Social representations of feelings experienced by patients with cancer

Representaciones sociales de los sentimientos experimentados por pacientes con cáncer

Representações sociais dos sentimentos vivenciados pelo paciente portador de neoplasia

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Abstract

The aim was to identify the social representations about cancer of patients undergoing cancer treatment. This is an exploratory-descriptive study with a qualitative approach with data that used the research grounds following assumptions of the proposed Theory of Social Representations. The research had a total of 92 patients of various cancer diagnoses during chemotherapy treatment. Data were collected through individual interviews, using a semi-structured questionnaire where the patient had to enumerate the first 5 words that came to their mind from the most important to the least important. Among the words evoked, the ones that were repeated the most were fear, death and treatment, sadness and healing. Evidencing, therefore, the fear that the patient feels in the face of cancer. In the fifth line of words, the most evoked terms were healing, faith, God, hope. At the beginning of the treatment, the patient is afraid of a disease that still has an important psychosocial impact on his daily life. Oncological therapy performed with quality and efficiency, by qualified professionals who assist the patient in all its dimensions, who know parts of their feelings during treatment, can help to reduce suffering and reduce the physical and psychological impacts on the patient.

Descriptors: Oncology; Emotions; Diseases; Health Care; Social Psychology.

Resumén

El objetivo fue identificar las representaciones sociales sobre el cáncer de pacientes en tratamiento oncológico. Se trata de un estudio exploratorio-descriptivo con abordaje cualitativo con datos que utilizaron los fundamentos de la investigación siguiendo supuestos de la Teoría de las Representaciones Sociales propuesta. La investigación contó con un total de 92 pacientes de diversos diagnósticos de cáncer durante el tratamiento de quimioterapia. Los datos fueron recolectados a través de entrevistas individuales, utilizando un cuestionario semiestructurado donde el paciente debía enumerar las primeras 5 palabras que le venían a la mente de la más importante a la menos importante. Entre las palabras evocadas, las que más se repitieron fueron miedo, muerte y tratamiento, tristeza y curación. Evidenciando, por tanto, el miedo que siente el paciente ante el cáncer. En la quinta línea de palabras, los términos más evocados fueron curación, fe, Dios, esperanza. Al inicio del tratamiento, el paciente tiene miedo a una enfermedad que aún tiene un impacto psicosocial importante en su vida diaria. La terapia oncológica realizada con calidad y eficiencia, por profesionales calificados que asisten al paciente en todas sus dimensiones, que conocen parte de sus sentimientos durante el tratamiento, puede ayudar a disminuir el sufrimiento y reducir los impactos físicos y psicológicos en el paciente.

Descriptores: Oncología; Emociones; Enfermedad; Sanidad; Psicología Social.

Resumo

Objetivou-se identificar as representações sociais sobre o câncer dos pacientes em tratamento oncológico. Trata-se de um estudo exploratório-descritivo com abordagem qualitativa com dados que utilizaram fundamentação da pesquisa seguindo pressupostos da Teoria das Representações Sociais proposta. A pesquisa teve o total de 92 pacientes de diversos diagnósticos de câncer durante o tratamento quimioterápico. Os dados foram coletados por meio de entrevistas individuais, utilizando um questionário semiestruturado onde o paciente precisou enumerar as 5 primeiras palavras que viessem a sua cabeça da de maior importância para a de menor importância. Entre as palavras evocadas as que mais se repetiram foram medo, morte e tratamento, tristeza e cura. Evidenciando, portanto, o temor que o paciente sente frente o câncer. Na quinta linha de palavras os termos mais evocados foram cura, fé, Deus, esperança. No início do tratamento, o paciente encontra-se temeroso diante de uma doença que ainda tem uma repercussão psicossocial importante no seu dia-a-dia. A terapêutica oncológica realizada com qualidade e eficiência, por profissionais qualificados que assistem o paciente em todas as suas dimensões que conhecem partes de seus sentimentos durante o tratamento, pode auxiliar na redução do sofrimento e diminuir os impactos físicos e psíquicos no paciente.

Descritores: Oncologia; Emoções; Enfermidade; Atenção à Saúde; Psicologia Social.

Introduction

Cancer is defined as a rapid and uncontrolled growth of cells, which can arise in any part of the body and when it reaches neighboring tissues and organs, it is called metastasis. The causes derive from several factors: environmental, genetic, habits, lifestyle, and aging itself. It is estimated that for the triennium 2020-2022, Brazil will present 625 thousand new cases of cancer. Of these, 177,000 will be from non-melanoma skin cancer, 66,000 from breast cancer, 66,000 from lung cancer, 41,000 from rectal and colon cancer, 30,000 from lung cancer and 21,000 from stomach cancer[1].

In 2018, the world estimate was 18.1 million new cases of cancer and 9.6 million deaths. Lung cancer was the most diagnosed (11.6%), followed by the incidence of breast cancer (11.6%), colorectal cancer (10.2%) and prostate cancer (7.1%). Lung cancer also had the highest mortality (18.4%) followed by colorectal cancer (9.2%), stomach cancer (8.2%) and liver cancer (8.2%). In men, the highest incidence and mortality was due to lung cancer and in women, due to breast cancer[2].

Given this statistic, the best alternative to reduce the risks of manifesting the disease is prevention. However, if the patient already manifests the disease, resorting to treatment is the best choice. According to a study[3], during treatment, many negative points can affect the patient, such as lack of information about the disease, limited financial resources, insecurity about the future, fear and distance from the family. Therefore, the nurse's role is extremely important during the patient's therapeutic trajectory. It is he who has a direct meeting with the patient, who talks, asks questions, evaluates, and shares information with the multidisciplinary team[4].

Cancer is the second disease with the highest mortality rate in the world, related to multifactorial causes. In addition, what feelings do patients with cancer have in face of the disease through social representations?

When we are aware of the feelings presented by the patient undergoing cancer treatment, it is possible that we can offer him a humanized and differentiated care, in order to, somehow, alleviate this suffering as much as possible. Being able to provide this patient with emotional support within the oncological therapy offered.

Oncological therapy performed with quality and efficiency, by qualified professionals who assist the patient in all its dimensions, tends to minimize suffering and reduce the psychic and even physical impacts on the patient.

Thus, this research aims to identify the social representations of cancer patients undergoing cancer treatment. Although there are several published studies on this subject, it is necessary that more information be researched and disseminated, in order to facilitate the understanding of cancer patients about their feelings. Especially because when the difficulties faced by the cancer patient are identified, during the treatment one can adopt strategies that reduce the negative feelings. Therefore, this study is extremely important, not only for the population, but also for health professionals.

Methodology

This is an exploratory-descriptive study with a qualitative approach with data that used research grounds following the assumptions of the Theory of Social Representations proposed by Serge Moscovici. The research was carried out with patients assisted in the Oncology Sector of the São José Hospital and Maternity (HMSJ) in the Municipality of Colatina-ES. As inclusion criteria: being over 18 years old, regardless of sex or gender, being enrolled in cancer treatment at the HMSJ Institution. As an exclusion criterion: not being up to date with their treatment and people who received a medical diagnosis of cancer within a period of less than three months.

Data were collected through individual interviews, using a semi-structured questionnaire and the free word association technique (TALP). Therefore, after the patient agreed to participate in the research and signed the Free and Informed Consent Term (ICF), the term "Cancer" was presented. Then, the participant was asked to say the first five words that he remembered and that he could enumerate from 1 to 5 according to the importance they appeared. Then, the questionnaire with sociodemographic questions was applied and an interview with open questions was carried out. The speeches were transcribed and submitted to content analysis. For the analysis of sociodemographic and clinical data, Microsoft Excel 2016 software was used. The evocations, in turn, which followed the assumptions of the Theory of Social Representations proposed by Serge Moscovici, were analyzed through the website OpenEvoc 0.92. In order to preserve the identity of the patients, they were identified as P1, P2, P3...P100.

This research was approved by the Research Ethics Committee of the Centro Universitário do Espírito Santo - UNESC, meeting the criteria designed by the National Commission for Ethics in Research (CONEP). CAAE 46591021.0.00005062.

Results and Discussion

Among the 91 study participants, there was a predominance of females (66) and with a greater concentration of the age group greater than or equal to 60 years of age (40).

Table 1. Words most evoked from the inducing term Cancer. Colatina, ES, Brazil, 2022 (n=91)

Words	1st	2nd	3rd	4th	5th	Total
Cure	7	7	6	11	17	48
God	3	7	8	6	7	31

Faith	5	4	4	4	12	29
Treatment	8	6	6	5	1	26
Hope	2	2	7	9	5	25
Death	8	8	1	4	1	22
Fear	12	3	4	1	1	21
Sadness	7	3	2	3	2	17
Confidence	0	3	5	3	1	12
Pain	4	3	3	0	1	11
Suffering	1	5	2	2	1	11
Tranquility	1	3	3	1	2	10
Victory	0	2	2	2	4	10
Despair	4	3	1	0	0	8
Worry	5	0	1	1	1	8

Table 2. Frequency X Summon Order (TabFreq). Colatina, ES, Brazil, 2022 (n=91)

++	Frequência >= 3 / Ordem de evocação < 3		+-	Frequência >= 3 / Ordem de evocação >= 3	
5.71%	tratamento	2.42	10.55%	cura	3.5
4.84%	morte	2.18	6.81%	deus	3.23
4.62%	medo	1.86	6.37%	fé	3.48
3.74%	tristeza	2.41	5.49%	esperança	3.52

-+	Frequência < 3 / Ordem de evocação < 3		--	Frequência < 3 / Ordem de evocação >= 3	
2.42%	dor	2.18	2.64%	confiança	3.17
2.42%	sofrimento	2.73	2.2%	tranquilidade	3
1.76%	desespero	1.63	2.2%	vitória	3.8
1.76%	preocupação	2.13	1.1%	angústia	3.2
0.88%	incurável	1.25	1.1%	força	3.4
0.88%	família	2	0.88%	força de vontade	3.25

Source: Site OpenEVOC 0.92.

Regarding marital status, 50 were married and 52 considered themselves to be Catholics. As for the location of the disease/tumor, the most prevalent was breast cancer (41), diagnosis of 45% of patients, numbers that confirm the predominance of breast cancer cases in Brazil. Below is the result of the 5 most evoked word classes from the inducing term "cancer" as shown in Table 1.

The words that make up the upper left quadrant are elements/words that probably make up the central core, they are elements with higher frequency and lower average order of evocations, that is, quickly cited. The words treatment, death, fear, sadness, are usually feelings expressed by the patient at the beginning of the treatment.

In the upper right quadrant, it is composed of elements/words from the 1st periphery, evoked more frequently, but with less importance than those from the central nucleus. They are the most important peripheral elements due to their high frequency, mentioned later, being healing, God, faith and hope.

The lower right quadrant presents the elements/words of the 2nd periphery, the most peripheral of the representation, they are the least frequent and of lesser importance. Being, confidence, tranquility, victory, anguish, strength and willpower.

Finally, the lower left quadrant presents the contrast elements, with low frequencies, but considered of extreme importance by the patients. Pain, suffering, despair, worry,

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incurable and family were the elements of this quadrant. These words compose negative dimensions of representation and reflect the social and psychological adaptation of patients to their diagnosis.

Cancer in general can generate several feelings for the patient, sadness is one of them, the incapacity and weakness generated by the treatment prevents the individual from carrying out their routine, prevents them from living and making future plans with their family. The disease can cause low self-esteem, stress and even depression. In this way we observe that not having a disease directly relates health to happiness. Body image is a great difficulty faced, this change causes damage to the image and generates great psychological suffering, being observed through fear, anxiety, depression and uncertainty about the future and consternation with the body image. In moments of distress, patients draw strength from their limitations, this occurs when they are part of a social environment that offers them support and security through their reality, promoting a feeling of belonging to a social group[5-7].

The words fear and death present in the central nucleus of this research, expression conditions related to the history of the disease. We can say that these words participate in the collective memory associated with neoplasms, even though they were mentioned in the past, however, they still threaten the patient with cancer. This conclusion is based on the position of memory in the structure of social representations, and one of the characteristics of the central nucleus would relate the definition of the collective memory of a group, involuntary to its values and social conditions. A study on the social representations of the disease assures that the cancer-related brand has undergone changes over time, what was considered fatal, can now be considered as a lasting condition, although its epidemiological and therapeutic characteristics contribute to negative social representations. Although neoplasms are unrelated to the stigma attached to death, the disease still has a great impact on the well-being of the sick individual[8,9].

The patient diagnosed with cancer must be understood holistically, taking into account their religious or spiritual perspective, respecting their cultures and values. Religion can be a great ally when facing treatment, and can reduce the patient's burden of stress and anxiety. Studies show religion associated with well-being, happiness and contentment with life, religious people have less depression, fewer suicides and drug addiction. Another point to emphasize, in populations at risk, religion provides the patient with a better quality of life[6].

As an object of social representation, cancer research has theoretical foundations and indisputable results for all research moments and realities. However, there are new images, new concepts or attitudes that can be associated with representations to integrate different structures that affect the objects of the studied social group. Taking into account the complexity of patients' daily lives, regardless of personal or social origin, each representative element is important in the process of patient care by a scientifically qualified nursing team with fundamental tools for holistic care[9,10].

Final Considerations

The research objective was achieved by identifying the social representations in cancer patients undergoing chemotherapy. Cancer treatment causes patients to experience a variety of feelings and emotions, who need to deal with these daily challenges during the treatment process, which can be both physical and psychological. Thus, the nursing professional, who deals directly with the cancer patient and is part of the health team that works side by side with the patient during the health-disease process, will be able to intervene more effectively.

It is believed that through the results of this research, nursing can improve the care of cancer patients, seeking to provide an increasingly holistic care, in addition to helping to reduce suffering and reduce the negative impacts on the patient and even on the family, together the multidisciplinary team.

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