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Religious practices and surveillance mechanisms developed by patient families in the face of cancer

Práticas religiosas y mecanismos de vigilancia desarrollados por familias pacientes frente al cáncer

As práticas religiosas e os mecanismos de superação desenvolvidos por familiares de pacientes no enfrentamento do câncer

ABSTRACT

Considering cancer as a disease that is present in people's imaginary as a synonym of death and suffering, usually loaded with negative images and concepts. The aim of the study was to know the religious practices as a mechanism of overcoming developed by relatives of cancer patients. The study was guided by the assumptions of the Theory of Social Representations. The research used the qualitative approach and included 30 relatives of cancer patients undergoing chemotherapy at a national referral federal hospital for cancer treatment. Data were collected from semi-structured interviews and analyzed through Bardin content analysis, systematized by Oliveira, with the aid of QRS Nvivo 2.0 software. Through the study, we learn that families develop religious practices to overcome suffering, which provides courage and strength to experience the adversities that the disease carries.

DESCRIPTORS: Cancer; Family; Religiosity.

RESUMEN

Considerar el cáncer como una enfermedad presente en el imaginario de las personas como sinónimo de muerte y sufrimiento, generalmente cargado de imágenes y conceptos negativos. El objetivo del estudio fue conocer las prácticas religiosas como mecanismo de superación desarrollado por familiares de pacientes con cáncer. El estudio se guió por los supuestos de la Teoría de las representaciones sociales. La investigación utilizó el enfoque cualitativo e incluyó a 30 familiares de pacientes con cáncer sometidos a quimioterapia en un hospital federal de referencia nacional para el tratamiento del cáncer. Los datos se recopilaban de entrevistas semiestructuradas y se analizaron mediante el análisis de contenido de Bardin, sistematizado por Oliveira, con la ayuda del software QRS Nvivo 2.0. A través del estudio, aprendemos que las familias desarrollan prácticas religiosas como una forma de superar el sufrimiento, lo que proporciona coraje y fuerza para experimentar las adversidades que conlleva la enfermedad.

DESCRIPTORES: Gestión de Riesgos; Vigilancia de Guardia; Grupo de Enfermería.

RESUMO

Considerando-se o câncer como uma doença que está presente no imaginário das pessoas como sinônimo de morte e sofrimento, geralmente carregada de imagens e conceitos negativos. O objetivo do estudo foi conhecer as práticas religiosas como mecanismo de superação desenvolvido por familiares dos pacientes oncológicos. O estudo foi orientado pelos pressupostos da Teoria das Representações Sociais. A pesquisa utilizou a abordagem qualitativa e abrangeu 30 familiares de pacientes oncológicos em tratamento quimioterápico de um hospital federal de referência nacional no tratamento do câncer. Os dados foram coletados a partir da realização de entrevistas semiestructuradas e analisados através da análise de conteúdo de Bardin, sistematizada por Oliveira, com o auxílio do software QRS Nvivo 2.0. Através do estudo, aprendemos que as famílias desenvolvem as práticas religiosas como uma forma de superar o sofrimento, o que proporciona coragem e força para vivenciar as adversidades que a doença carrega.

DESCRITORES: Câncer; Família; Religiosidade.

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INTRODUCTION

This article is the result of part of the dissertation developed during the Master's Course in Nursing at the State University of Rio de Janeiro. It is considered relevant that nurses are attentive and sensitive to the needs and spiritual and religious dimensions that are built and experienced by cancer patients and their families, since it is believed that the elements identified in this research can support reflections and contribute to the construction of concepts referring to the experiences of the family that suffers when accompanying a loved one with a disease so full of uncertainties, metaphors, representational constructions and loaded with suffering.

In this way, the family members of cancer patients have a very particular way of perceiving the process of falling ill due to this morbid entity and that of living with a sick family member. For many families, cancer is perceived as a monster that invades life and takes over and dominates it in such a way that it takes away peace and quiet, that is, suffering involves both the patient and his family. In addition to the emotional deterioration that cancer causes in people's lives, it is still seen as a disease that also destroys the body, causing the

loss of the physical and emotional health of everyone involved in this process of illness⁽¹⁾.

In this sense, coping with the disease with the help of religiosity has been shown to be positive, since it contributes for the patient to have an improvement in their quality of life by reducing stress, anxiety, increasing their adherence to the proposed treatment, and contributing to the process of overcoming the disease.

Currently, the word coping has been replaced by Coping. "The Portuguese language has no word to express the complexity of that term, but its translation means "to deal with"; to face "or" to adapt to". Coping has been described as the union of strategies used by people to cope with situations that are uncomfortable, such as stress or illness.

Among Coping strategies, religiosity stands out, which can have a positive effect on the patient, contributing to a decrease in negative experiences caused by cancer and causing an improvement in their quality of life⁽³⁾.

Religiosity can be understood as a set of beliefs and practices belonging to a doctrine, which are shared and followed by a group of people through cults or rituals that necessarily involve the notion of faith. Spirituality, on the other hand,

is constituted by an existential intimate feeling, a search for the meaning of living and being in the world, which is not necessarily linked to the belief in something greater, such as a God⁽⁴⁾.

Carrying out health education for nurses and other health professionals on the subject is important for everyone to be prepared, as this way, the care offered will be done in a humanized way, assisting the client and their family members in a holistic way, since contemplating spiritual and religious issues will provide moments of comfort and peace, transmitting security to face this difficult moment. In view of the above, the objective of this study was to learn about religious practices as a coping mechanism developed by family members of cancer patients.

METHODOLOGY

The present study was characterized by being a descriptive qualitative research that has as an essential focus the desire to know the community, its characteristic features and its problems⁽⁵⁾. In addition, it is intended to describe, with accuracy, the facts and phenomena of a given reality, without intending to carry out any intervention process in the studied reality. The qualitative study is

concerned with the universe of values, beliefs, statements and meanings involved in human relationships and which cannot be quantified through numerical data or statistical analysis⁽⁶⁾.

Regarding the Theory of Social Representations, the procedural approach was chosen. This approach reveals that access to knowledge about social representations starts from the understanding of the human being as a producer of meanings, focusing on the analysis of symbolic productions, meanings and language, through which the subject builds the world in which he lives⁽⁷⁾. Thus, the procedural approach is the one that best suits the object of the present study.

The research had as field of study a public hospital of national reference in the treatment of cancer, located in the city of Rio de Janeiro. The number of subjects was 30 relatives of adult cancer clients who followed the patient during the nursing consultation carried out before starting outpatient chemotherapy.

The following criteria for inclusion of the subjects were adopted: preferably having first-degree kinship with the patient (father, mother, brother, son or spouse) and having accompanied their family member for at least one of the nursing consultations: the first time or return. The exclusion criteria used were family members under the age of 18 and not having accompanied the patient in one of the nursing consultations. To guarantee anonymity, the subjects were identified by the letter E followed by a number.

After approval by the Research Ethics Committee, data collection was started through semi-structured interviews, which are guided by a previous script and are characterized by their re-elaboration in the investigation process, covering issues and themes that were not included in its beginning⁽⁶⁾. The interviews were recorded on magnetic tapes, transcribed in full in Word file and returned to the subjects for confirmation of their testimonies. From the in-depth reading of the interviews and the mate-

rial collected, the thematic categorization was performed.

After collecting the data and transcribing the tapes, the data exploration phase was carried out with the aid of the Qualitative Solutions Research Nvivo 2.0 software (QRS Nvivo 2.0), which was designed for qualitative data analysis. This software is based on the principle of encoding and storing texts in specific categories. Thus, the analysis occurred from the previous definition of the representational dimensions classically considered by the main authors of the theory^(8,9), as feelings shared by family members of cancer patients undergoing chemotherapy treatment; images, metaphors and concepts of cancer for family members facing the disease; prejudices and stigmas in the experience of cancer; the different coping practices developed in the context of the disease and the process of becoming ill with cancer; knowledge about cancer and some anchoring elements; the experiences of nurses who work in oncology and their contributions to the family. For the purpose of this article, the dimension related to different coping practices developed in the context of the disease and the process of becoming ill with cancer will be further developed.

RESULTS AND DISCUSSION

It is estimated, for Brazil, biennium 2018-2019, the occurrence of 600 thousand new cases of cancer, for each year. Apart from non-melanoma skin cancer (about 170 thousand new cases), 420 thousand new cases of cancer will occur. Noncommunicable diseases and conditions (DANT) are already the main responsible for the illness and death of the population in the world. It is estimated that, in 2008, 36 million deaths (63%) occurred as a result of UHD, with emphasis on cardiovascular diseases (48% of UHD) and cancer - 21%⁽¹⁰⁾.

Concerns about what their existence will be like, after having a disease such as cancer, make the patient and his fa-

mily feel distant from the possibility of reordering their lives. The loss of control over life causes suffering and creates a feeling of helplessness, anguish, and isolation. Family members, in the daily life of the disease and treatment, have the need to balance their own feelings, dealing with the practical issues of life and, also, affective, and psychologically supporting the person affected by the tumor. Suffering is then disguised, guarded, transformed into an agreement of tacit silence that, apparently, keeps things in their proper places, but which prints, day by day, a 'time bomb' configuration in which a small change tends to vent all stored feelings⁽¹⁾.

In this context, to face the disease and illness with more meaning and meaning, many patients start to use spirituality as a fundamental strategy to be able to go through this whole process, giving them strength to overcome, courage, relief in suffering, which contributes in the process of adherence and adaptation to treatment. In these moments of resignification, religiosity and spirituality can act as a benefit for the patient, contributing to the reduction of negative experiences caused by cancer and improving their quality of life⁽¹¹⁾.

Spiritual support can generate hope, reorganization and adaptation to the illness process. It is understood that spirituality, when compared to an anchor, can symbolically mean something to "hold on", to hold on to, not to succumb and, thus, to serve as a stimulus/driving force necessary to face the disease⁽¹²⁾.

Despite the different beliefs, the speeches show us that, in the most difficult moments of coping with cancer, people turn to religion as a way to find hope for a cure and even a little comfort in the faith.

"Everything that you know can lead you to death is bad, even knowing, as today I am an evangelical, and for people who are evangelical, they have to go through that, we believe that, I believe

that my wife will cure, but believe that the treatment is 90% and 100% God, because unfortunately we know that people do, the medicine that comes and the nurse is there to apply the medicine in the best possible way, for her to have a cure, but it doesn't depend on the nurse, it doesn't depend on the doctor [...]" (E32).

Spirituality ends up helping in the process of redefinition of cancer, causing a motivation and relieving possible fears or erroneous beliefs that may arise, since the help of a supernatural force, or not, becomes an important ally in the fight against suffering. But it is important to emphasize that spirituality can arise after the impact of the disease, since being closer to the presence of faith eases the feeling of being closer to death⁽¹³⁾.

It is evident, in the subjects' statements, the presence of a superior force that guides and protects them in the face of adverse situations arising from cancer and its treatment. The problems are placed in the hands of the Divine so that he can act and operate in order to solve the case that, initially, seemed to have no solution.

"What I thought, because thank God, I am a person who has a lot of faith and I trust God a lot, understand? I put my faith in God, trusting Him, that he was going to operate, that he was going to heal, that the problem was very serious, it was in the rectum, that the doctor had said that he would not be able to remove that bag, the colostomy, that it is to separate forever, trusting the faith that I have and trusting Jesus, thank God, he will be able to take it out in time, after chemotherapy. I trust in God and in the name of Jesus he will be healed, right?" (E19).

When you have the feeling that everything is lost, the search for reli-

giosity and faith becomes an element that drives new spirit and hope in people's lives. Furthermore, the individual's possibility or belief in healing appears in the form of a miracle about to happen. It is observed that faith and trust represent a driving force that, combined with belief in God, can provide people with the hope of a cure for the disease. Faith acts as a positive element in coping with the disease and, in this context, it is interpreted as a strategy used to deal with the uncertainties of the disease and overcome the crisis situations experienced⁽¹⁴⁾.

When facing cancer, it is possible to observe that spiritual support mobilizes psycho-emotional mechanisms capable of easing pain, suffering, fear, and uncertainties. These mechanisms, in addition to providing the necessary support for reflection, enable the reassessment of feelings, behaviors and attitudes in the way of facing the disease and treatment and, consequently, transformations and/or adaptations in their way of life⁽¹²⁾.

It is through the path of spirituality that it is often possible to find possibilities of intervention that assist in patient care within the treatment. Faith is able to rekindle feelings like hope in people, something fundamental within the framework of hospitalization, since there is a series of fears about cancer built and reinforced socially⁽¹⁵⁾.

"I think the mood of the citizen contributes a lot to you. I'm a spiritist. Within the spiritism says that who has cancer can be a karmic disease, right? But evidently I will not be left with this side alone. Or you may have been born with a defective cell, let's call it that, if that term exists. Within this more spiritual concept it is said that it is a karmic disease, but I cannot stay on that. Karma is something you bring from other lives. I am not a profound connoisseur of spiritism, but I also had conversations with people

who know, who are spiritists, as if you brought them from other lives [...]" (E35).

The disease coping strategy implies the participation of family members and the search for religiosity. When feeling afflicted by a disease, people, in general, become more reflective and question their own religious and spiritual beliefs. Religion represents an important support and support for coping with the disease. Faith provides comfort and security, being interpreted as a strategy to deal with uncertainties regarding the evolution of the disease⁽¹⁶⁾.

The following speech shows us the importance of religious practice as an instrument that strengthens, encourages, and gives courage and hope to the lives of family members of cancer patients.

"I trusted God, but even people thought that my husband was going to die, because he was really sick, everyone, even his children thought, my children thought about being sick, he came to me and said, mother, just a miracle, only a miracle. In the name of Jesus, you will see the miracle!" (E19).

As we can see in the speech, the families of cancer patients indicate how insecure and vulnerable they feel in the future. However, faith is highlighted by these people and shows that this feeling comforts them and eases their suffering. It appears, then, that faith represents a powerful force capable of leading and driving the confrontation of illness based on the hope of a cure or as a mitigation of possible imminent suffering.

Thus, it becomes evident the need for the health professional to be attentive to the patient's religious faith, as well as to his family members, recognizing the spiritual dimension of these individuals as it brings them encouragement, courage and hope to face the disease. Faith becomes a source

of support for facing the diagnosis by patients and their families, as well as to be able to withstand the challenges caused by different treatments, or even comfort themselves in the face of the impossibility of cure⁽⁴⁾.

“Nobody really wants to have it, but it is something without explanation, because only God himself knows what we have to go through and what we don't have to go through, so I think it's an obstacle that we have to go through, win, show everyone that is a victory” (E21).

It is known that religiosity has a positive influence on coping with the disease, but it is necessary to expand studies to deepen the topic in question so that the patient is seen holistically. Given this, it is important for

people from churches to participate in hospitals or places where patients are, so that they can have moments when they can express their faith and live their religiosity.

CONCLUSION

In view of what is exposed far from this article, it is necessary to understand the images and concepts of cancer for families that have a loved one in this condition. Understanding this complexity requires the involvement and commitment of professionals who deal with this type of public for an effective improvement in the quality of life, both for the patient and his family. Caring for the other must involve not only the improvement of technical interventions, but much more than that, it involves attention focused on individuality and the symbolic struc-

ture inserted in each human being.

Contemplating the purpose of this study, the knowledge and appreciation of religious practices from the perspective of nurses, spirituality in the actions of care for patients/cancer users is still incipient, little valued, with implications for the professional training evidenced by the unpreparedness of professionals/nurses to deal with the aspects that integrate the spiritual dimension.

It is essential that nurses are attentive to the needs and religious dimensions brought by patients and their families, including requesting the collaboration of religious representatives, which is essential for the clinical management of the patient and his family, especially those who are in palliative care. Research that contemplates the theme is suggested in order to equip the professional nurse for his practice. ■

REFERENCES

1. Souza MGG, Gomes AMT. Sentimentos compartilhados por familiares de pacientes oncológicos em tratamento quimioterápico: um estudo de representações sociais. Rev. enferm. UERJ. 2012 abr/jun; 20(2):149-54.
2. Antoniazzi AS, Dell'Aglio DD, Bandeira DR. O Conceito de coping: uma revisão teórica. Estudos de Psicologia. 1998; 3(2):273-294.
3. Thuné-Boyle ICV, Stygall LJ, Keshtgar MRS, Davison TI, Newman SP. Religious coping strategies in patients diagnosed with breast cancer in the UK. Psycho-Oncology. 2011; 20(7):771-782.
4. Murakami R, Campos CJG. Religião e saúde mental: desafio de integrar a religiosidade ao cuidado com o paciente. Revista Brasileira de Enfermagem. 2012; 65(2):361-7.
5. Triviños ANS. Introdução à pesquisa em ciências sociais. São Paulo: Atlas; 2009.
6. Minayo MCS, organizador. Pesquisa social: teoria, método e criatividade. 6. ed. Petrópolis: Vozes; 1996.
7. Banchs MA. Alternativas de apropiación teórica: abordagem processual y estructural de las representaciones sociales. Educ cult Contemp. 2004; 1(2):39-60.
8. Moscovici S. Representações sociais: investigações em psicologia social. 6. ed. Petrópolis: Vozes; 2009.
9. Sá CP. Representações sociais: o conceito e o estado atual da teoria. In: Spink MJ. O conhecimento no cotidiano. São Paulo: Brasiliense; 1993.
10. Santos DL, Barreto DCOV, Silva LA, Marques LR, Machado PRF, Marta CB. Contributos que afetam a saúde mental do enfermeiro: revisão integrativa. Saúde Coletiva (Barueri). 2019 abr/mai/jun; 48:1291-1295.
11. Gobatto CA, Araujo TCCF. Religiosidade e espiritualidade em oncologia: concepções de profissionais da saúde. Psicol. USP. 2013; 24(1):11-34.
12. Siqueira HCH, Cecagno D, Medeiros AC. Espiritualidade no processo saúde-doença-cuidado do usuário oncológico: olhar do enfermeiro. Rev enferm UFPE on-line. 2017 ago; 11(8):2996-3004.
13. Cardoso AHA. Espiritualidade e câncer em pacientes submetidos a tratamento quimioterápico. 2014. 35 p. Monografia (Graduação em Enfermagem) – Universidade Estadual da Paraíba, Campina Grande. 2014.
14. Benites AC, Neme CMB, Santos MA. Significados da espiritualidade para pacientes com câncer em cuidados paliativos. Estudos de Psicologia. 2017;34(2):269-79.
15. Sousa FFDPR, Freitas SMFM, Farias AGS, Oliveira MDSC, Araújo MFM, Veras VS. Enfrentamento religioso/espiritual em pessoas com câncer em quimioterapia: revisão integrativa da literatura. SMAD-Revista Eletrônica Saúde Mental Álcool e Drogas. 2017; 13(1):45-51.
16. Pinto AC, et al. A Importância da espiritualidade em pacientes com câncer. Rev. Saúde.Com. 2015; 11(2):114-122.