

FAMILY COPING OF PATIENTS IN ONCOLOGICAL TREATMENT**ENFRENTAMENTO DE FAMILIARES DE PACIENTES EM TRATAMENTO ONCOLÓGICO****ENFRENTAMIENTO DE FAMILIARES DE PACIENTES EN TRATAMIENTO ONCOLÓGICO**

Fábio da Costa Carbogim¹, Ramony Zanotti de Assis Pereira², Franciane Silva Luiz³, Rodrigo de Oliveira Andrade⁴, Ana Carolina Carraro Tony⁵, Andyara do Carmo Pinto Coelho Paiva⁶

ABSTRACT

Objective: to understand how the relatives of people undergoing cancer treatment deal with the disease. **Method:** it is a descriptive-exploratory study with a qualitative approach, performed at the medical and surgical clinic of a Philanthropic Oncology Hospital of the State of Minas Gerais, Brazil. Ten companions of hospitalized patients were interviewed through a semi-structured questionnaire. The selection was carried out using random invitation at the hospital. Data were analyzed using the content analysis technique. **Result:** a change in family routine was identified, as well as the report of feelings of despair, lack of acceptance, insecurity, lack of preparation, anguish and fear of losing the loved one affected by cancer. The complexity and slowness of conventional resources intensifies the suffering of family members. In contrast, spirituality emerges as a resource for coping with the disease. **Conclusion:** family members perceive spirituality/religiosity as a resource for coping with the disease.

Descriptors: Nursing; Neoplasms; Family relationships; Caregivers; Cancer Care Facilities.

RESUMO

Objetivo: compreender como os familiares de pessoas em tratamento oncológico lidam com o enfrentamento da doença. **Método:** estudo descritivo, exploratório de natureza qualitativa, realizado na clínica médica e clínica cirúrgica de um Hospital Oncológico Filantrópico do interior do Estado de Minas Gerais. Foram entrevistados dez acompanhantes de pacientes internados, por meio de um questionário semiestruturado. A seleção foi através de convite aleatório no hospital. Os dados foram analisados utilizando-se a técnica de análise de conteúdo. **Resultado:** foi identificado mudança de rotina familiar, além do relato de sentimentos de desespero, inconformismo, insegurança, despreparo, angústia e medo de perda do ente acometido pelo câncer. A complexidade e a morosidade dos recursos convencionais intensificam o sofrimento dos familiares. Em contrapartida, a espiritualidade emerge como recurso para enfrentamento da doença. **Conclusão:** os familiares percebem a espiritualidade/religiosidade como recurso para enfrentar a doença.

Descritores: Enfermagem; Neoplasias; Relações familiares; Cuidadores; Instituições oncológicas.

¹ RN. Doctorate in Sciences. Associate Professor at Faculdade de Enfermagem da UFJF.

² RN. Nursing residente in Health Mental at UFJF.

³ RN. Master student in Nursing - Nursing Post-graduation Program at UFJF.

⁴ RN. Master student in Nursing - Nursing Post-graduation Program at UFJF.

⁵ Undergraduation student in Nursin – UFJF.

⁶ RN. Doctorate in Nursing. Associate Professor at Nursing School UFJF.

RESUMEN

Objetivo: comprender cómo los familiares de personas en tratamiento oncológico tratan con el enfrentamiento de la enfermedad. **Método:** estudio descriptivo, exploratorio de naturaleza cualitativa, realizado en la clínica médica y clínica quirúrgica de un Hospital Oncológico Filantrópico del interior del Estado de Minas Gerais. Se entrevistó a 10 acompañantes de pacientes internados, a través de un cuestionario semiestructurado. La selección fue a través de invitación al azar en el hospital. Los datos se analizaron utilizando la técnica de análisis de contenido. **Resultado:** se identificó un cambio de rutina familiar, además del relato de sentimientos de desesperación, no aceptación, inseguridad, despreparo, angustia y miedo a la pérdida del ente acometido por el cáncer. La complejidad y la morosidad de los recursos convencionales intensifican el sufrimiento de los familiares. En cambio, la espiritualidad emerge como recurso para el enfrentamiento de la enfermedad. **Conclusión:** los familiares perciben la espiritualidad / religiosidad como recurso para enfrentar la enfermedad.

Descriptor: Enfermería; Neoplasias; Relaciones familiares; Cuidadores; Instituciones Oncológicas.

INTRODUCTION

The increasing aging of the population has caused changes in its morbidity and mortality profile, which implies the need for assistance readjustments, with major emphasis on non-communicable diseases.¹ Among the non-communicable diseases, cancer stands out and becomes relevant for its lethality.

For the biennium 2018-2019, there is an estimate of 1.2 million new cases, with the most incident ones being prostate, lung, female breast, colon and rectum cancers, in addition to cervical, stomach and esophagus cancers.¹

Early diagnosis of cancer and the appropriate treatment setting are important outcome factors.² Between the onset of signs and symptoms and identification of cancer, there is a complex route in health care, which is usually covered by patient and family.³

Regarding social support networks for the cancer patient, the family is a particular feature because of the emotional proximity to the patient, experiencing all the uncertainties, expectations, hopes and needs for daily reorganization.³ Studies highlight the appropriate family support as an intervening factor in access and compliance with treatment, being one of the major predictors of maintenance of quality of life and resilience during oncological treatment.⁴⁻⁵

On the other hand, family members are not always prepared to effectively deal with the diagnosis, treatment and therapeutic guidelines, which can contribute to stress and negative implications for the quality of life of these people.⁵⁻⁶ It is not uncommon to find family members and/or caregivers with stigmatized perceptions about the cancer, associating it with death, finitude, which results in not mentioning the name of the

disease and even the omission of the diagnosis to the patient.⁶

In this context, in addition to the technical nature of interventions, it is for nurses and other health professionals to understand the family dynamics of the patient, make use of interpersonal communication skills and planning as strategies to minimize the impacts of the disease.^{3,6}

However, it is imperative to understand family experiences of patients in cancer treatment as a device for the care planning and provision of appropriate services. Assuming that the relatives of patients undergoing cancer treatment also suffer from the illness, questions emerge about the prospects, possibilities or despair in the care process of a loved one with cancer.

Studies indicate high prevalence of depressive symptoms in family of cancer patients, as well as risk factors for sadness, insomnia, stress, allergies and body pain.⁴⁻⁶ This issue raises the need for further studies that help and point out effective strategies in helping family to deal with the disease. Thus, this study is justified as it aims to understand how the relatives of patients undergoing cancer treatment cope with the disease.

METHOD

It is a descriptive-exploratory study, with a qualitative approach, performed at the medical and surgical clinic of a Philanthropic Oncology Hospital of the State of Minas Gerais, Brazil.

The study included ten relatives, men and women, inpatients' companions, contacted through random invitation at the hospital. There was no refusal or withdrawal in participating in the study. The inclusion criterion was: family member aged 18 or over and who was directly involved in the patient care since the beginning of the disease. Patients' relatives in ambulatory cancer care were excluded.

Participants were informed about the research objectives and the interview, giving their consent by reading and signing the Informed Consent. To ensure the anonymity and confidentiality of information provided by family members, the letter "P" was used, meaning participant, followed by numbering from 1 to 10, according to the order of the interviews.

Data collection, conducted by the researchers, took place from August to September 2016, from a semi-structured script, containing sociodemographic data such as age, gender, religion, in addition to the guiding questions: how did you found the cancer in your family? What is your reaction and feelings with the discovery of cancer? What are the needs that arose from

the cancer news? How have you lived and faced this reality after cancer news?

The interviews were individual, lasting an average of ten minutes, recorded on audio via digital recorder and later transcribed in full. Data collection was performed at the time it was perceived the frequent repetition of the manifest content in the statements.

Data were analyzed by the technique of content analysis⁷, divided into the following phases: pre-analysis, the material exploitation and processing of results, inference and interpretation. Pre-analysis aims to operationalize and systematize the preliminary ideas, generally approaching to the text to compose an analysis corpus. The material exploitation and the treatment of the results gathered corpus characteristics with similarity, then, by counting rules, aggregate, sort and categorize. In the phase of inference and interpretation, the synthesis and layering of information was done for analysis and critical interpretation of the findings, conducted by the objectives of the study.

It should be noted that the research started after the approval of the project by the Research Ethics Committee, under the Opinion number 1.701.001, CAAE 58364716.1.0000.5147, following the recommendations of resolution 466/2012 of the National Health Council.

RESULTS

Of the ten participants, most were female, the patient's spouse, evangelical religion and with average age of 46 years. Three categories arose from the identification and classification of the interviews analysis, as follows:

The discovery of the disease and feelings of family members

In the reports below, it is clear that the discovery of cancer causes significant impact on family life. They are reported Feelings of hopelessness, nonconformity, lack of preparation and anguish. Furthermore, the initial lack of adequate information arouses the fear of loss, as reported by the participants:

Such a despair, you know? Because no child, no family is prepared and want to see that for a mother, right? It is immediately great despair that invades us. (P03)

When we knew it, we gathered in the yard, my daughters and I. They were crying very, very much and I did not have any reaction. I did not accept it, I did not know what to do, but I put everything in the hand of the Lord. (P05)

At first, it's hard, right? You get scared. With no information how things will happen. (P07)

We felt sad because my father went through the same problem and died. Then, we get worried without much information fearing the same thing to happen. (P08)

In addition, after the discovery of cancer, feelings of nonconformity, fear of loss, insecurity are common, causing emotional instability, as seen in the speeches:

A feeling of grief. It's sad, it's worse than I imagined and, at the same time, we try not to pass the negativity of this disease to her. (P02)

We get scared of losing her, seeing the situation, we turn thinking that the worst happen. In my family there had never been anything like that, you know? It has been a blow since I knew it. (P06)

At first, the earth moves under our feet. Wow! Then it was a deep depression, a very sad thing, it shook the whole family, both my and his family. Everyone was destabilized. (P01)

Changes in family life

The family has changed their daily routine because of the support needs and monitoring of the patient, requiring aid and physical presence, extra financial demands and deprivation are not uncommon, as can be seen in the speeches of the participants:

I'm missing a lot to the school, because I'm looking at him three times a week. My aunt had to come from Uba, she had to leave her children there to help. Has changed a lot in our routine, she had to quit her job to be able to come. (P01)

I had to take care of home and work, was accumulating all, had to study at night. It

was very difficult for me, I had to leave things to take care of it. It is difficult to do other things. (P04)

Changes everything, you stop your life to live for the other, but this, to me, is not a non-weight. We do not have health insurance and we are Petropolis, so much increased spending. (P09)

Quite spending even with treatment by SUS, there are fuel costs, because I live far spent on food. My routine has changed because I do not go out anymore. (P10)

Changes in family daily life

Family has its daily life changed because of the need for support to the patient, requiring help and physical presence. Extra financial demands and deprivation are not uncommon, as it can be seen in the participant speeches:

I am missing a lot of classes, because I am taking care of him three times a week. My aunt had to come from Ubá, she had to leave her children there to come and help. It changed our routine a lot, she had to quit her job to come. (P01)

I had to take care of the house and work at the same time, everything was accumulated, I had to study at night. It was very hard to me, I had to quit things to take care of him. It is difficult to do any other thing. (P04)

Everything changes, you have to stop your life to live in self-giving to

others, but this, for me, is not a burden. We do not have health insurance and we are from Petrópolis; so, our expenses increased a lot. (P09)

Many expenses, even with the treatment by SUS, there are expenses with fuel, because I live far away, expenses with food. My daily life also changed, because I cannot go out anymore. (P10)

Attitudes toward the disease: conventional and spiritual resources

Access to conventional health care resources, from diagnosis to treatment, is described as complex, time consuming and difficult, which increases the suffering of the patient and family:

It's not fast, you know? It does not get right to the point. I had to race against time, because we were almost two months going to UPA. The pain was treated with medication and then, he was discharged. One day he was admitted to oncology and the treatment began. (P06)

We suffered much, you know? I do not know if you are aware, but come up to here and get treatment is time consuming. That's not what people talk about out there, that there is priority. At each visit, we thought it would be solved, but not. (P03)

On the other hand, the spiritual dimension was recognized by family

members as a key resource for coping with uncertainty, to acceptance and overcoming the disease. Spirituality, through prayer, rites and interaction with a higher being, is understood as an adjunct to conventional treatment:

We always have the perseverance, right? Ask God to show the way, the solution. I'm Catholic, my family is Catholic and my hope is in God and doctors, who are guiding here. (P02)

It's just God. What helps is faith, then I pray the Rosary, pass the rosary on him, stay there blessing him, these things of mine. I know that God is first, second is the treatment and professionals. (P01)

I have great faith in God, but at the same time, I'm afraid, it is not easy. People are here and, all of a sudden, they pass away. I have faith, great faith in God and I ask Him to get him out of this situation, this hospital and suffering. (P03)

DISCUSSION

The family caregivers of patients undergoing cancer treatment are usually partners/spouses or relatives in the first degree, ascending and descending, as parents and children. However, not always the degree of relationship is crucial to care provision, since there are found cousins, uncles, grandparents, friends and even professionals/caregivers paid by the family.

Corroborating other works⁸⁻¹⁰, in this research, the majority of family

caregivers were women, partners/spouses of the patients. Despite important changes in contemporary society, in relation to gender issues and care provision, it is still frequent the female figure takes the task of assistance and care.⁹

Studies⁹⁻¹¹ point it is not uncommon for partners/wives make it their priority the care of the partner/husband, to the detriment of their own well-being. Many women lose or leave their jobs and suffer a high degree of physical and emotional stress, requiring health care, as the patient.

The diagnosis of cancer, the generic term for chronic diseases with uncontrolled growth of cells and tissue invasion, is in common sense often associated with death.¹² Thus, when reported, the family and the patient suffer great emotional impact, which causes fear, anxiety, depression, frustration, besides changing in family routine.^{8,11}

The way the disease is reported may help to trigger and/or intensify the family stress.¹² In general, before diagnosis, the patient and his family have gone through various health services and professionals and underwent several tests, what puts them in expectant position. This situation alone generates anguish and, when associated with poor information, lack of multidisciplinary intervention and an abrupt communication, most likely, will break with balance and emotional resources of the

family.^{6,8,10,12} Sometimes, family members and patients report through their experiences that the complexity and length of the health system causes physical and mental wear.

With the start of treatment, new challenges arise and affect the family dynamic, establishing the need for adjustments, changes and abdication.⁸ Both for the patient and the family caregiver, the treatment and its consequences affect the perception of autonomy and independence of the subjects. This is related to the frequent hospitalizations or visits to clinics, with functional impairments posed by adverse effects and increased financial demands.^{10,13}

It is known that the social vulnerability that oncological diseases impose can be intensified by the precarious social, economic and cultural conditions of the patients and their family.¹⁴ In this sense, studies^{13,15} indicate that effective multidisciplinary care, with guidance, planning, social support, prevention of avoidable health problems and appropriate interventions, positively impacts the treatment and affects the family's expenses. A clinical trial¹⁶ trial showed that daily monitoring of signs and symptoms, from the reports of patients and families, significantly influences the treatment and clinical outcomes. Moreover, the possibility of frequent contact of the family with the

professional reduces feelings of apprehension, insecurity and stress at a time characterized by overload.

On the one hand, the delays for access to conventional resources generates apprehension, spirituality emerges as a coping and reliable resource for the family. Spirituality connects man to the sacred and the transcendent, which may or may not be manifested by religion. The latter is linked to the ritualized practices and symbolism of a particular creed or culture.¹⁷

The role of spirituality/religiosity stands out as a therapeutic resource in situations of psychological distress after a cancer diagnosis in the family. Researches have shown important role of this resource in stimulating patterns of effective responses to stress, helping people make complex decisions in a context of high uncertainty.¹⁷⁻¹⁹

In this regard, in view of the patient's and family's belief system, the nurse can include in his/her care plan the spirituality/religiosity as a resource for strengthening the emotional well-being. However, in order to take therapeutic use of it, there is need for awareness of specific beliefs and use of appropriate tools to assess the religious and spiritual needs.¹⁸

CONCLUSION

This research allowed us to understand how relatives of people

undergoing cancer treatment cope with the disease. It was identified that, in addition to routine changes, the family had feelings of hopelessness, nonconformity, insecurity, lack of preparation and anguish, as well as the fear of losing the one with cancer, due to lack of information on the treatment and the disease. It was also shown that the suffering of the patient and family is aggravated due to the complexity and length of conventional resources.

In this sense, the possibility of contact of the health professionals with the family of cancer patients by providing information, answering questions and making use of alternative resources in addition to conventional resources, such as spirituality/religiosity, may decrease the feelings of apprehension, insecurity and stress.

As limitation of the study, it is emphasized that the results cannot be interpreted as representative of a population or group of families, considering it was held in two rooms of the same hospital. In this sense, the results should be interpreted with caution and further researches with qualitative and quantitative approaches are indicated to broaden the discussion.

It is expected that this study will contribute to reflections on the health care of family members of cancer patients in order to determine strategies that qualify

comprehensive care and strengthen the emotional well-being of this population.

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