Cancer Patients and their Social Representations about the Disease: Impacts and Confrontations of the Diagnosis

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Pacientes com Câncer e suas Representações Sociais sobre a Doença: Impactos e Enfrentamentos do Diagnóstico Pacientes con Cáncer y sus Representaciones Sociales sobre la Enfermedad: Impactos y Confrontaciones del Diagnóstico

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ABSTRACT

Introduction: The diagnosis of cancer affects several aspects, whether emotional, relationships, spiritual and financial, making it an important public health problem worldwide. **Objective:** To analyze the structure of social representations of cancer for adult hospitalized cancer patients and reveal its relations with daily aspects of coping with the diagnosis and sickening by this pathology. **Method:** Qualitative, descriptive and exploratory study based in the Theory of Social Representations. The scenario was a federal cancer hospital in the city of Rio de Janeiro, with 111 participants living the oncological sickening. Free evocations related to the inducing term "cancer" were collected and a questionnaire was applied to characterize the patients. The EVOC 2005 software was utilized for the analyses. **Results:** Mostly male participants (69.3%), with elementary education (57.6%) appeared as probable core nucleus: disease, sadness and death. The reified knowledge of cancer is given through the word disease. The predominance of negative elements is recognized, although there are some positive ones such as treatment, cure and God in the representation of the group. The current disease carries stigma, making coping a painful and sad process. **Conclusion:** It is possible to detect the regret the patients express for being with cancer, while hope exists and moves them towards the cure. It is identified the need for the nurse to focus on the spiritual and religious dimensions during the caring process, understanding the individual as a unique and complex being that demands centered care. **Key words:** neoplasms; patient care; psychology, social; oncology nursing; adaptation, psychological.

RESUMO

Introdução: O diagnóstico de câncer atinge diversos aspectos, como emocionais, de relacionamento, espirituais e financeiros, tornando-o um importante problema de saúde pública mundialmente. Objetivo: Analisar a estrutura das representações sociais do câncer para pacientes oncológicos hospitalizados adultos e apontar sua relação com aspectos do cotidiano de enfrentamento do diagnóstico e do adoecimento por essa patologia. Método: De natureza qualitativa, descritiva e exploratória, embasado na Teoria das Representações Sociais. O cenário foi um hospital federal de câncer, no município do Rio de Janeiro, com 111 participantes vivendo o adoecimento oncológico. Foram coletadas as evocações livres ao termo indutor "câncer" e aplicado o questionário para caracterização dos pacientes. A análise se deu por intermédio do software EVOC 2005. Resultados: Participantes, majoritariamente homens (69,3%), com ensino fundamental (57,6%). Apresentaram-se como provável núcleo central: doença, tristeza e morte. O conhecimento reificado do câncer ocorreu por meio da palavra doença. Reconhece-se o predomínio de elementos negativos, ainda que hajam alguns positivos como tratamento, cura e Deus na representação do grupo. A doença em voga carreia estigma, tornando o enfrentamento um processo doloroso e triste. Conclusão: É possível observar o pesar de estar com câncer na visão dos pacientes, ao passo que a esperança existe e os move em direção à cura. Identifica-se a necessidade de o profissional enfermeiro dar enfoque no que diz respeito à dimensão espiritual e religiosa em seu cuidado, entendendo o indivíduo como um ser único e complexo que demanda cuidados individuais.

Palavras-chave: neoplasias; assistência ao paciente; psicologia social; enfermagem oncológica; adaptação psicológica.

RESUMEN

Introducción: El diagnóstico de cáncer incide en diversos aspectos, ya sean emocionales, relacionales, espirituales y económicos, convirtiéndolo en un importante problema de salud pública a nivel mundial. Objetivo: Analizar la estructura de las representaciones sociales del cáncer en pacientes adultos con cáncer hospitalizados y señalar su relación con aspectos cotidianos del afrontamiento del diagnóstico y la enfermedad por esta patología. Método: Cualitativo, descriptivo y exploratorio, basado en la Teoría de las Representaciones Sociales. El escenario fue un hospital federal de cáncer, en la ciudad de Río de Janeiro, 111 participantes viviendo enfermarse de cáncer. Se recogieron evocaciones gratuitas del término inductor "cáncer" y se aplicó un cuestionario para caracterizar a los pacientes. El análisis se realizó mediante el software EVOC 2005. Resultados: Mayoritariamente varones (69,3%), con educación básica (57,6%). Aparecen como un probable núcleo central: enfermedad, tristeza y muerte. El conocimiento cosificado del cáncer se da a través de la palabra enfermedad. Se reconoce el predominio de elementos negativos, aunque existen algunos positivos como el tratamiento, la cura y Dios en la representación del grupo. La enfermedad actual conlleva un estigma, lo que hace que el afrontamiento sea un proceso doloroso y triste. Conclusión: Es posible observar el arrepentimiento de estar con cáncer en la mirada de los pacientes, mientras existe la esperanza y los mueve hacia la cura. Identifica la necesidad del profesional de enfermería de centrarse en la dimensión espiritual y religiosa en su cuidado, entendiendo al individuo como un ser único y complejo que demanda cuidados individuales.

Palabras clave: neoplasias; atención al paciente; psicología social; enfermería oncológica; adaptación psicológica.

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INTRODUCTION

Cancer is a non-communicable multi-causal disease with distinct associated infirmities and abnormal growth of cells, generated by modifiable and non-modifiable factors. As health professionals, nurses should acquire as much knowledge as possible on preventive measures, its development, treatment and control¹⁻³.

At world level, cancer is identified as the second main cause of death accounting for 9.6 million deaths in 2018. For each year of the triennium 2020-2022, it is estimated 625,000 new cases except non-melanoma skin cancer for Brazil⁴. As cases are increasing consistent with higher life expectancy, it is a fearsome diagnosis because many individuals have already lived with someone close with this pathology, going through the process of diagnosis and treatment, creating relationship with the object and building up its representation^{1,5}.

More than often, the sickening process raises uncertainties about the future, therapeutic approach and potential adverse effects, routine change, and loss of privacy due to hospitalization. These factors might lead patients and the society to negatively interpret the disease by creating a taboo, associating the infirmity with death, uncertainty, fear and insecurity about what lies ahead^{5,6}.

For being a strongly stigmatized disease, the diagnosis of cancer may put finitude and suffering in the scenario of those who find themselves affected by this pathology, extending to the family, support network, friends, possibly leading to psychic disorders as anxiety and depression^{5,6}.

The current study adopted the Theory of Social Representations to better understand the relation of the group with the object, as a form of socially shared knowledge. It helps health professionals to comprehend the scenario when they approach the consensual and reified universe of the group, unveiling the mental process related to cancer and identification of the patient's needs, essential for nursing care planning to those who cope with the oncologic sickening process⁸.

Cancer-related representational constructions for hospitalized adult patients can show relations with the daily coping with the diagnosis and sickening, influencing the formation of knowledge through practices and attitudes. As a consequence, the following research question was made: which is the social representation of cancer for those living with the disease and its relation with elements of daily life of coping with the diagnosis and sickening by this pathology?

The thematic requires more discussion in the scholar context, given that there is still a disposition for a biomedical model prioritizing the pathological dimension of the disease. As such, the study contributes to the production of knowledge in health, enhancing the improvement of oncologic nurse care in the perspective of full, holistic attention following specific agenda of this social group.

The objective of this study was to analyze the social representations of cancer in its structural approach for oncologic patients and reveal its relation with aspects of the daily life of coping with the diagnosis and sickening by this pathology.

The rationale of the present study hinges around the necessity of deepening the comprehension of social representations of cancer and its implication in the patients' life with this diagnosis to determine nursing care and respond to their physical, spiritual, social and emotional demands. With this, their quality-of-life improves and helps to accept better the diagnosis and therapeutic adherence because of a stronger bond, listening to the patient and search for life meaning through the contact with the transcendent, finding strength and perseverance in coping with the diagnostic and therapeutic process.

It is important to understand the representation of the group for potential intervention in the care, considering that it can change because of the constant technological advances of treatment, more accuracy, improving the quality-of-life. Former studies revealed that for oncologic patients the representations of the disease are overwhelmed by negative aspects due to the transformations caused in their lives and of those close to them and suffering during the often-long treatment, as the inevitable adverse events, affecting the life in general⁹⁻¹¹.

METHOD

Qualitative, descriptive and exploratory study based in the theoretical-methodological reference of the Theory of Social Representations (TSR) in it structural approach proposed by Jean-Claude Abric⁷, whose hypothesis suggests that the representation is organized around a core and a peripheral system through cognems relating among each other. These are construed as cognitive elements created from the relation of the group with the object¹². The study was conducted at the onco-hematologic and an oncologic surgery infirmary of a Federal Institution in the municipality of Rio de Janeiro, Brazil from October to December 2019.

111 patients enrolled with confirmed diagnosis of cancer in treatment at one of the clinics where the study was developed in compliance with the ethics of research with human beings. The inclusion criteria were patients older than 18 years of age, both genders in surgical, chemotherapy and/or radiotherapy treatment.

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Time of diagnosis was not considered, only diagnostic confirmation. The exclusion criteria were patients in palliative care, either surgical or clinic because of different representations based in their experiences and lives.

Data were collected with a sociodemographic questionnaire and free-association technique of words induced by the word "cancer". It consists in bringing words, expressions and adjectives that appear quickly in the participant's mind after hearing and visualizing the inducive words¹³. The investigator asked the participants to say five words that popped up in their thoughts as soon as the inducive term was uttered, at least three words would be acceptable and entered into the questionnaire.

Investigators collected the data at the onco-hematologic and oncology surgery clinic in a secluded room or at the bed according to the clinical status of the participants and inclusion criteria. Bed-ridden patients were approached when not being submitted to procedures, while eating, with some discomfort and/or pain during the development of the study and during the visit to avoid embarrassment. Most of them had companions who left the room to not interfere in the dialogue investigator-patient and possible tampering the study.

Forms were utilized to write down the participants characteristics and words evoked from the word "cancer" and tabulated in a Microsoft Excel for Windows[®]. Later, the words were analyzed through a chart with four quadrants processed by the software *Ensemble de Programmes Permettant Analyse de Evocations* (EVOC), version 2005.

This analysis is based in the structural approach of the representations¹², whose terms, word, expressions and/or cognems are divided in four quadrants from the crossing of the two axes, the horizontal for the frequency of the words and average order of evocation (AOE) in the vertical, also called Rang. At the left upper quadrant, the eligible elements to the central nucleus due to its high frequency and low Rang, indicating they were evoked promptly. At the left lower quadrant, the contrast zone including words with low frequency and low Rang. In this space, there are words opposed to the central core, suggesting the existence of a population subgroup from words evoked and present in this quadrant. Both in the upper and lower quadrant at right, there are the elements that form the first and second peripheries, respectively. These words are related to the most immediate context and practical, but flexible to accommodate the changes and protect the central core^{14,15}.

The possible central core is more solid and hardly changes giving meaning to the representation. It displays the most frequent terms that were evoked more times and less worthy average orders of evocation, configuring the words more promptly verbalized. The other peripheral elements are mutating and match the representations: first periphery, contrast zone and second periphery^{7,12,15}.

The analysis of similarity by co-occurrence was carried out where it was attempted to determine the limit of similarity between the words that form the chart of four quadrants and the quantity of existing connections. For that purpose, the maximum tree with the lexical identified in the representation was created¹⁶.

The maximum tree is a graphic representation of the connection between the words where the links are exposed, beginning with the highest levels of similarity, being impossible to close circles or have two ways to reach the same word. The similarity is calculated, dividing the number of times two words included in the chart are referenced by the same individual divided by the number of participants who spoke at least two words present in it. The analysis of similarity does not allow the confirmation of the centrality of the elements of a representation in the structural approach, becoming a second indicator of a likely centrality of the elements contained in the chart of four quadrants¹⁶.

The Institutional Review Board approved the study on October 9, 2019, report number 3,630,783, CAAE: 19774719.1.0000.5274 in compliance with Ordinances 466/2012¹⁷, 510/2016¹⁸ and 580/2018¹⁹ of the National Health Council.

RESULTS

The study sample consists in 111 participants, mostly males (69.3%). Of these, 50.4% were 60 years or older, predominantly married (52.2%) and complete elementary school (57.6%). Regardless of the study site located in Rio de Janeiro, the origin of a substantial number of patients (56.7%) was off-state because the institution is a reference site for cancer treatment. 45% claimed they were Catholic, 54.9% practiced other religions.

78.3% of the participants have confirmed diagnosis for more than three months and 54.5% reported history of cancer in the family. After free-association from the inducive term "cancer", 547 words were evoked, 216 of them different. The mean frequency utilized was 13, the minimum was 6 and the *Rang* mean was 2.80 in a 1-5 scale. Table 1 portrays how the four quadrants organize the data of social representation of cancer identified from the individuals' evocation.

The analysis of the evocation of the inducive term "cancer" resulted in the four quadrants chart with its construction and representational organization. The elements "disease", "grief" and "death" are present in the probable central core localized in the upper left quadrant.

AOE < 2.80				≥2.80		
Mean Frequency	Term evoked	Frequency	AOR	Term evoked	Frequency	AOR
≥ 13	Disease	41	1.341	Cure	33	3.455
	Grief	14	2.571	God	32	4.281
	Death	13	2.769	Treatment	19	3.263
< 12	Poor	10	1.9	Норе	12	2.917
	Pain	10	2.6	Ha∨e faith	12	3.167
	Suffering	10	2.8	Fight	11	3
	Fear	9	2	Difficult	8	2.875
	Sad	9	2.333	Family	7	3.143
	Horrible	8	2.625	Courage	6	3.333
	Concern	6	2.125			

Source: Data of the study (2021).

Caption: AOE = Average order of evocation.

The term "disease", the most promptly evoked and more frequently, brings with it feelings of grief and a portion of suffering because of the individual's ill condition and the limitations of the disease, changing its routine, and carrying a strong stigma. The diagnosis of cancer impacts the individual who listens to it, influencing its way of thinking, cope and live in the social mean because of the common thought of incurability associated with the disease.

Still in the probable central core, the words "grief" and "death" appear, strengthening the presence of negative elements associated with the illness, that can connect to different ideas, feelings and memories which are constructed through the media, personal experience and communication with other patients in the therapeutic process.

In the contrast zone, the words "poor", "pain", "grief", "fear", "sad", "horrible" and "concern" are found corroborating even more the number of negative elements and their relations with the central elements and supports a representational dimension of assessment of coping with the disease, encompassing organic systems (pain) and psychosocial aspects (suffering and concern).

In the first periphery, the terms "cure", "God" and "treatment" stand out as a triad encompassing the transcendent and the expectations about the future. In the second periphery, it appears the practical dimension of the representations beyond the pathological that the diagnosis ensues. The presence of the elements "hope" and "have faith" recall a human practical action, strengthening even more the connection with the transcendent. The cognems "difficulty", "fight" and "courage" carry within them a dimension of attitude, while the term "family" refers to the support network while coping with the disease. To understand the internal relations and the number of connections created by a word of Table 1, the analysis of similarity was carried out through which the maximum tree as built up (Figure 1) with 19 words of the same table as expressed by the 87 participants who evoked at least two of them to establish the connections with the terms.

The analysis of similarity allowed the identification of two thematic blocks: "disease" and "cure". The word "disease", allegedly central in the chart of four quadrants has more possibility of centrality due to the number of connections and strong bonds with other elements indicated as peripheral and central in the representation. The term identified as "disease" established connection with nine elements present: "treatment", "fight", "suffering", "God", "poor", "horrible", "death", "cure" and "sad", and the latter has high index of similarity with "cure" (0.138) and "God" (0.138), followed by "treatment" (0.069) and "horrible" (0.057).

The term "cure" has a set of specific and positive meaning involving "hope" and "have faith", while "God" was kept isolated, connecting only to the word "disease". It draws the attention how the term "treatment" does not connect to the word "cure", but to "disease", instead, which shows how social thinking still present believes that a disease can be treated and that the cure of this disease is connected to some hope, but possibly not the case in many cancer diagnosis.

The reified knowledge of cancer is given through the lexical "disease", identifying in its surrounding the predominance of negative elements regardless of some positives as "treatment", "cure" and "God". The chart of four quadrants and the analysis of similarity are connected

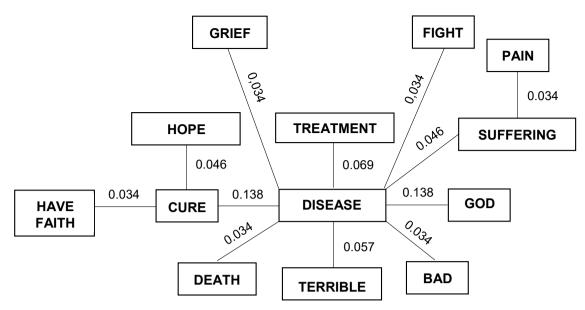


Figure 1. Analysis of similarity related to social representation of cancer. Rio de Janeiro/RJ, 2019 (n=87) **Source:** Study's data (2021).

to a tension present in the relation between the scientific knowledge, an evaluation process with more negative character and an aspect of positive perspective on the other side, the latter, less important than the former.

DISCUSSION

The social representation of cancer for hospitalized adult oncologic patients in a first moment expresses around the triad affective-cognitive through the cognems "disease", "grief" and "death" present in the central core. From these two dimensions, it is observed the common sense by means of the idea of the disease while grief is an affective manifestation in face of the possibility of sickening and death as a direct relation bound to the diagnostic of cancer^{9,20}. It means that from the perspective of its structure the social representation is grounded in a relation of negative elements as it was found.

The process of coping with cancer for the hospitalized patient is potentiated by the loss of privacy, constant manipulations, several exams, tiredness, noises, anguish, anxiety, discomfort and desire to be at home. The physical distance of the supporting network added to tackling with situations that cancer brings up impacts the individual routine, including change of family roles affecting the quality-of-life of the patient and most of the times, its social isolation^{9,20}.

Currently, cancer is permanently the major theme of preventive and educative campaigns in vehicles of great circulation as television, newspapers and various Internet websites. With this, the population gets acquainted with scientific and technical knowledge that are reinterpreted under the light of social, cultural, symbolic and religious codes among others^{21,22}.

Simultaneous with the more cognitive process of representational construction, the affective dimension stands out, present in social groups that cope with the pathology in its nearest mean, in addition to those which are exposed to image, scenes and situations of strong emotions in shows, soap operas, movies and currently, in diffuse information in the social networks, corroborating the study findings^{21,22}.

This phenomenon consubstantiates a set of attitudes in face of cancer, sometimes grounded more in the cognitive and informational aspect with more objective and detached analysis or more personal and private because of affection involvement in this relation. When this analysis occurs from empirical data of persons living with this pathology, thinking of caring actions becomes relevant such as more information and problematization of the feelings. Simultaneously, the naive perception that the acquisition of knowledge necessarily leads to daily life changes and in its representations should be dropped²³.

Cancer has a strong social stigma, among them some of the elements of social representation, herein represented through the words "death", "grief", "suffering" and "horrible"^{24,25}. The uncertainty about the future, fear and anxiety related to cure, effects and possible mutilations resulting from treatment are in the mind of who lives with the disease. Many doubts involving potential side effects of the therapeutic of the individual exist, in addition to physical, emotional and economic wearing, among others which substantially change the quality-of-life of the person with cancer²⁶. While analyzing the similarity tree, it is possible to visualize the actual strong connection of the cognitive and affection elements, revealing the thought of the group, whose rationality is minimally linked to the emotional and, with this, an inner conflict appears, the respective transcendental (God) is associated with the disease likewise the disease is bound to the cure with the same intensity. The connection God and disease in the same process of sickening deserves attention because of the presence of a transcendental element addressed during the infirmity, being suggested, according to the study herein, the inclusion of spiritual support within health care, in the process health-disease and until the end of the treatment, extended to friends and family⁸.

Other studies already associated the diagnosis of a disease with a dismal prognosis and growth of spirituality and religiosity and its relation as an important factor in the process of coping²⁶. The action of the divine the science does not grasp, cure through faith, the cognem present in the second periphery and the connection to cure in the similarity tree expose the factors directly connected to coping and link with the transcendental. Due to this, it must be included in nursing practice for positive outcomes while living and coping in this phase.

Because of the impacts from the diagnosis and treatment, feelings of grief and suffering found in the study outcomes appear due to significant changes the disease causes physically and emotionally, further in the patient's daily activities and routine. This situation is consistent with the literature. In addition, it causes, quite often, roles changes in the family, indignation, unacceptance and anger with the diagnosis²⁵.

In this process, the action of skilled professionals to render the bad news is important for this process in conjunction with the multiprofessional team since the diagnosis through well-coming, qualified hearing, doubts clarification and acceptance of the patient, explaining the procedures it will undergo, based in scientific evidences, and emphasizing the uniqueness of each human being with its own experience.

In the course of the treatment, the individual reflects about the consequences mainly those associated with body changes, affecting self-esteem and way of living; depression and denial play an important part of this process²⁷. These feelings can be compared to the phases of bereavement when the patient goes through important losses and a 5-steps process: denial, anger, bargain, depression and acceptance²⁸. It is important that the patient is able to cross all the phases, processing the mourning by the disease it carries, lost image and acceptance of what still lies ahead²⁸.

At a second moment, this representation develops around the practical dimension encompassing, paradoxically, the possibilities of death and cure and the relation with the transcendental through the cognem "God". This practice of representation forms, in a certain moment, a structure of control of its existence in face of a severe disease, with strong symbolic meaning, possibility of body disfiguring and death with considerable levels of suffering.

In addition, it was detected an important relation of the patient with spirituality and faith, mainly after the diagnosis confirmation. According to the patients, believing in God and Its actions and purposes grants meaning and control of the patient's life, helping to accept its present condition²⁴.

They emphasize yet that faith gives strength to cope with the difficulties caused by the disease, offering support and well-coming^{24,28}. Everything that occurs since the diagnosis until the treatment is described by actions of God, further to the belief that the individual needs to go through this moment by a divine will associated with spiritual practices that bring comfort, relief and strength in this period^{24,29}.

During the treatment, the relation between faith and the transcendental element identified as God in studies of persons living with HIV/aids, religious beliefs and individual ritualistic practices give new meaning to life, influenced by the religious context where the patient is immersed⁸.

Faith acts as a fuel giving strength to cope with the disease and the difficulties inherent to it, bringing tranquility and hope to reclaim the life as it was before. Health recovery through cure and search for self-esteem lived before the diagnosis are also important factors to be highlighted^{5,6}.

Each patient has its own understanding about coping, realizing the limits and how to overcome the obstacles, adjusting to new changes the infirmity has brought up. However, when associated with spirituality and faith, there is a positive repercussion in their lives because spiritual support help users and family to face the challenges since the diagnosis until treatment²⁹.

A good care offered to the oncologic patient occurs within an individual and holistic context expressed in actions involving religious and spiritual perspectives, effective communication between professional and patient, respect to diversity among other aspects; the result is better adherence to the therapeutic because of the well-being and well-coming³⁰⁻³².

The impossibility of generalization of the results and the utilization of only one technique of analysis, of what is being resolved, are the study limitations, since there are other techniques to collect and analyze the data.

Therefore, common sense and reified knowledge are important elements in studies of social representation and

were present in the empirical data. Within the context of a diagnosis and treatment demands, social representations help the individuals to gain more control of their daily lives and challenges based in shared and socially elaborated experiences.

CONCLUSION

The present study addresses the representational structure through cognitive, affection and practical perspectives, expressing in feelings, knowledge, attitudes and a spiritual-religious dimension beyond the pathology itself. In addition, the chart of four quadrants reveals negative elements encountered in the cognition of the group even in face of significant advances of technology being utilized in the treatment.

The outcomes show that the social representation of the group about cancer has antagonistic conceptions, that ranges from death, present in the possible central core up to the cure found in the first periphery, reinforcing the importance of the action of professionals to consolidate and deconstruct some representations by means of the care provided.

The person with cancer resists to accept the diagnosis and adjustment in face of a new reality. It is necessary that the nurse provides patient-centered care which are wider than the diagnosis of cancer itself to help him holistically, attempting to change the social thought still imbued with disease-related negative aspects.

Spiritual and religious support appear as paramount in health services according to the patient reality, because studies have already concluded the positive impact regarding the acceptance of the diagnosis, adherence to the treatment and coping with the disease. While respecting the needs as they are expressed by the patient, the health professional can create a bond with him to go through the arduous process of the treatment by finding the meaning of life, grounded in faith and source of support and better disposition for self-care, minimizing negative emotional aspects related to the diagnosis and treatment.

As broad and deep the biopsychosocial understanding the professional has about the patient during hospitalization, more benefits will appear since it is a significant stress-generating process. The inclusion of social and spiritual dimensions in the care, further to technical and administrative activities carried out, contributes to a less painful coping in this phase, resulting in more cooperation and interest, in the treatment proposed and less hospital length of stay as a consequence of the reduction of complications. The noise in the environment is a limitation because the instrument utilized was based in the dialogue between the investigator and the patient.

CONTRIBUTIONS

Rachel Verdan Dib, Antonio Marcos Tosoli Gomes, Raquel de Souza Ramos and Luiz Carlos Moraes França contributed to the study design, acquisition, analysis and interpretation of the data, wording and critical review. Leandra da Silva Paes and Mariana Luiza de Oliveira Fleury contributed to the wording and critical review. They approved the final version for publication.

DECLARATION OF CONLICT OF INTERESTS

There is no conflict of interests to declare.

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