

SOCIAL REPRESENTATIONS ABOUT CANCER AMONG RELATIVES OF PATIENT UNDERGOING ONCOLOGICAL TREATMENT

REPRESENTAÇÕES SOCIAIS SOBRE O CÂNCER ENTRE FAMILIARES DE PACIENTES EM TRATAMENTO ONCOLÓGICO

REPRESENTACIONES SOCIALES DEL CÁNCER ENTRE FAMILIARES DE PACIENTES EN TRATAMIENTO ONCOLÓGICO

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ABSTRACT

Cancer is a disease surrounded by stigmas which emotionally affects their carriers as well as their families. The research aimed to apprehend the social representations of cancer among relatives of patients undergoing cancer treatment in a hospital in São Luís-Ma. This was a study of exploratory and descriptive qualitative approach, where for reasons of research, followed by the assumptions of the Social Representation Theory. The study subjects were 102 relatives of patients in outpatient cancer treatment and the sample of random and spontaneous type. Data were collected through the Summoning Technique Free of words and analyzed with the assistance of the software EVOC 2003. The analysis of the four houses picture showed a negative representation of cancer by family members, with the words, despair, pain, fear, death, suffering, treatment and sadness as the centerpiece of representations, and the word hope is the first periphery. The study on the social representations of cancer among family members of cancer patients proved to be of great importance, as presented in the present feeling among the families of those affected by the disease.

Keywords: Nursing; Neoplasms; Family; Oncology Nurse.

RESUMO

O câncer é uma enfermidade cercada de estigmas a qual afeta emocionalmente seus portadores, assim como os seus familiares. A pesquisa teve como objetivo apreender as representações sociais sobre o câncer entre familiares de pacientes submetidos a tratamento oncológico em um hospital de São Luís-Ma. Tratou-se de um estudo de natureza exploratório-descritiva com abordagem qualitativa, em que se seguiram os pressupostos da Teoria das Representações Sociais para fundamentação da pesquisa. Os sujeitos da pesquisa foram 102 familiares de pacientes em tratamento oncológico ambulatorial e a amostra foi do tipo aleatória e espontânea. Os dados foram coletados a partir da Técnica de Evocação Livre de Palavras e analisados com o auxílio do software EVOC 2003. A análise do quadro de quatro casas demonstrou uma representação negativa do câncer por parte dos familiares, com as seguintes palavras: desespero, dor, medo, morte, sofrimento, tratamento e tristeza como núcleo central das representações. E a palavra esperança constitui a primeira periferia. O estudo sobre as representações sociais do câncer entre os familiares de pacientes oncológicos mostrou-se de grande relevância, pois apresentou o sentimento presente entre os familiares daqueles acometidos pela doença.

Palavras-chave: Enfermagem; Neoplasias; Família; Enfermagem Oncológica.

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RESUMEN

El cáncer es una enfermedad rodeada de estigmas que afecta emocionalmente tanto a los pacientes como a sus familiares. La presente investigación tuvo como objetivo aprehender las representaciones sociales del cáncer entre familiares de pacientes sometidos a tratamiento oncológico en un hospital de San Luís-Ma. Se trata de un estudio cualitativo exploratorio y descriptivo que siguió las concepciones de la teoría de las representaciones sociales. Los sujetos del estudio eran 102 familiares de pacientes en tratamiento oncológico ambulatorio; el muestro era aleatorio espontáneo. Los datos eran recogidos siguiendo la técnica de evocación libre de palabras y analizados con ayuda del software EVOC 2003. El análisis del cuadro de cuatro casilleros indicó que la representación del cáncer de los familiares era negativa, con las siguientes palabras: desesperación, dolor, miedo, muerte, sufrimiento, tratamiento y tristeza como núcleo central de las representaciones. La palabra esperanza era la primera periférica. El estudio sobre las representaciones sociales del cáncer entre familiares de pacientes oncológicos resultó ser de gran importancia pues mostró el sentimiento latente entre los familiares de los afectados por la enfermedad.

Palabras clave: Enfermería; Neoplasias; Familia; Enfermería Oncológica.

INTRODUCTION

The cancer is considered a set of more than 100 diseases with the uncontrolled growth of cells that invade tissues and organs as something in common. Cancer causes can be external, when related to the environment, habits and customs of a society; or internal, when linked to genetic predispositions and the body's ability to defend from external aggression, both interrelated.¹ This is a group of diseases understood by society as something serious, often associated with an imminent risk of death.²

It is known that in recent years, there has been an advance in the diagnosis and treatment of this disease, but despite these advances, unwanted and unpleasant reactions in cancer coping process are often observed such as physical aspects change, pain, adverse effect therapy, mutilations, and death. Thus, this disease causes psychological impacts to affected people, resulting in the emergence of feelings of different kinds and intensities.³

In fact, the diagnosis of cancer opens the way to an uncertain, painful, prolonged, painful and frightening treatment, which often weakens plans and makes the imminent possibility of death.⁴ In this context, one of the main consequences of the diagnosis of cancer news is the feeling of uncertainty related to the problems and changes that affect patients and their families.

The disease process by cancer undoubtedly affects families who experience the daily treatment intensely, also having changes and reorganizations in their structure to meet the demands of the family member in his monitoring.^{5,6}

Moreover, it is noteworthy that cancer has a social stigma of incurable disease and, in this scenario, the life perspective of the family is shaken and affected by the feeling of fear of facing unwanted experiences they have to live.³ Cancer diagnosis often causes a shock perceived by the desperation of families who believe that this is an incurable disease and undeniable relationship with death.⁷

This perception makes sometimes facing the most complex disease because death is related to the convergence of nu-

merous unpleasant feelings and questions, highlighting the suffering experienced by those who stay. Moreover, despite is undeniable, it is a sad, dramatic event and destroying hopes.^{8,9}

Therefore, the families are faced with stigmas and myths related to cancer permeating the social imaginary, causing negative impacts on the acceptance process of the disease. This has high cost, considering that the family is fundamental for the assistance to these patients.⁵

The cancer stigma causes difficulties among family members of cancer patients in dealing with the disease. They point out that this is an extremely feared disease that combines the idea of death and causes unpleasant feelings such as panic, fear, worry, insecurity, anxiety, nervousness, distress, restlessness, anguish, despair, scare, and fear.⁵

By being a disease fenced of stigmata, which induces fear and affects people emotionally, it is believed that facing cancer is difficult for both the patient and the family. Although there are publications that focus on the inclusion of family members in the care of cancer patients, this research was justified by the fact that little has been produced in the association between social representations of family members of patients with cancer treatment and their implications for its coping in the care process.

Thus, the research aimed to identify the social representations of cancer among relatives of patients undergoing cancer treatment in a hospital in São Luís, MA starting from the assumption that such social representations have direct repercussions in fighting the disease in the family, interfering with feelings and reactions.

METHODOLOGY

This is an exploratory-descriptive study with a qualitative approach that, for being a research, the assumptions of the Theory of Social Representations proposed by Serge Moscovici were followed, from the structural aspects of Jean-Claude Abric. Research execution took place at a referral hospital for cancer care in São Luís, Maranhão.

Data collection took place in January and February 2014 in the outpatient hospital room in the morning shift on weekdays. All families who were invited agreed to participate. Thus, there were 102 families interviewed randomly and spontaneously, according to the following inclusion criteria: be older of 18 years old, be a first degree relative of the patient and accompany him regularly in his treatment. The exclusion criteria decided to exclude the family of patients who did not do regular treatment in the study object hospital, who were monitoring other conditions other than cancer or who were still investigating in the diagnostic process.

Data were collected from the Word Free Association Technique (TALP). The questionnaires were applied in the waiting room for consultation, and after the individual's consent, an inductive term with the word cancer was presented to the participants. After presenting the inductive term, they were asked to say five words that come to mind and, listing each according to the order of importance, because, in their most recent studies, Abric¹⁰ suggests replacing the *criterion of rang appearance of the rang criterion of importance*, resulting of the rank made by the subject.

The data analysis was done with the help of software called EVOC 2003-*Ensemble Programmes Permettant L'analyse des Evocations*. The analysis came from the organization of words mentioned in *Word for Windows*, grouped in alphabetical order according to their synonyms, forming the word dictionary. Then, the corpus was built with the help of Excel for Windows. Upon completion of the corpus, it was released in EVOC-2003 software program, which provided standardized data that were grouped under four houses, which corresponded to the structural approach of social representations proposed by Abric.¹⁰

In the structural approach, the core is understood as a subset of the SR, having other complementary structural functions, called peripheral and recognized. It is important for the theory, to know the proper object of representation, showing what is being represented. This form of theoretical reference of the key elements and the periphery shows the internal organization of the Social Representation, which are characterized by mobility, flexibility, and individualized expression.¹¹

The corpus analysis resulted in 485 words cited, with 143 different words, with the average order of evocations (AOE) of 3.01, and the intermediate frequency was established as 17 and the minimum of eight.

For the implementation of this study, the project was first submitted for analysis of the Research Ethics Committee (CEP) of UNICEUMA University, through Brazil Platform, according to the regulations of the National Research Ethics Commission (CONEP). It was approved by the opinion issued 469,832 on 12.17.2013. The recommendations set in the Na-

tional Health Council Resolution 466/2012 were followed to meet the ethical criteria.

RESULT AND DISCUSSION

The research had a sample of 102 relatives of patients undergoing cancer treatment, and 80.4% were female. Of this total, 2.9% were under 20 years old, 25.5% were from 20 to 30 years old, 37.3% were 31 to 40 years old, and 34.3% were older than 40 years old. As the patient's treatment time, 55.9% had less than one year, 38.2% from one to five years and 5.9% over five years of treatment.

A table with 4 homes was built (Table 1), with the purpose of presenting the most evoked words and less frequently evocation. To understand the situation, the words that are in the upper left quadrant are probably the core elements of the study representation. Those words that are in the upper right quadrant and the lower right are the most clearly peripheral elements. The words that are in the lower left quadrant are the contrasting elements considered.

Table 1 shows the structure of social representation of cancer among family members of patients undergoing cancer treatment in a hospital in São Luís, revealing in its upper left quadrant the words that have higher frequencies and were more readily evoked, presenting a possible core of this representation the words despair, pain, fear, death, suffering, treatment and sadness. The words that make up the core reveal negative feelings among family members about cancer, possibly resulting from existing stigmas in the disease.

The term despair is in the core, reflecting the family feeling of imbalance, especially at the time of cancer diagnosis discovery in the family, because people feed the feeling that this disease does not occur in their family environment.

After the discovery of the unexpected diagnosis, the family members start a stage of sadness and grief, feelings that were evoked by them during the research, which are reflections of the negative stigma surrounding cancer. Desperation comes from the initial face the diagnosis of cancer; the family member is emotionally shaken by having to accept cancer in their midst and at the same time having support for the loved one carrier of the disease.¹²

The word pain was the second most mentioned, representing suffering for the family of the patient with cancer because the pain is one of the symptoms feared by the patient, as well as the family that accompanies him daily. Pain provides the patient with a depressive state becomes not possible to improve when the symptom is not extinguished in the individual's body. The individual can assume a state of incapacity to make plans and maintain the interest in life because of the suffering caused by this symptom, and it could be reversed when there is effective treatment for the relief of pain associated with psychological support.¹³

Table 1 - Structure of the social representation of cancer among relatives of patients undergoing treatment in an oncological reference hospital – São Luís. 2014

1º Quadrant – Core elements – central core			2º Quadrant – Elements of the 1st peripheral		
Frequency ≥17		Rang <3	Frequency ≥17		Rang ≥3
Evoked Term	Freq.	Rang	Evoked Term	Freq.	Rang
Despair	22	2.409	Hope	21	3.048
Pain	26	2.692			
Fear	25	2.360			
Death	21	2.905			
Suffering	19	2.316			
Treatment	23	2.696			
Sadness	36	2.417			
4º Quadrant – Contrast elements			3º Quadrant – Elements of the 2nd Peripheral		
Frequency <17		Rang <3	Frequency <17		Rang ≥3
Evoked Term	Freq.	Rang	Evoked Term	Freq.	Rang
God	13	2.538	Anguish	13	3.231
			Healing	12	3.167
Disease	8	2.750	Family	8	3.375
			Strength	10	3.600
Overcoming	12	2.667	Patience	12	3.833
			Victory	8	3.375

The terms fear and death evoked by family members reflect what they believe to be the prognosis of cancer that despite the progress in studies of the disease, they continue in a state of fear about the possibility of the loss of their loved one. The fear of death is related to the severity of the clinical and individual denial of feeling, becoming prevalent aspect of spiritual pain, caused by the way the patient deals with their own symptoms.¹²

The term treatment evoked by many of them emerges as a means of reversing the unexpected by all of them, a cure for cancer diagnosed in the family. With the treatment, it is believed that death will not come or will come later, leaving the family confident and desiring not to stop it because they believe that no interruption of treatment is favorable for a possible cure.

The treatment causes a routine change especially in the family, loving, social and physical relationships in the family affected by cancer.⁶ The treatment is also shown as a possible cure or prolongation of life of the loved one affected by cancer. Thus, the family act as motivators not to let the loved one to stop treatment because of adverse reactions present during it.¹⁴

The first periphery in the upper right quadrant have words that have high frequency, but not formed the core of not having enough average of evocation. In the first periphery, it is observed a positive feeling about cancer, contrary to the core, which has negative feelings. The first periphery is composed of

the word hope, which reflects the desire of the family to have a good prognosis at the end of treatment.

Hope can help the family to remain firm next to their loved one to help them holistically, believing that the situation will be different from those initially.⁶ This feeling is driven by external factors, such as their religion, love for them, enjoyment of life and the very possibility of death.

In this second periphery in the lower right quadrant, there are elements susceptible to influences from the external environment. The terms in this quadrant also reflect a positive feeling of the family about cancer. The words patience, strength, healing, family and victory represent the family’s wish that their loved one achieve success in cancer. In contrast, there is the word anxiety as a negative element.

When the family gets, the diagnosis of cancer feels responsible for contributing in the course of their loved one’s treatment. Thus, the family comes together to become a secure support for the family affected by the disease. They believe that with the union becomes strong and that strength is reflected the patient who comes to believe in healing and emerge victorious from the unexpected situation that arose in the course of his life.¹⁴

In the lower left quadrant, called as contrast elements, there are the words that were evoked more readily, but at low frequency and do not constitute the core. In this quadrant,

there are the words God and overcoming disease, representing the influence of religiosity of the family in coping with cancer.

Religiosity helps in receiving the diagnosis of cancer and helps in search of meanings for the disease, helping individuals in their face. Moreover, it is also attributed to the possibility of healing, since it is related to a Supreme Being. It is believed to contribute to the treatment, increasing the possibility of healing.¹⁵

The fact that the family has an attachment to God proves that religion is a practice already present in their reality but strengthened with the emergence of this new reality, which is the discovery of the disease. When winning each stage of the disease, there is the overcoming won with faith having the existence of a higher being that has the power of healing.⁴

CONCLUSION

Considering these results, it was concluded that although the medicine with its progress has transformed the prognosis for many types of cancer and in many cases, it allowed the cure, using it as an inducer term; the word cancer still evokes negative feelings. This was proven in the central core of this representation, composed of words such as fear, death, pain, sadness, despair, suffering and treatment. The family also has the idea that cancer is related to the death.

The peripheries have less negative feelings, evoking words like hope, healing, strength, patience, family and victory as integral elements of the quadrants, opposing only the term anguish. Religiosity is highlighted in the discourse of the family and can be understood as a possible element to overcome the disease in their family environment.

The study on the social representations of cancer among family members of cancer patients showed that the word cancer evokes the ideas ranging from fear to hope, demonstrating the need for deconstruction and strengthening of some representations during the care process. Thus, the research highlights the importance of the provision of investments in the production of information about cancer in nursing care spaces to transform the ideas that still stigmatizes the prognosis of the disease and therefore weakens the people involved in this process.

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