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RESEARCH

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Cancer Patient in The Final Stage of Life Undergoing Palliative Care: The Family Caregiver Experience

Paciente com Câncer na Fase Final de Vida em Cuidados Paliativos: Vivência do Cuidador Familiar

Paciente con Cáncer en la Fase Final de la Vida en Cuidados Paliativos: Experiencia de Cuidador Familiar

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ABSTRACT

Objective: The study's main purpose has been to comprehend the experience of the family caregiver of a cancer patient in the last stage of life undergoing palliative care. **Method:** It is an exploratory study with a qualitative approach, carried out in a hospital in the city of *João Pessoa, Paraiba* State. 15 family caregivers were interviewed, during the period of May to July in 2019. A semi-structured interview was used to collect data. The information were analyzed according to the content analysis technique. **Results:** The analysis of the empirical material allowed the construction of two thematic categories: I – Repercussion in the physical and psychological health of the family caregiver and II – Future perspectives in the face of the proximity of a loved one's death. **Conclusion:** It is important for professionals to use in their care tools that facilitate the process of adaptation of the caregiver to the new situation, seeking to reduce physical and emotional overloads, and preparing them so that they can continue their life after the loss.

Descriptors: Palliative care, Family caregivers, Terminal care, Oncology, Death.

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RESUMO

Objetivo: Compreender a vivência do cuidador familiar de paciente com câncer na fase final de vida em cuidados paliativos. **Método:** Estudo exploratório com abordagem qualitativa, realizado em um hospital da cidade de João Pessoa – PB. Foram entrevistados 15 cuidadores familiares, no período de maio a julho de 2019. Utilizou-se um roteiro semiestruturado para coletar os dados. As informações foram analisadas conforme a técnica de análise de conteúdo. **Resultados:** A análise do material empírico possibilitou a construção de duas categorias temáticas: I – Repercussões na saúde física e psicológica do cuidador familiar e II – Perspectivas de futuro diante da proximidade de morte do seu ente querido. **Conclusão:** É importante que o profissional utilize na sua assistência ferramentas que facilitem o processo de adaptação do cuidador à nova situação, buscando reduzir sobrecargas físicas e emocionais, e o preparando, para que ele possa dar continuidade a sua vida após a perda.

Descritores: Cuidados Paliativos, Cuidador Familiar, Assistência Terminal, Oncologia, Morte.

RESUMEN

Objetivo: El propósito del trabajo es comprender la experiencia de los cuidadores familiares de pacientes con cáncer en la fase final de la vida en cuidados paliativos. **Método:** Este es un estudio exploratorio con enfoque cualitativo, realizado en un hospital de la ciudad de João Pessoa, estado de Paraíba. Se entrevistó a quince cuidadores familiares de mayo a julio de 2019. Se utilizó un script semiestructurado para recopilar los datos. La información se analizó de acuerdo con la técnica de análisis de contenido. **Resultados:** El análisis del material empírico permitió la construcción de dos categorías temáticas: I - Repercusiones sobre la salud física y psicológica del cuidador familiar y II - Perspectivas futuras en vista de la proximidad de la muerte de su ser querido. **Conclusión:** Es importante que los profesionales utilicen en sus herramientas de cuidado que faciliten el proceso de adaptación del cuidador a la nueva situación, buscando reducir las cargas físicas y emocionales, y preparándolos para que puedan continuar su vida después de la pérdida.

Descriptores: Cuidados paliativos, Cuidador familiar, Cuidado terminal, Oncología, Muerte.

INTRODUCTION

The current population reality, patterns and lifestyles, have changed the reality of people's health in recent years, as well as the care taken. The concern for care has grown in such a way as to increase the demand for hospital care, thus seeing the need to increasingly implement differentiated support for chronic patients, so that they can re-ceive the same support in the hospital environment or at home.[1] In this context, pallia-tive care emerges.

Palliative care is aimed at patients and family members who go through chronic diseases with no possibility of cure, in the final stage of life or not. It always seeks to alleviate pain and suffering, with medication, nutritional, spiritual, and psychological support.[2]

Many chronic conditions may require palliative care, such as cardiovascular, chron-ic respiratory diseases, Acquired Immune Deficiency Syndrome (AIDS), diabetes, kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital abnormalities, drug-resistant tuberculosis, and cancer.[3]

Cancer is the second leading cause of death in the world. In 2018 it caused 9.6 million deaths globally. In developing and underdeveloped countries, this disease usually presents at an advanced stage.[3] This means that these patients are eligible for palliative care.4 In Brazil, malignant neoplasms were responsible for 236,345 deaths in 2015.[5]

This reality represents an important challenge for public health and justifies the integration of policies to improve the quality of life of people with advanced diseases and their families, through services that provide palliative care in a timely, safe, effective, and efficient manner.

The care of patients with chronic diseases, especially the patient with cancer who is in palliation, should also extend to caregivers and family members, whether directly connected to the patient or a contracted professional responsible for the assistance. Its function is of real importance in the patient's lifestyle, personal care, medication, hy-giene, walks, among others.[6]

The family must always be part of palliative care and the assistance team must be effective in conduct aimed at reaching the entire context, providing better support to the patient and preparing family members and caregivers for the person's death who is in the final stage of life, mitigating consequences,[7] in the grieving process.

Therefore, the importance of a multidisciplinary approach, since palliative care aims not only at patient care, but also at family and caregiver so that they can better face the period of mourning. Such an approach should be even greater with spouse family caregivers. Study findings observed greater vulnerability in this population, since they may experience some degree of depression in the period of mourning.[8]

Thus, it is essential that the team make the family caregiver of cancer patients in the final phase of life as a partner and target of care, thus favoring improvement in the practice of palliative care. For this, new investigations are needed to discuss the theme, since there is a small number of studies in the national literature aimed at palliation from the understanding of the meanings arising from the experiences of family members in the care process.

Considering the relevance of the theme, this study starts with the following guid-ing question: What is the family caregiver's experience of cancer patients in the final stage of life in palliative care? To answer this question, the study has the objective of understanding the family caregiver's experience in the final phase of life in palliative care.

METHODS

This is an exploratory study with a qualitative approach. This approach works with the universe of meanings, beliefs, values, and attitudes, delving into the world of meanings of human actions and relationships.[9]

The research was carried out in a hospital, located in the City of *João Pessoa, Paraíba* State. This hospital is philanthropic, with 100 beds for long-term and palliative care, with multi-professional assistance to patients with chronic diseases in an advanced stage and in the final stage of life.

Fifteen family caregivers of patients in palliative care with oncological disease at the end of life participated in this research, selected from the following criteria: family caregiver over 18 years old, being a family caregiver of the patient for more than six months. Technical caregivers who were not related to the patient and family caregivers under 18 were excluded.

Data were collected from May to June 2019, using the interview technique, using a semi-structured script, to record data related to the participant reports included in the study.

The data collection started after the project was approved by the Research Ethics Committee, of the *Universidade Federal da Paraíba*, which received the approval certificate No. 2.553.408. Thus, the ethical observances contained in Resolution 466/12 from the National Health Council,10 which regulates research involving human beings in the Brazilian scenario. It is worth mentioning that, to ensure the anonymity of the study participants, the letters "FC" were used to identify the Family Caregiver, following the numerical sequence of the interviews.

To analyze the empirical material, we used the content analysis technique, following three steps: the pre-analysis that can be identified as an organization phase; the exploration of the material, in this phase the coding units are chosen; and the last one corresponds to the inference and interpretation of the content.[11] Thus, it was possible to construct two thematic categories: Category I - Effects on the family caregiver's physical and psychological health and Category II - Future perspectives in the face of the proximity of a loved one's death.

RESULTS AND DISCUSSION

Concerning the characterization of the 15 study participants, most of them are female. The age range of these participants varied between 18 and 72 years old. Regarding marital status, 11 are married, 4 are single and the majority of those interviewed are Catholic. Thereafter, the two analyzed categories of the study will be presented.

Category I - Effects on the family caregiver's physical and psychological health

In this category, it is noticed that the family caregiver's withdrawing from their daily work, home, and leisure to a hospital environment with its strict schedules and routine, in addition to facing the suffering of their loved one, they feel overwhelmed both physically and psychologically. As the excerpts from the following reports show:

> *[...] I am tired and with a headache, sometimes I can't even come here with that feeling of discomfort and weariness (feeling of emptiness). And that gets in the way of my things, I end up doing nothing. (FC 1)*

> *[...] my back is making me all sick, I think it's because I help to carry him [...], but he's my old man I have to take care of. (FC 2)*

> *Worry leads us to feel things that I didn't have before. More frequent migraines, body aches, high levels of stress and I often feel very fragile. (FC 3)*

> *I think the worst is the physical and emotional exhaustion, because I have to take care of the house, my son and husband, work and take care of my father, and it ends that I get tired a lot, sleep a little and get stressed very fast, I have been crying quite a lot too, sometimes even for no reason. (FC 4)*

> *[...] The issue of unregulated sleep, a little weakness for eating badly, [...], and stress, not to mention also mental tiredness. (FC 5)*

> *[...] I've been feeling a lot of physical tiredness, difficulty sleeping. I've been eating badly and emotionally. (FC 6)*

> *[...] I started to get very tired, I lose my patience easily and I feel a lot of stress [...]. (FC 8)*

> *I have a leg deficiency, you know! I have difficulty walking straight, but since I started taking care of him, the pain has increased, my spine also hurts a lot and I can't sleep properly. The hospital staff is very good for me, but sleeping is difficult. (FC 9)*

> *I feel a lot of back pain, but I think it is from sleeping in that chair, it is good, but our bed is better, and the accumulated tiredness that never goes away, because I am almost living here in the hospital. (FC 10)*

> *I always take care of myself, I think that's why I don't feel so much, but sometimes [...] there is a little pain in my back and legs, but it must be like getting him to clean and change diapers because he is big and heavy. (FC 11)*

> *I have been getting very tired in caring for her, since the bath, changing diapers, and all of this in a way brings us some physical damage, a little back pain, a bad night's sleep is part of it, but we are gradually taking it. (FC 14)*

The speeches revealed by the caregivers attributed physical tiredness and stress to issues inherent to the care of their relative with cancer in the final situation of life.

A study[12] reports that family caregivers present positive aspects when caring for the patient in the final stage of life, however, they also report the stress present in caring for this family member, which often causes physical and psychological disorders to the caregiver.

The caregiver's physical and psychological problems are directly linked to the responsibility and burden of care and the proximity of the death of their loved one. The findings of this study revealed that some caregivers experienced feelings of exhaustion related to the psychological reactions or physical conditions of patients and others described their feelings of caring for family members sick with advanced cancer as frustrating for not being familiar with the skills of caring.[13]

The caregiver's suffering is the summation of everything they live with the patient, the greater the burden on him in care, the greater the consequences generated physically and psychologically.[14]

A study states that the rate of depression among caregivers of family members in the final stages of life is between 12% and 59%, whereas the prevalence of anxiety is present between 30% and 50% of family caregivers, signaling a worrying statistic, showing that the depression and health problems of the caregiver may reduce their ability to care for the patient properly, in addition to the damage to their health.[15]

Findings indicate that in the caring for the patient facing the finitude of life, in the hospital environment, with the proximity of death, family caregivers feel fatigued, anxiety, stress, tension, poor quality of sleep, and reduced quality of life, which tend to cause a high personal charge, facing the care of the family member in the final phase of life.[16,12]

The reports point out that caregivers experience fear, especially of death; guilt in feeling helpless in the face of their relative's situation are stressors and emotionally draining factors, as can be evidenced in the following statements:

> *[...] I live under profound stress at all times, unexplained body pain and the fear of death is distressing and exhausting. (FC 7)*

> *[...] I'm fine, what I really feel are my things, because I'm a little old, [...], nothing because of my brother, I won't blame him for anything. (FC 12)*

> *I realized that I have been more tired, less willing, eating little and sleeping even less, but for my mother, it is worth all the effort, and I will continue here beside her helping and protecting. (FC 13)*

> *The tiredness is great in her care, the physical and emotional exhaustion, and it all interferes in our day, right, and it is difficult to face all this smiling always. (FC 15)*

Through the reports of the caregivers, it was possible to observe that with the progression of the limitations imposed by cancer and the approach of death, feelings such as fear, guilt, and sadness manifest themselves. A study identified that the caregiver's physical and emotional suffering is directly linked to the progression of the patient's illness in the final stage of life, stating that the caregiver tends to show a decline in their functions,[17] another finding indicates that sleep disorders originated from the overload of the caregiver, increase with worsening of the patient's clinical and functional status[18] and generally has a negative impact on the well-being of family caregivers.

The family caregiver needs support in the care and preparation of the imminent loss of their patient in the final stage of life, which will tend to show an increase in their condition of depression, guilt, and non-acceptance, for much longer periods, than the caregivers who are prepared previously. Thus, the intervention of the multidisciplinary team in palliative care is important to minimize the damage in this difficult time.[19]

It is important to mention that terminal cancer generally advances rapidly, which makes it challenging for family caregivers to deal with care at the end of their loved ones' lives. Thus, professionals need to be attentive to understand the care needs of family members who accompany the patient in the hospital daily, seeking to meet their fears, anxieties according to each culture and values.

Category II - Future perspectives in the face of the proximity of a loved one's death

The reports included in this category reveal that while some family caregivers of cancer patients receiving palliative care experience a phase of anticipatory grief, others look to the future with difficulty to resume life in the face of the possibility of losing a loved one, as highlighting the following excerpts:

> *At the moment it is difficult to draw any plans for my life. I see my mother in the last days or months of life, so I just want to enjoy it as much as I can with her, taking care, giving affection, hugging and feeling her close. Because I know she's going to be sorely missed in my life immensely, and I ask God to guide me when that happens. (FC 3)*

> *To have the strength to bear the loss, to get attached to my children and my family, and to try to touch life and my projects. [...] look at people differently, with love and understanding, enjoy all the time you have with those you love. (FC 6)*

> *I wanted to take my brother home, but the doctor already said there is no way. So, I will take care of my land to forget this great sadness. (FC 12)*

> *[...] my wife is all I have and I will take care of her until the end of it all, winning this battle with cancer. I want to be able to take care of my grocery store with my wife who is everything in my life, take care of our children and wait for our grandchildren who will soon be arriving to pamper. The rest I already have is my family. (FC 14)*
>
> *I wanted to go back to work, [...] I'm going to my little house. I stopped everything; I think I want to go back. But I also want to be closer to my family, have a little fun with them and stay together. (FC 1)*
>
> *I want to do my gardening again, stay at home with my old man, take care of my chickens, as we used to do before. I miss my place and so does he. (FC 2)*
>
> *I intend to go back to my routine, give more attention to my family, my son who misses me, my husband, and keep working. (FC 4)*
>
> *Returning to studies, continuing my life, returning to my normal working hours, in a way giving more value to my family and friends, and making a reflection as a whole of my life from this moment on. To love others more, not to be attached to material goods, to live love. (FC 5)*
>
> *I want to do my little things again, take care of my daughter and my land, and see him better, right, to help me take care of our little girl. (FC 10)*
>
> *I want to go back to school, finish my course for her, who always wanted that, [...] that I was someone in life. I think my focus will be on this later, trying to fulfill all the dreams she had for my life. (FC 13)*
>
> *I want to go back to work, and I will seek to specialize in this area of oncology, to help more people who need support and assistance, helping as much as they need. (FC 15)*

Caregivers can present future plans for returning to their normal routine, others indirectly demonstrate that they are unable to build plans, considering the care of their relative as the only thing that matters, demonstrating that there is no emotional balance prepared for the impending loss of their relative.

The loss of the family member causes a considerable load of stress that favors the aggravation or emergence of diseases, totally affecting the individual, making it difficult to resume life in the period of mourning. This phase of adaptation and change of routine brings social and physical damage to the caregiver, who cannot assimilate the loss, nor the resumption of life, in the professional and family scope, and often needs psychological monitoring to understand this phase[20] and resignification of the afterlife of someone so dear and loved.

It is possible to consider in some of the reports of caregivers, who seek to somehow deny that their patient is in the final stage of life, hiding this suffering and pain, and feeding the hope of returning home with their family member several times, in which they are aware that it will not happen.

From the moment of diagnosis of a life-threatening disease, through progressive physical and emotional deterioration during the progress of the disease, it induces psychological suffering, requiring great adaptive efforts on the part of the caregiver. This experience that occurs before the real loss, where the grieving person gradually separates their ties with the dying person, is called anticipatory grief.[21]

When it comes to a loved one with advanced cancer who receives palliative care, the feelings of fear and suffering multiply, since everyone is confronted with their limits and vulnerabilities, wondering about the meaning of the life they are living, what can result in a process of denying reality.[22]

In palliative care, family caregivers are often faced with these reactions related to anticipatory grief, which when identified early facilitates adjustment to post-mortem grief. Therefore, it is necessary to find methods to identify and measure anticipatory grief in family caregivers of cancer patients who receive palliative care.[23]

In this process, while recognizing finitude, the continuity of life is also affirmed. The way family members will react to the loss of a loved one is associated with the affective level that the patient represents and the relevance of the role that they played before being affected by the disease.[24]

Regarding the intrapsychic processes in the experience of anticipatory grief, Planning for the future is a category of contexts, experienced in the mourning gradually by those involved: patient, family caregivers, and family.[25]

This planning consists of assuming future changes and experiencing the reactions associated with this perception, predicting possible changes related to the post-death period and planning practical situations that need to be faced after death.[25]

Thus, it is observed that the continuity of the caregiver's life is directly linked to the way they will face the death of their relative and how much they will be prepared for this moment. This demonstrates the importance of the intervention of the multidisciplinary team in palliative care, to provide full support to the caregiver and facilitate their return to their normal routine after the loss of the relative.

CONCLUSIONS

The present research concluded that the repercussions on the physical and psychological health of the family caregiver are directly linked to the responsibility, the burden of care and the condition of proximity to the death of their loved one. It was observed that family caregivers suffer from the manifestations of the limitations of terminal illness and, mainly, with the approach of the death of their relative, which trigger feelings such as fear, guilt, and sadness.

It was evident that family caregivers of cancer patients who receive palliative care experience anticipatory grief. They make plans for the future in an attempt to reshape life with the imminent loss of a loved one. The intervention of the multi-professional team is important to minimize the damage caused in this process of finitude and supporting the grief.

The study presented limitations regarding the scenario, as it was carried out in a single hospital, which allows the results to be considered, only for the population in question.

More research is needed aiming at family caregivers of patients in the final stages of life, seeking to broaden the look and care. Thus, this research can contribute to health professionals and institutions to contribute to the care provided to this population.

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