. Four part table for the term "palliative care" inducer for the group of Nursing professionals studied (n = 103). São Luís (MA), Brazil, 2014.

According to the Theory of Social Representations, [11] the elements in the upper left quadrant are those more readily evoked, constituting the most immutable part of the representations, therefore, it is the least capable of changes due to the external environment or the practices that permeate the group thus, forming, the possible Central Core of representations, which, in this study, corresponds to the words "love", "care" and "pain".[12]

Leaving for the elements located in the upper right quadrant, we have what we call the first periphery or intermediate elements of the representation, where are situated the words that also obtained high frequency but did not reach the average position in order to integrate the central nucleus, "attention" and "death". They also constitute those words that were evoked less readily, being considered, due to their high frequency, the most important peripheral elements of the representation.

Following the order, the terms in the third quadrant, in this research represented by the words "affection, understanding, patience, suffering, terminal and sadness", are the least evoked and most peripheral. As the second periphery, the terms located in this quadrant are the elements most susceptible to change due to their marginality, since they are directly influenced by the information transmitted in the external media, especially, the media.

Finally, the terms in the fourth quadrant are what are calle the contrasting elements of the representations in which the evocations are given that have obtained a low frequency. However, the average order of the evocations of these words reveals that because they have been readily evoked, this set of words may mean for the subjects the existence of a subgroup that bears a representation different from that already observed in the social group studied, and may constitute a possible central nucleus of representations.[10,13]

DISCUSSION

The first word that makes up the central nucleus of the representations is the term "love", being promptly evoked by Nursing professionals. It can convey the perception that they have the competence to be able to feel the condition of the patient, that due to the hospitalization and circumstance of being outside therapeutic therapeutic possibilities, undergoes alterations of all orders (bio-psycho-social and spiritual).

The patient therefore needs to feel that it is not only an object of action but a human being who needs a care that goes beyond the technical approach and is also based on the affective aspect, through the action of professionals who understand the importance of involvement with the other. This will contribute to the development of a broad therapeutic relationship with a patient who has a short life span, making it one of the

main principles of palliative care, which is to provide quality of life for patients in finitude.

When nurses value love, joy thrives on patients, and that feeling is able to alleviate the suffering these patients go through, which is more valuable than any opioid for treating pain. Therefore, we have the capacity to develop a more welcoming assistance, forming connections that can break the tension in this assistance and make the patient see the palliation as a therapy that adds quality of life to their days and not their days of their lives.[14]

The second term of the central nucleus, "care", points to a conception that the Nursing team has about the essence of care that must be provided to the patient, that is, literally the care the patient needs to receive, such as food, hygiene , Procedures such as curatives and general care, which translate into the fulfillment of basic human needs.

Research calls this view "professional care" and states that the action of care is the foundation of Nursing practice, but, the act of caring is not restricted only to benevolence and vehemence, professionals make use of their technical knowledge And clinical weighting to perform their work, constituting what we call Scientific Nursing.[15] However, when this professional care is reported to the terminally ill patient, Nursing professionals understand that, although they perform it, the ultimate goal is no longer the cure and Rather an effective palliative care, unveiling the skills of caring for the team.

The representational centrality of the term "pain" ratifies the professionals' knowledge about the patient's needs, because it is one of the most present clinical conditions in the patient outside curative therapeutic possibilities. Thus, to give due importance to this condition is to plan palliative care according to what the World Health Organization recommends in relation to pain, which is its prevention and relief to increase the patient's quality of life1. The pain approach is the way that Nursing professionals find to offer the lowest conditions of life in the time that remains to the patient, seeking to return to the same their "autonomy", through the transgression of the painful sensation, be it physical or emotional or spiritual.[16]

It is impossible to work with palliative care and not address human finiteness. In this study, the treatment of this theme arises with the evocation of the term "death" in the 1st periphery, showing that the professionals understand that the objective of the care they are carrying out is precisely to close the cycle of human life. This vision materializes when Nursing team brings to light the evocation of the word "terminal" in the 2nd periphery. It is said that, for most professionals, coping with death is not something that is easy, since facing this event occurs based on the experience of the other, without ever having access to the reliable extension of death.[17]

Although death and the dying process are difficult to understand and confront, it has assumed a different connotation in recent times in the context of palliative care, since Nursing professionals, as well as the palliative care team, come to realize Death as a relief to patients. Thus, palliative care professionals have created a new social representation of death, which allows the withdrawal of this event from biological extension, transgressing it to something that can be socially accepted.[7]

The sadness and suffering that were evoked in the 2nd periphery are inevitable experiences for professionals and when such feelings are associated with death, we can infer two interpretations. In the first, the professionals are emotionally involved with the patients because they are the longest by their side, giving rise to the usual feeling that occurs with professionals who deal with palliative care. The second is the understanding that the assistance to be provided needs to promote the relief of suffering and sadness to provide a worthy death to the patient. There is also a feeling that their care is not adequate enough for the patient and that the professional could have done more.

In this sense, the total lack of understanding of death and the impotence that arises through this, brings to the professionals of the team, a range of feelings that make them render a more solicitous and humanistic assistance to the patient outside of curative therapeutic possibility, and this can be inferred when The subjects of the research evoke the words "attention", in the first periphery, and "affection", "understanding" and "patience", in the second periphery. These feelings are concretized by the actions evoked in the contrast element, represented by the words "comfort", "dedication", "humanization" and "quality of life".

The feelings experienced and the actions performed by the Nursing team translate into the effort to produce a permeated care of humanization in a context where death is eminent. Therefore, having dedication and patience, promoting comfort and providing care is to develop a sensitive care, using humanization not only with a care tool, but as

a principle that allows to reformulate the care, creating new ways of caring that propose the best for the Patient.[9]

The composition of the contrast elements reveals that these may point to a possible second social representation within the group studied, since the professionals evoked words that refer to an image content, totally characteristic of palliative care, being: "comfort", "Dedication," "God," "family," "humanization," "quality of life, "and" respect." This set of words reports to something essential in palliative care, the integrality of care, since the professionals give space within the care for the family, that comes to be seen as a unit of care, for the spiritual dimension and respect The patient and their wishes.

Some professionals have instilled in the mind that providing quality of life to the patient in palliative care is something of extreme complexity. However, simply allowing the family to approach the care context and offering support so that it can also take care of the Patient, are already simple and effective ways to provide such quality. The insertion of the family in the care is valued affirming that, for the patients to be in a place where the relatives can be inserted and with access to information that goes from medical bulletins until the understanding of each step of the process of death and to die, causes completeness of care is enforced.[18]

Attention to the spiritual aspects of palliative care can help in the delivery of patient care. Studies have pointed out that having a religious engagement brings a life with a more prolix and proficient course.19 Thus, the appreciation of the spiritual dimension, demonstrated by the Nursing team helps when it comes to working with the relief of human suffering at the end of life. It is necessary, however, for Nursing professionals to have a broader knowledge of the spiritual issue, in order to be able to approach spirituality and integrate the being, making the patient feel at peace and with sensation that his life was complete.[3]

In order to legitimize a more holistic care, there must be respect for the autonomy and valorization of the patient in his final stage of life, where it is incumbent upon the professionals to recognize the patient as a singular being who has a power of choice and can appropriate his treatment through decision-making. The best way to put patient autonomy into practice is by exercising the ability to communicate, that is, by listening to what it has to say. This mechanism is the most effective instrument to validate client participation in the planning of their care and keep their respect during assistentece.[20]

CONCLUSION

Assistance in palliative care is permeated by two types of care: the first is professional care, where the physical needs of the patient are literally perceived and met, such as pain relief, sanitation, food and others. The second type of care is the sensitive, in which Nursing uses its art to palliate, making use of love, patience, dedication, understanding, affection and respect, all of which are represented in the humanization of care.

Unveiling the social representations of the Nursing team in relation to palliative care is a way of knowing how these professionals perform their representative activity on the object studied, since such representations guide the behavior of the subjects, shaping the elements within the scope what behavior will emerge. In this way, it is a harbinger of the action of these professionals.

In this study, the representation obtained shows that Nursing professionals seek an approximation with the emotional aspect of care, and may reveal the profile of a training that seeks to break the stigma that the distance between patient and professional must permeate health and Nursing care . In addition, learning to understand the social representations of the Nursing team makes it possible to infer through a collective means, how professionals understand palliative care, which does not revoke that it can be applied to an individual intervention.

Thus, it can be concluded that palliative care does not need to be something devoid of feelings and that not taking the patient to a desired cure does not mean that it is a failed or useless care, More and more, so it can break with the paradigm of healing and begin to carry out care that provides an orthotanasia to the terminal patient. And Nursing, being the art of caring, must foster ways for this change to take shape.

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