

BIOPSYCOSOCIAL ASPECTS OF CANCER FOR RELATIVES OF HOSPITALIZED PATIENTS

Ingrede Tatiane Serafim Santana*

Ana Cleide Rezende dos Santos**

Anny Giselly Milhome da Costa Farre***

Ana Carla Ferreira Silva dos Santos****

Hertaline Menezes do Nascimento Rocha*****

ABSTRACT

Cancer is a chronic disease that directly and indirectly affects the life activities of families because of the influence of biopsychosocial aspects of the disease process. In this sense, the present study aims to know the biopsychosocial aspects brought about by cancer for family members of hospitalized patients. This is a qualitative and descriptive research with data collected through interviews in the period from November to December of 2015 and submitted to Thematic-Categorical Content Analysis. The main feelings mentioned by family members were sadness, fear, worry, shock, acceptance and hope; the disease causes changes in well-being, and in the professional, sexual and personal life, diminishing the self-esteem and confidence of the family; religiosity and family are the main sources of strength, and all family members understand the importance of their support to the patient. The study shows that family members are affected by different changes of biopsychosocial aspects, and they search sources such as religiosity to face the disease. Knowing these aspects is essential for proper care and improvement of the quality of life.

Keywords: Impacts on health. Carcinoma in situ. Family relationships.

INTRODUCTION

Cancer is considered the second largest cause of death in Brazil and a major public health problem with direct impact on social, epidemiological and economic spheres⁽¹⁾. People of all ages, genders, social classes, levels of education, beliefs and ethnicities can develop cancer, and all those who live the patient directly or indirectly affected⁽²⁾.

Patients and their relatives experience physical, psychological and financial loads that can greatly alter the dynamics of family relationships from the diagnosis of the disease to the treatment and its outcomes⁽³⁾. During this journey, the family is the main source of support for cancer patients and the relatives who are closer and provide more direct care are considered the caregivers⁽⁴⁾.

The family is considered a dynamic unit constituted by people who recognize themselves and coexist for a certain period of time and who are structured and organized to achieve common goals,

building a joint life history, and united by consanguineal bonds of adoption, interest and/or affection⁽⁵⁾.

Family caregivers are usually the companions during the hospitalization process for complications of cancer patients. Study pointed out that about 77.2% of cancer patients had sought hospital emergency services during the period of the disease, of which 63.2% were hospitalized, and the three main complaints were pain, breathing difficulties and gastrointestinal problems⁽⁶⁾.

Family members/companions actively participate in the care routine to their hospitalized relative. This can have physical, psychological and social impacts on their own health and, as a consequence, affect the much needed support in this process⁽⁷⁾. The partner of a woman with cancer, for example, feels the same threats from disease and his ego is affected. It is, thus, essential to recognize his needs and provide help targeted to his weaknesses so as to ensure a holistic assistance⁽⁸⁾.

The nursing team has a fundamental role in

*Nurse. Master student in the Graduate Program in Applied Health Sciences of UFS - Lagarto Campus. Lagarto, Sergipe, Brazil. E-mail: ingredetatiane@hotmail.com

**Nurse. Lagarto, Sergipe, Brazil. E-mail: rezende.ac@hotmail.com

***Nurse. PhD in Nursing. Professor of the Nursing Department of UFS - Prof. Antônio Garcia Filho Campus. Lagarto, Sergipe, Brazil. E-mail: annygiselly.enfermagem@gmail.com

****Nurse. Master in Health Sciences. Professor of the Nursing Department of UFS - Prof. Antônio Garcia Filho Campus. Lagarto, Sergipe, Brazil. E-mail: carlafss@yahoo.com.br

*****Nurse. Master in Parasitic Biology. Professor of the Nursing Department of UFS - Prof. Antônio Garcia Filho Campus. Lagarto, Sergipe, Brazil. E-mail: hertaline@hotmail.com

recognizing biopsychosocial needs of family members/companions during the hospitalization process of cancer patients. Nurses expect that the care actions to be effective, but also capable of increasing the satisfaction of the involved with the care⁽⁹⁾.

The importance of knowing these aspects for the planning and implementation of the assistance has been demonstrated by studies approaching the family in the health-disease process and the care of hospitalized cancer patients. These studies had contributed to broaden the discussion on the exposed topic and to the strengthening of nursing care.

In view of the above, the present study has as a guiding question: "What are the biopsychosocial aspects of cancer for family members of hospitalized patients?". The objective of this study is to describe the biopsychosocial aspects of cancer for family members of hospitalized patients, considering that by knowing these needs, nursing could expand health care to the patient/family binomial and guarantee a care focused on the priorities and global needs in oncology.

METHODOLOGY

This is a descriptive and qualitative study carried out with 16 family members/companions of patients with confirmed diagnosis of cancer and hospitalized at the University Hospital of Lagarto (HUL), Federal University of Sergipe (UFS), Brazil.

The HUL is a public institution that integrates the urgency and emergency network of the State, being characterized as a general hospital of medium size, with hospitalization in medical and surgical clinic, intensive therapy and pediatric wings. It covers an approximate population of 250 thousand people and has 172 beds, of which 112 are operational.

In a preliminary survey, researchers identified an average hospitalization of 10 patients per month for cancer-related complications and with confirmed or suspected diagnoses of the disease, which rose by up to 20% in some months of the year.

In the months of November and December 2015, a total of 16 patients were hospitalized with confirmed diagnosis of cancer and their relatives/caregivers constituted the research sample. Inclusion criteria were: to be a relative and main companion of adult and elderly patients with confirmed diagnosis of cancer. "Main" companion meant being present during most of the hospitalization period.

Data was collected through an interview with the family member at a moment considered most appropriate, and was guided by a semi-structured script prepared by the authors in the course Writing of Scientific Articles of the Undergraduate Nursing Course. This instrument was organized in two parts: 1) Identification data of the family member; and 2) Biopsychosocial aspects of cancer experienced by the family member.

Wanda Horta's theory of Basic Human Needs (BHN) guided the elaboration and order of questions related to the levels of needs: physiological, safety, love/relationship, esteem and self-accomplishment⁽¹⁰⁾. The aspects addressed were related to the feelings experienced and changes in well-being, professional and personal life, friendships, sexuality, self-confidence, spirituality and family value.

Resources such as active listening and observation were used to record the verbal and non-verbal language of the family member, respecting the individual limits and weaknesses/sufferings evidenced.

The collected data were analyzed by means of the Thematic-Categorical Content Analysis technique with the steps of floating reading, determination of registration units (RU), definition of units of meaning or themes and thematic analysis of RUs. The results explore cursive descriptions followed by examples of meaningful registration units for each category⁽¹¹⁾.

The ethical and legal aspects of the research were respected by signing an Informed Consent Form, guaranteeing anonymity and secrecy of the information. The project was approved by the Human Research Ethics Committee of UFS under Opinion 1,315,692.

RESULTS AND DISCUSSION

Among the 16 relatives, 15 presented ages between 21 and 60 years and only one over 60 years; 11 were female; three were spouses and 10 children; seven were single and six married/living common-law-marriage stable marriage; 12 were Catholics. Half of the relatives lived in the same household as the patient and received a monthly income greater than a minimum wage, of which 11 had some paid work. On schooling, seven had complete higher education and eight, complete/incomplete primary education.

Family members/companions, who were mostly young adults, had a close kinship with the patient. There

was a diversity regarding marital status, schooling and monthly income, but it is observed that women prevailed as the main responsible for the care of the sick family member. This fact may be related to the provision of care is still a female task, mainly in the Northeast of Brazil, based on an anthropological view in which the man is considered the provider and the woman, the caregiver⁽¹²⁾.

Even in the face of some limitations, such as the reduced number of family members participating in the interviews, the presence of paid caregivers and the absence of caregivers with the patient, the registration units on the biopsychosocial aspects of cancer experienced by family members gave origin to three categories presented below.

Diversity of feelings: from sadness to hope

To learn that a loved one has cancer make family members experience different feelings during the disease process, as they also feel themselves the pains and sufferings of the sick relative⁽⁴⁾. The relatives mentioned different kinds of feelings experienced upon discovering that a loved one has cancer, being the most common the feeling of sadness, followed by fear, worry, anxiety, shock, and hope.

Relatives, like patients, go through different stages when they receive the news of illness. Denial is usually the first phase identified, although this can also appear in later moments. Then comes anger, bargaining as a state of negotiation, depression and, finally, acceptance⁽¹³⁾. Although cancer is a disease difficult to understand, most of the relatives reported that the first feeling presented was the acceptance of the disease, seeking the strength to move forward.

It's sad to find out that my father has this disease but we had to be strong and accept what was happening so we could help him. (A1)

Unfortunately we were already waiting for this news, we were already suspecting of it, so accepting was easier than denying reality. (A2)

Nine family members reported that the discovery of cancer was not a surprise, since other cases of the disease had occurred in the family had happened in the same way as in the current case.

For me and my brothers it was no surprise, she was just the way our aunt was when she had cancer, we were waiting for the news, but we did not want to believe it. (A3)

Doctors had warned us since the start of the tests the

possibility of cancer, as there are other cases in our family, so we were not surprised. (A4)

Other family members, however, did not show their feelings; in this sense, the companions of women with cancer often opt to hide their true feelings towards the disease, once they feel responsible for making the role those who give strength to their sick relative⁽⁸⁾. There were also reports of different feelings:

I felt resentment to find out, they hid from me that my father was sick. (A5)

I felt strong chest pain; it was as if my world was collapsing. (A6)

The family is an interconnected system and when one component is affected by an illness, the entire family structure goes through negative emotional, biological and behavioral modifications⁽¹⁴⁾. In addition to different feelings, the family's life was affected in different ways, in the biological, psychological and social aspects, shaking the balance and the well-being of the individuals.

Personal, family and social aspects affected by caring

All participants stated that the discovery of the disease affected their well-being, with manifestations such as loss of appetite ($n = 12$), sleep ($n = 15$) and weight ($n = 14$). Some reported that after confirmation of the diagnosis, they began to present gynecological problems and sexual pains, increased anxiety, dizziness, increased nervousness, loss of will to live, headaches and increased daily worry.

Regarding their professional life, 10 family members stated that they were affected because they could not work on the days of follow-up at the hospital or did not have the concentration to perform their duties due to worries and discouragement, resulting in lower work income, resignation, lack of time and need to ask suspension in the work to take on the role of caregiver.

Before crises of events such as illnesses, the family tends to rearrange itself, often dividing tasks in order to be a source of support for its members, maintaining the understanding and respect, valorization and preservation of the family unit⁽¹⁵⁾.

The relative ends up assuming a different role in the structure of the family, starting to play roles that they did not have before, mainly in rural families, in which the man is considered head of the house. Due

to the need for changing roles, the diagnosis often stops the progress of individual and collective life plans⁽¹⁶⁾.

Interpersonal relationships were also affected, with an increase in family arguments, changes in family structure, lack of attention to relationships, less time to go out and do things for oneself due to the need to always be with the patient. The sexual life of eight family members changed, with a decrease in the number of sexual relations and reduction of libido related to psychological factors. Three family members reported to have reduced sex life to the point of complete inactivity.

Trust was also an aspect influenced by the disease because the family member became less confident about the situation; in contrast, some participants (n = 6) reported having an unshakeable confidence and even became more confident. Twelve family members reported that their self-esteem declined, with no interest in caring for themselves due to sadness and discouragement, or admitting that this attitude had begun long ago. Only one relative reported that he did not let the problems affect his self-esteem.

I feel very bad, I no longer have the will to take care of myself, I worry and I dedicate myself a lot to her. (A7)

My self-esteem remains the same; I do not let problems affect me. (A8)

Family support is fundamental in different aspects for the cancer patient and represents the basis for coping with the disease, for financial and emotional support, and is manifested, most of the time, through demonstrations of kindness and leisure moments⁽¹⁷⁾. The family members interviewed said that it is very important to be with the loved one. They stated that this is the moment when the sick person needs them the most, and that they must reciprocate the affection and care received in other times, being with the patient to the end, and offering what he needs most: love, company, care and attention.

This is the time she needs more people next to her, I'm with her all the time. (A9)

He's my father, it's my duty to take care of him. He took care of me and now I take care of him. (A10)

Because he needs someone of confidence; a helping hand. (A11)

Because she gets fragile and needs family support. (A12)

Cancer patients and their caregivers need quality

care as well as effective medical assistance, which is a major concern when the disease is diagnosed⁽¹⁸⁾.

Religiosity and overcoming

When asked if they had hold onto something to face the disease, 15 family members reported their religious beliefs and five reported to have hold onto the family, who represented the basis for moving forward and keep strong; only one reported not having clung to anything. Belief in something greater, able to provide the support needed to deal with the difficulties and the fears in the course of the disease strengthens the family by providing hope, as well as assists in the process of accepting the disease⁽¹⁵⁾.

Religiosity is considered as one of the factors responsible for improving the quality of life of people affected by diseases and their relatives. It causes an improvement in the health and in the physical-emotional well-being, with a typical intensification of faith at the most difficult moments⁽¹⁹⁾:

I have clung to God and my father, he needs me and I trust in his God. (A13)

I hold onto my Jehovah and my family. (A14)

It is notorious that faith was used as an important support tool for family members. Religiosity, regardless of religion, intensity and starting point, is a resource that accompanies family members in the health and illness process. They turn to it to strengthen themselves during the hospitalization period, which prompts feelings of comfort and hope, helping to accept the prognosis⁽¹⁵⁾.

People seek religion when they experience limiting situations, such as illness, addiction, unemployment, family disharmony, among others. They resort to religiosity in the search of support to face the suffering they are experiencing⁽²⁰⁾. Family and patients find hope in faith/religion, a stronghold to fight cancer. In this way, it can be said that spirituality and faith are fundamental tools to deal with the disease and to have a better quality of life, both for cancer patients and for their families⁽¹⁹⁾.

FINAL CONSIDERATIONS

The biopsychosocial aspects of cancer in the lives of family members of hospitalized patients, both privately and socially, are diverse and affect their quality of life, bringing remarkable consequences in the daily life of each family member. The study showed that family members are mainly affected by

psychobiological alterations, with diverse feelings during the health-disease process.

It was also observed that the disease affects their well-and their professional, personal and sexual life, self-esteem and confidence. However, the family member seeks the strength to move forward, sticking mainly to religiosity and to the family to confront the disease.

In addition to making it possible to know the

repercussions of cancer in the biopsychosocial aspects of relatives of patients, the present study also enabled us to identify the importance of a holistic view and a more humanized assistance to the families. Health professionals should take a closer look at the needs of each family member, in order to provide comprehensive care to everyone involved in the cancer process.

ASPECTOS BIOPSISSOCIAIS DO ADOECIMENTO POR CÂNCER PARA FAMILIARES DE PACIENTES HOSPITALIZADOS

RESUMO

O câncer é uma doença crônica que afeta de forma direta e indireta as atividades de vida do familiar, pela influência dos aspectos biopsicossociais do processo de adoecimento. Nesse sentido, o presente estudo tem como objetivo conhecer os aspectos biopsicossociais do adoecimento por câncer para familiares de pacientes hospitalizados. Trata-se de uma pesquisa descritiva qualitativa, cujos dados foram coletados no período de novembro e dezembro de 2015, por meio de entrevistas, e, em seguida, submetidos à Análise de Conteúdo Temático-Categorial. Os principais sentimentos mencionados pelos familiares foram tristeza, medo, preocupação, choque, aceitação e esperança; a doença provoca mudanças no bem-estar, na vida profissional, sexual e pessoal, além de diminuir a autoestima e a confiança dos familiares; a religiosidade e a família são as principais fontes de força, e todos os familiares compreendem a importância do seu apoio ao paciente. O estudo evidencia que o familiar é acometido por diferentes mudanças nos aspectos biopsicossociais, procurando fontes como a religiosidade para o enfrentamento da doença. Conhecer esses aspectos é fundamental para uma assistência adequada e melhoria da qualidade de vida.

Palavras-chave: Impactos na saúde. Carcinoma in situ. Relações familiares.

ASPECTOS BIOPSISSOCIALES DE LA ENFERMEDAD POR CÁNCER PARA FAMILIARES DE PACIENTES HOSPITALIZADOS

RESUMEN

El cáncer es una enfermedad crónica que afecta directa e indirectamente las actividades de vida del familiar, por la influencia de los aspectos biopsicosociales del proceso de la enfermedad. Así, el presente estudio tiene como objetivo conocer los aspectos biopsicosociales de la enfermedad por cáncer para los familiares de pacientes hospitalizados. Se trata de una investigación descriptiva cualitativa, cuyos datos fueron recolectados entre noviembre y diciembre de 2015, a través de entrevistas; y, después, sometidos al Análisis de Contenido Temático-Categorial. Los principales sentimientos mencionados por miembros de la familia fueron tristeza, miedo, preocupación, choque, aceptación y esperanza; la enfermedad provoca cambios en el bienestar, la vida profesional, sexual y personal, además de reducir la autoestima y la confianza de los familiares; la religiosidad y la familia son las principales fuentes de fuerza, y todos los familiares comprenden la importancia de su apoyo al paciente. El estudio resalta que el familiar es afectado por diferentes cambios en los aspectos biopsicosociales, buscando fuentes como la religiosidad para el enfrentamiento de la enfermedad. Conocer estos aspectos es fundamental para una atención adecuada y la mejora de la calidad de vida.

Palabras clave: Impactos en la salud. Carcinoma in situ. Relaciones familiares.

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Corresponding author: Ingrede Tatiane Serafim Santana. Rua Agenor Menezes Lima, 155. Paripiranga, Bahia, Brazil. (79) 999930492. E-mail: ingredetatiane@hotmail.com

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