Caring for people undergoing palliation: the look of the family caregiver

Cuidar de pessoas em paliação: o olhar do familiar cuidador

Cuidar a personas en paliación: la mirada del cuidador familiar

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RESUMO

Objetivo: Compreender a visão do familiar ao assumir o papel de cuidador de um ente em paliação. **Método:** Estudo exploratório e descritivo de abordagem qualitativa, realizado com 27 familiares cuidadores de pacientes com diagnóstico oncológico acompanhados num ambulatório de uma cidade de grande porte no estado de Pernambuco. Os dados foram coletados usando a entrevista semiestruturada e organizados no Software IRaMuTeQ®, considerando a Técnica de Análise de Conteúdo de Bardin, possibilitando assim a sua análise e discussão à luz da Teoria de Enfermagem Humanística. **Resultados:** Foi possível inferir que os familiares têm conhecimento sobre o diagnóstico de câncer; conhecem os riscos da doença e tratamento e, demonstram resiliência e altruísmo ao prestar os cuidados com amor e afeto. Reconhecem que para uma boa adesão ao tratamento, paciente e família precisam se sentirem acolhidos por toda equipe, com ênfase na equipe de enfermagem. **Considerações finais:** Possibilita refletir sobre a importância do familiar no processo de tratamento, e aponta para a necessidade de que a equipe esclareça sobre as mudanças que este familiar enfrentará no processo de cuidar, assim como de que seja dada visibilidade ao que são os cuidados paliativos, de modo a proporcional alívio ao sofrimento do paciente e família.

Descritores: Cuidados paliativos; Família; Cuidadores; Equipe de enfermagem.

ABSTRACT

Objective: To understand the view of the family member when assuming the role of caregiver of a person undergoing palliation. **Method:** Exploratory and descriptive study with a qualitative approach, carried out with 27 family caregivers of patients with an oncological diagnosis followed at an outpatient clinic in a large city in the state of Pernambuco. Data were collected using semi-structured interviews and organized in the IRaMuTeQ® Software, considering Bardin's Content Analysis Technique, thus enabling its analysis and discussion in the light of the Humanistic Nursing Theory. **Results:** It was possible to infer that family members are aware of the cancer diagnosis; they know the risks of the disease and treatment and demonstrate resilience and altruism when providing care with love and affection. They recognize that for good adherence to treatment, the patient and family need to feel welcomed by the entire team, with an emphasis on the nursing team. **Final considerations**: It makes it possible to reflect on the importance of the family member in the treatment process, and points to the need for the team to clarify the changes that this family member will face in the care process, as well as to give visibility to what palliative care is, in order to provide relief in the suffering of the patient and family.

Descriptors: Palliative Care; Family; Caregivers; Nursing Team.

RESUMEN

Objetivo Comprender la mirada del familiar al asumir el rol de cuidador de una persona en paliación. **Método:** Estudio exploratorio y descriptivo con enfoque cualitativo, realizado con 27 cuidadores familiares de pacientes con diagnóstico oncológico seguidos en un ambulatorio de una gran ciudad del estado de Pernambuco. Los datos fueron recolectados mediante entrevista semiestructurada y organizados en el Software IRaMuTeQ®, considerando la Técnica de Análisis de Contenido de Bardin, posibilitando así su análisis y discusión a la luz de la Teoría Humanística de Enfermería. **Resultados:** Se pudo inferir que los familiares conocen el diagnóstico de cáncer; conocen los riesgos de la enfermedad y el tratamiento y demuestran resiliencia y altruismo al brindar atención con amor y afecto. Reconocen que para una buena adherencia al tratamiento, el paciente y la familia necesitan sentirse acogidos por todo el equipo, con énfasis en el equipo de enfermería. **Consideraciones finales**: Permite reflexionar sobre la importancia del familiar en el proceso de tratamiento, y apunta la necesidad de que el equipo aclare los cambios que este familiar enfrentará en el proceso de cuidado, así como dar visibilidad a lo que son los cuidados paliativos, con el fin de brindar alivio en el sufrimiento del paciente y su familia.

Descriptores: Cuidados Paliativos; Familia; Cuidadores; Grupo de Enfermería.

ORIGINAL

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Introduction

With the increase in life expectancy, population aging has been observed as well as the increase in the prevalence of chronic non-communicable diseases, such as cancer. In a positive way, there has also been technological evolution in the context of health sciences, which has contributed favorably so that many people diagnosed with oncological disease can count on conservative treatment, enabling greater longevity and relief from suffering.[1]

When there is a need for hospitalization or outpatient follow-up for chemotherapy or radiotherapy, the family assumes the role of caregiver and performs all the accompanying with the patient in this new process and both are mobilized beyond their personal and social routine.[2] Thus, taking into account the principles of palliative care that prey for comprehensive care, directed to both the patient and the family and caregiver, it is important to recognize that the care unit (patient/family/caregiver) needs attention, respect for its beliefs, and support in the physical, emotional, social and spiritual aspects as well as qualified listening, thus favoring an empathetic and supportive communication[3-4].

In this context, it is necessary to have a differentiated look at the family caregiver based on integrality and individuality, not only during the period of patient care, but also in the experience of their grief. Given that the family experiences suffering in the face of the loss of their loved one and especially by their inability to solve many situations experienced.[5]

Faced with the presence of the revelation of the diagnosis of cancer, as well as other life-threatening diseases, the family has a whole life and routine altered in a significant way. The family experiences a circle of active relationships and this becomes more intense affecting personal, reciprocal and obligatory connections and bonds.[6] At the same time that family support is one of the main treatment resources used by the patient to cope with the disease, family members suffer considerably when dealing with the impact on the loved one. It is in this sense that cancer can be considered a "family disease", given the impact it causes in this sphere of conviviality.[2,6]

Faced with this complex and challenging portrait of reality, Palliative Care presents itself as a care approach that has been gaining ground in the world and in Brazil in recent years.

In 2020, the concept of Palliative Care as proposed by the World Health Organization (WHO) in its last update in 2002, was revised and expanded by the International Association for Hospice &Palliative Care (IAHPC) from a consensus definition, in order to highlight that these are integral and active care, offered to people of all ages who are in intense suffering related to their health, coming from severe illness, especially those people who are at the end of life. The goal of Palliative Care is, therefore, to improve the quality of life of patients, their families and their caregivers. They are applicable in all care spaces and levels of care, with an interdisciplinary team.[4]

In this perspective, the present study has as a research question, how does the family caregiver perceive himself when caring for a palliated entity in the face of a diagnosis of oncological disease? Thus, the objective of this study is to understand the view of the family member when assuming the role of caregiver of a loved one in palliation.

Method

This is an exploratory and descriptive study with a qualitative approach, considering the complexity of the object of study, the care of an entity in palliation, a social phenomenon and human behavior demarcated by intersubjective aspects.

The study included 27 relatives of patients in palliation with a diagnosis of oncological disease in outpatient follow-up. The inclusion criteria were to be over 18 years of age, to be the main family caregiver of the patient and to accompany him during the chemotherapy sessions. And, as an exclusion criterion, the person who played the role of formal caregiver, or the family member who performed the follow-up of the patient sporadically.

The study was conducted in the outpatient clinic of a public hospital in the city of Petrolina-PE, a specialized oncology service, a historical reference in the region. Data collection took place between September and October 2019, using semi-structured interviews, organized in two parts, the first referring to sociodemographic data and the second with open questions, namely: How do you perceive the care provided by the health team? How did you learn about your loved one's illness? What does it mean to take care of your loved one?

The interviews were audio-recorded on a portable voice device, then transcribed in full for later analysis. When observing the repetition of data and the non-increase of new elements, these were closed, considering that the data saturation had been reached.[7] Thus, new elements regarding the perspectives and perceptions about the object of study ceased to emerge, so that the interviews were closed in the 27th participant. Regarding the principle of secrecy, an alphanumeric code was used to identify the participants, with a view to protecting the data collected and ensuring anonymity, following as an example: F1 (Family 1), F2 (Family 2) ...

To organize the data analysis, the software IRaMuTeQ® (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires) was used for textual analysis, which enabled the construction of graphic images. This is a data processing tool in order to convert the results into a product to be explored, which requires the researcher to interpret the processed results with due scientific rigor.[8] In addition to the use of the Software, the Content Analysis Technique was applied, as proposed by Bardin.[9]

The pre-organized data with the necessary encoding and identification, went through a process of cleaning characters that if maintained, would make it impossible to read by the IRaMuTeQ® Software. After this processing, these were organized and distributed by words/words in an easily understandable and visually clear way, through graphs, images, tables and tables automatically generated with the purpose of facilitating inferences. With the use of the IRaMuTeQ® Software, the similarity analysis and the production of a word cloud were performed.

From the figures generated in the data processing, we moved to the second stage using the Content Analysis Technique, following the three phases proposed: 1) Pre-analysis; 2) Exploration of the material and 3) Inference that corresponded to the interpretation of the images/graphic representations generated by the IRaMuTeQ® Software (word cloud and similitude trees) as they emerged from the speeches.[9]

The results were discussed in the light of the Humanistic Nursing Theory, considering that its concepts seek to describe what is defined as humanistic practice, ratifying the importance of an effective dialogue, which involves the encounter, based on the relationship between someone who cares and someone who receives care.[10]

The study respected the ethical principles according to Resolutions No. 466/12 and 510/16 of the National Health Council (CNS), which deal with research with human beings, being evaluated by the Ethics and Research Committee of the University of the State of Bahia, obtaining a favorable opinion under protocol No. 053997/2019.

Results

Of the 27 study participants, 24 were female and three were male. Of these 14 were children, six spouses and the other seven represented by nephews, daughters-in-law and grandchildren. It is important to highlight that 21 of them have children and to accompany in the care of the family member in treatment, they need to leave the children with relatives or neighbors. Regarding the activities of daily living, they were asked about their leisure activities, most of them reported not performing physical or leisure activity, due to the routine of care, which according to them did not have time left for themselves.

The interviews, after being transcribed, were stemmed and grouped by similar meanings in nuclei of meanings, and then processed in the IRaMuTeQ® Software, generating images such as word clouds and similitude trees.

The first image generated was a word cloud as shown in Figure 1. With regard to the elaboration of the cloud, the grouping and graphic organization of the words took place according to their frequency, which allowed the rapid identification of the keywords in the textual corpus and a simple lexical analysis.[11]

Figure 1- Word cloud generated based on the perception about the care provided by the health team. Senhor do Bonfim (BA), Brazil, 2023.

The cloud originated from the answers to the first question: How do you perceive the care provided by the health team? The word that had the highest frequency was "nurse", the central word highlighted. The other words, which appear in less prominence, were evoked in smaller quantities in the participants' statements.

> I think it's very beautiful the way they treat us, the doctor, the nurses, the technicians, even the cleaning staff. They give attention, affection to everyone here. To the patients and the family. (F-1)
>
> [...] From the doctor to the cleaning girl, the nurse? No words say how wonderful they are, everyone! Sincerity, I have no words, I have no words, it is gratitude even! (F-3)
>
> It's excellent! The nursing staff here are very helpful, they treat everyone well, the patient, the family. (F-6)
>
> The service is very good, especially by the nurses, who are cheerful, helpful, my grandmother even speaks very well of them. (F-15)
>
> I think great, great, very good the care of the nurses, the attention of the nursing technicians, they play, distract the patient. (F-20)
>
> The treatment here is good, even too good, it's great, we don't have anything to complain about, the care of these nurses, my God, it's wonderful. (F-25)

Other elements of the textual corpus enabled the analysis of similarity giving rise to two trees as presented below (Figures 2 and 3).

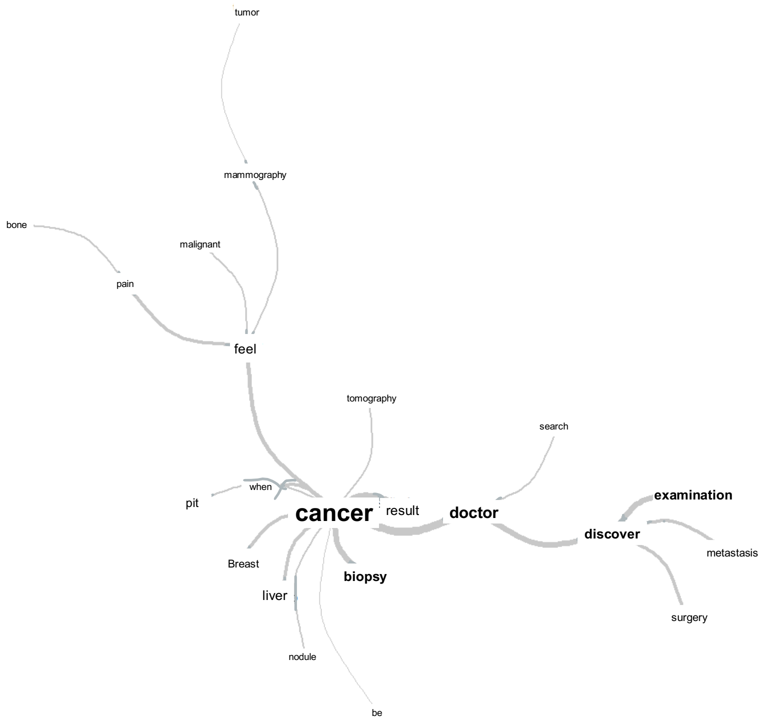

Figure 2- Tree of similarity about how he had knowledge about the family member's disease. Senhor do Bonfim (BA), Brazil, 2023.

The first tree of similarity derived from the answers to the question: How did you learn about your loved one's illness? It is identified, in the structure of the tree, the existence of a central nucleus, being the word "cancer" the most prominent and three smaller nuclei "biopsy, medical and examination", interrelated branches and that has a close connection with the central word.

> She was playing with her girl and the girl hit the tooth in place [of the tumor] and it hurt, then she went to find out that it continued to hurt and the pain did not pass then went to the doctor, did ultrasound tests and discovered a lump and she spoke to her husband then went to the breast doctor even though they were already suspicious and then she told me that the result gave cancer. (F-5)
>
> I learned through my brother that she went to do a routine exam [...] when she arrived she gathered all the siblings, and communicated that Mom had to undergo a procedure, that she had a diagnosis of cancer. (F-13)
>
> She started her abs, she started to get bigger, and we thought that was weird. Then when it started to grow we went to the health center and was referred to do a CT scan, then it found out that it was uterine cancer. (F-14)
>
> She started feeling a lot of pain in her spine, because her cancer is already relapsing right?! She's had it before, 10 years ago. (F-16)
>
> She took a shower, groping her chest and felt a lump then we went to the doctor to do an ultrasound, [...] they asked for the biopsy, then it worked. (F-17)
>
> At first she felt a lump in her breast and [...] who took the result of the biopsy was me and as I worked in the same clinic as the doctor I was the one who took it and showed it to him and then I had to give the news to her and the whole family, it was a desperation. (F-18)

The second tree of similarity (Figure 3) brings the result of the answers to the third question: For you, what does it mean to take care of your patient/family member?

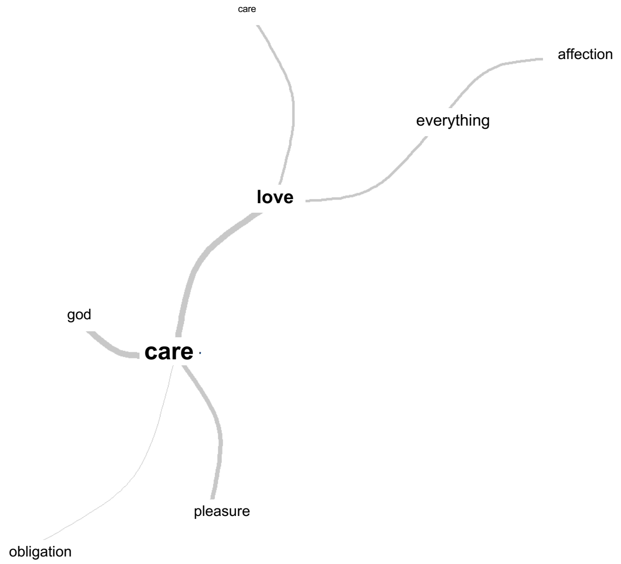

Figure 3- Tree of similarity about the representation of care for the loved one. Senhor do Bonfim (BA), Brazil, 2021.

In the structure of the tree, two nuclei of meaning are identified, and the central terms that are interconnected are "caring" and "love". It is revealed, in the branches, the existence of subgroups interrelated to the points that can be linked to the central terms.

> It represents everything, because, like this, what I can go through, the best for her, [...] a lot of positive thinking, a lot of kindness, a lot of love, affection, F-2 care).
>
> Like I'm taking care of my mother, my daughter, taking care of a part of me, taking care of myself, caring for love! [CHORO] (F-4).
>
> It's doing the best I can for her, or rather, doing everything for her, for her betterment, it's giving my best, whatever I can do for her (F-5).
>
> She is our mother, there is only one and there will never be another one, so we take care of and thank God. She is also very strong and fights against the disease, [...] care, this affection (F-13).
>
> You have to drop everything! For my mother I drop everything, I feel good, even going through moments of sadness. (F-14)
>
> It is my duty as a wife and second that we have to help others, it is bad to see the person with the health problem and not help and even more with his problem of cancer. (F-21)
>
> It represents everything! Because he had his problem and when he was in the middle of his treatment my breast appeared and he himself sick accompanied me, took care of me and I just have to thank God for this husband and so much [CHORO] and today I do the same for him (F-25).

Discussion

It is observed that there is a predominance of female family members as the main caregiver and as for the degree of kinship, they are generally the daughters of the patient. This profile was perceived in a similar study on the characterization of caregivers of patients in palliative care conducted in the South of Brazil, where it can be evidenced that most caregivers were female (85.7%), with a partner (77.1%) and that regarding the degree of kinship, most caregivers were spouses (37.1%) or children of patients (28.6%).[2]

Regarding the first figure represented by the word cloud, the term most prominently observed was "nurse", which may be associated with the constant presence of the nursing team in the care, both to the patient and to the family caregiver throughout the treatment, because it is this team that is closest and full-time, ready to provide a humanized care, understanding them and supporting them in all their needs, during the process of illness. Nursing care requires presence, flexibility, co-responsibility, sharing of feelings, knowledge and solidarity.[12]

Regarding the perception about the care provided by the health team to the loved one, the answers of the family caregivers also evidence the importance of the nursing team within all health services, from low to high complexity. It is the encounter between the caregiver and the being cared for, with the intention of creating an empathic link that will guide the actions for care as described in the Humanist Theory.[10]

For the theorists of the Humanistic Theory, Josephine Paterson and Loretta Zderad, caring in itself requires integrality, whether it is to the patient or to the family caregiver, who renounces his routine to live for long moments or days within a hospital institution and when the team plays its role, based on an integral care, reinforcing the principles defended by the Humanistic Theory, With a practice that seeks to provide benefit to the other, care is present and moves towards the recovery of the totality of human dignity.[10] This care is seen in the speech of the family members where they can identify the members of the health team and recognize that the good care of the nursing team is good for the patients and brings confidence in the service provided.

Here it is worth mentioning that the word NURSE as the central term of the word cloud is a symbolic representation of the entire nursing team, which demonstrates a performance in tune with the basic principles of the Humanistic Theory, structured in three fundamental concepts, namely: dialogue, communion and Phenomenological Nursing.[10] In this case, the concepts of dialogue and communion are applied, when a dialogical action is observed from the intersubjective relationship between the nursing team (nurses, nursing technicians and auxiliaries) and the family caregivers.

As well as, the communion established from the relationship between two or more people (nursing team, family and patient) and that generates a meaning of existence from the sharing of relationships about a certain phenomenon, in this context the care of a being in palliation.

Communion and dialogue are also marked by welcoming attitudes, assumed as a tool for the humanization of health services, based on qualified listening, favoring the construction of bonds and the guarantee of access to the population, which presupposes the responsibility of professionals for the care provided. By listening to the user (patient and family), the professionals will demonstrate improvement in the relationship and development of a more collaborative partnership, where dialogue becomes reciprocal and relationships are strengthened, which allows an effective exchange of information and knowledge.[12]

Receiving the diagnosis of an oncological disease is not easy to be accepted by the patient and the family caregiver, because the unknown begins to cohabit and the fear of uncertainties can leave them, patient and caregiver, facing an abyss. Thus, it is up to the entire nursing team to be sensitized to the unmet needs, and to insert in the care plan a comprehensive care.[12-13]

Here it is also possible to observe the concept of "communion" present in the Humanistic Theory[10], when observing that the people involved expose common ideas and thoughts, in a perspective of communion of experiences, about the care of a being in palliation, even if they are people with different knowledge and skills, but who bring in themselves a common goal.

And, the professionals of the nursing team, because they are closer to the patient and family in difficult moments, are requested by the family and the patient when they need clarification or immediate care. Thus, these singular actors end up dealing with the suffering and thus develop skills to provide qualified care, evaluating the patient and his family in an integral way, which requires this team a large and complex act of donation, often generating feelings of anguish and fears that may arise during the care process, After all, we're talking about people taking care of people.[14]

The first tree of similarity refers to the ways in which family members and patients came to know about the diagnosis of the disease, presenting as a central word, CANCER, worth highlighting the ramifications represented by the complaints of PAIN, SORE BREAST, NODULE, causing him to seek help from a MEDICAL professional, when it was possible to perform EXAMS such as those of imaging such as CT TOMOGRAPHY or anatomopathological study, the BIOPSY, and upon receiving the RESULT conclude with the diagnosis of CANCER and thus have the defined conduct to treat.

For most of the family caregivers, the history of cancer was already relapsing and was rediscovered when periodic follow-up examinations were performed that occur every six months or annually, or for those who did not yet have the diagnosis, began to feel some pain or perceived the presence of nodules at the time of self-palpation. In this way, with the new, the discovery of the diagnosis, the patients and family members who went through the first diagnosis. Studies have already pointed out that cancer puts patients and their families in a condition of fragility due to the stigma of the disease itself.[15]

Inserting the family member in the process of treating the disease and in the care is fundamental for the positive results expected from the patient, knowing that the diagnosis of cancer generates emotional and physical imbalances that go beyond the patient's bodily aspect, requiring reorganization in different dimensions of family life, including the social dimension.[15]

In this context, in view of the suffering of caregivers resulting from the direct consequences of their relative's disease, family caregivers sometimes fall ill and may compromise the care provided, considering that the support of this caregiver has its influence on the treatment of the patient's cancer. Thus, due to the suffering and changes brought about by the diagnosis of cancer, thinking about the care of this family member and, avoiding their illness, studies[13,16] recommend that the family caregiver of the patient receive monitoring and support from the health team, including recognizing that they often become anonymous patients.

The support of the multidisciplinary team has the purpose of being a source of support to the family caregiver in coping with the process of illness and treatment of their loved one, and its need becomes more evident when a low level of knowledge and preparation of the family caregiver in coping with the disease is observed.

The results of this study indicate that the family caregivers interviewed reported feeling able to take care of their loved one and when asked about the existence of some dialogue regarding end-of-life care and about thinking about the issues of finitude, only two interviewees reported having knowledge on the subject, which was acquired from dialogues between them and health professionals, but that this information did not emerge on the part of the team. This denotes a lack of preparation of the team to equip the family member regarding end-of-life care and anticipatory mourning.

Other studies[2,16] indicate that, even if the family caregiver is able to care, the lack of preparation about the process of dying and how to deal with death, makes the fear and fear of the death of the other is increasing. This refers to the need for discussions about human finitude on the part of health professionals and in favor of clarifying doubts of the patient and family, providing information and using resources ranging from the support of spirituality, or even religiosity, in order to reduce the fear and fear of the departure of a loved one.

Thus, the study corroborates with the perspective of the Humanistic Theory of Nursing, where in a holistic approach and an interdisciplinary practice, it seeks to respect the individuality of the being, as well as an attitude of relating to others in time and space, going beyond a unilateral, competent and creative relationship, but seeking to achieve a good practice of Nursing for the benefit of others, valuing the human being, preserving their autonomy and decision-making capacity while acting comforting family members with a view to the development of well-being and becoming.[10]

Regarding the meaning about the representation of caring for the loved one, the second tree of similarity has as its central word CARING and LOVE. Family care is a multidimensional, visible and at the same time abstract phenomenon, which encompasses feelings of affection, harmony and responsibility necessary for such an attitude.[17] Caring for a family member with cancer, through the manifestation of authentic solicitude, makes the caregiver enter the existential dimension of the other and become-with-the-other,[10] thus ratifying the concept of environment, which favors an atmosphere conducive to the inclusion of Palliative Care, involving the world of both, family caregiver and patient, in a harmonious relationship with the needs of both.

From the moment the family caregiver places himself as the main source of care and takes full responsibility for this task, he initiates a process of positive influence on the coping strategy that the patient uses, as well as in decision-making, daily self-care tasks and demonstration of affection between both.[2] A true act of love, not an OBLIGATION, an evocation that appears among the words of the tree of similitude, but LOVE, CARE and AFFECTION for a being that is considered part of itself.

The word OBLIGATION perhaps passes through the meaning of a belief in a sacred that demonstrates a Judeo-Christian moral formation that is bound by a care as a demarcation of religious otherness from the divine in the life of that family caregiver. This is striking from the perspective of looking at oneself as a caregiver, a divine mission to be fulfilled and that influences the personal and social life of family caregivers.

When asked about the changes that occurred in the routine of life and the impacts that they had on their personal lives, the family caregivers reported having changed in many aspects of their lives, some left their formal jobs and others in addition to performing their functions, organize themselves to exercise care and stop performing leisure and health activities and many even attend their churches.

Thus, the analysis of the changes generated in the lives of family caregivers is similar to the results of a study18 conducted in a Support Service for Relatives of Chronic Patients of the University Hospital of Maringá (HUM), which points out that among all family members, wives and daughters stand out and, in general, only one person to be responsible for providing care to their loved one, worrying about activities ranging from feeding, medication administration, hygiene, social relations, with the aim of bringing well-being to the patient in addition to worrying about the uniqueness of the moment lived.

Even though they are overwhelmed and although many of them have had the need to renounce part of their routines to exercise such care, these family caregivers feel good,[13] and see this condition as an opportunity to express feelings of pleasure, love, affection and care, directed to the person in the process of dying, a true altruistic action of care of their loved one in palliation.

Final Considerations

The results of the study allow a reflection on the importance of the presence of the family caregiver in the process of caring, treatment and monitoring of their loved one in palliative care. They emphasize the value of knowledge about the disease and care for the needs of the family member and patient in favor of dialogue and communion, conditions that favor positive results, whether in outpatient follow-up as was the setting of the study or in hospitalization scenarios.

It is possible to observe a variety of conditions and changes in the routine of these family members when some demonstrated the need to stop working to care, others can already associate their work activities and care, however in both situations, it was observed the need for a preparation of this family caregiver, based on the support of the health team, worth the question: who takes care of the caregiver? It is necessary to think about this issue and recognize that these family caregivers can be anonymous patients and that they have not received the proper look from the team.

The view of the family member when assuming the role of caregiver of a being in palliation presupposes the need for a welcoming and humanistic environment, based on dialogue and communion in order to favor a humane and dignified care to patients with an oncological disease. However, the results point to the need for the team to provide guidance not only about the general care to the patient, but also to offer directions and support related to changes in the routine of life of the family member who accompanies the patient, also having a look at the family caregiver.

The limitations of the study are centered on conducting the study in a unit that has patients in palliation, but neither the team nor the patients and family members have the knowledge about what palliative care actually is, so that these principles are not yet assumed as a care practice, it is worth noting that one of the philosophical principles of palliative care is the recognition of the care unit as patient/family/caregiver.

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