



ONCOLOGICAL PATIENT IN PALLIATIVE CARE: THE PERSPECTIVE OF THE FAMILY CAREGIVER

PACIENTE ONCOLÓGICO EM CUIDADOS PALIATIVOS: A PERSPECTIVA DO FAMILIAR CUIDADOR

PACIENTE ONCOLÓGICO EN CUIDADOS PALIATIVOS: LA PERSPECTIVA DEL FAMILIAR CUIDADOR

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ABSTRACT

Objective: to know the perspective of the family caregiver of an oncological patient in palliative care. **Method:** this was an exploratory and descriptive study with a qualitative approach, conducted with 12 family caregivers of people with cancer in palliative care treated in two hospitals in Maceió/AL. We used the technique of recorded interviews, later transcribed and analyzed by Discursive Analysis. **Results:** three categories emerged: << The perception of the family caregiver about death: impotence, denial, acceptance, and spirituality >>; << Reflecting on the location of the terminal illness: death at home or in the hospital in the perception of the family member>>; << Subsidies to support the family member>>. **Conclusion:** the results confirm the perspective of fear and the fear of dealing with the death of a family member, emphasizing the need for a multidisciplinary approach. Other identified subsidies of support were faith and spirituality. **Descriptors:** Oncology; Palliative Care; Family.

RESUMO

Objetivo: conhecer a perspectiva do familiar cuidador de paciente oncológico sob cuidados paliativos. **Método:** estudo exploratório e descritivo, com abordagem qualitativa, realizado com 12 familiares cuidadores de pessoas com câncer em cuidados paliativos, atendidos em dois hospitais de Maceió/AL. Utilizou-se a técnica de entrevista gravada, posteriormente transcrita e analisada por meio da Análise Discursiva. **Resultados:** emergiram três categorias: << Percepção do familiar sobre a morte: impotência, negação, aceitação e espiritualidade >>; << Refletindo sobre o local da terminalidade: a morte em casa ou no hospital na percepção dos familiares >>; << Subsídios de apoio aos familiares >>. **Conclusão:** os resultados reafirmam a perspectiva do medo e o receio de lidar com a morte do familiar, ressaltando a necessidade do acompanhamento multidisciplinar. Outros subsídios de apoio identificados foram a fé e a espiritualidade. **Descritores:** Oncologia; Cuidados Paliativos; Família.

RESUMEN

Objetivo: conocer la perspectiva del familiar cuidador del paciente oncológico sobre cuidados paliativos. **Método:** estudio exploratorio y descriptivo, con enfoque cualitativo, realizado con 12 familiares cuidadores de personas con cáncer en cuidados paliativos, atendidos en dos hospitales de Maceió/AL. Se utilizó la técnica de entrevista grabada, posteriormente transcrita y analizada por medio del Análisis Discursivo. **Resultados:** surgieron tres categorías: << Percepción del familiar sobre la muerte: impotencia, negación, aceptación y espiritualidad >>; << Reflexionando sobre el local de la terminalidad: la muerte en casa o en el hospital en la percepción de los familiares >>; << Subsídios de apoyo a los familiares >>. **Conclusión:** los resultados reafirman la perspectiva del miedo y el recelo de lidiar con la muerte del familiar, resaltando la necesidad del acompañamiento multidisciplinar. Otros subsidios de apoyo identificados fueron la fe y la espiritualidad. **Descritores:** Oncología; Cuidados Paliativos; Familia.

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INTRODUCTION

Cancer is a public health problem whose incidence is on the rise. About 9 million people become ill, and 70% die each year worldwide.¹ According to the National Cancer Institute/INCA, the annual estimates of incidence are considered of great value, and the estimates presented for 2014 indicate that there may be 576,000 new cases of cancer in Brazil. The most incident types, except those of non-melanoma skin cancers, are prostate and lung cancer in men, and breast, cervix, colon, and rectum cancer in women.²

Palliative Care can be defined as a type of assistance whose objective is to promote the quality of life of patients and their families when facing diseases that endanger the continuity of life using strategies for the prevention and relief of suffering.³ In this perspective, palliative care should provide the relief of pain and other unpleasant symptoms; integrate spiritual and psychological aspects in patient care; support for the patient to actively live until the moment of death, and also support to family members and caregivers so they can confront the disease and mourning period.^{3,4}

In the last weeks and months of life, this care can be provided in the hospital setting or at home. The Home Health Care is a new assistance model that aims to decrease the length of hospital stay and offers new spaces and forms of organization of care technologies to patients.^{4,5} Ordinance No. 2529 of October 19, 2006 establishes the home care under the SUS, and defines it as "the set of activities provided at home to clinically stable people who require intense care beyond outpatient procedures, but can be kept at home, assisted by a team that is exclusively assigned for this purpose."⁶

Palliative care refers necessarily to the establishment of a caring relationship among people in the terminal illness process. When an individual becomes sick, the whole family suffers and feels the consequences of this experienced time. As the disease progresses, the patient's level of dependency in relation to the family increases, giving rise to difficulties arising from this daily care of the individual in palliative care.⁷⁻⁹ This care demands excessive time and dedication from the caregiver, which consequently leads to the abandonment of part of his daily activities and adjustment into a new routine of extreme dedication to treatment and care.

The situation of the family of a terminally

ill patient is characterized by the presence of great emotional impact, with multiple fears, fears that health professionals should recognize and address. The fear of the suffering of a loved one doubts about being able and have the strength to take care of him, acceptance of problems that can happen at the exact moment of death, or if they will know to recognize that there is death¹⁰ are concerns surrounding family members.

The interest in the study started on the fact that palliative cancer care is still gaining ground in health care in this country with a lack of understanding of the needs of caregivers of cancer patients. Thus, the nursing care can contribute to assist caregivers, and indeed, patients under palliative care.

Therefore, the question is: What is the perspective of family caregivers of cancer patients under palliative care? It is believed that the perspective of caregivers of cancer patients under palliative care is fear and fear of dealing with the loss of a family member. Hence, this study has the general objective to know the perspective of the family caregiver of cancer patients under palliative care and identify subsidies that enable support to family caregivers of patients with no chance of cure.

METHOD

This was an exploratory and descriptive study with a qualitative approach, and the result of the Nursing Course Completion work at the CESMAC University Center, Maceió, Alagoas. The study was conducted from August to October of 2013 in two hospitals of the Unified Health System (SUS) in the Palliative Care sector in Maceió/AL. A semi-structured and individual questionnaire was used for the interviews, which were recorded and later transcribed by the researchers. The questionnaire was divided into: I - Socio-Demographic Data and II - Semi-structured interview.

The following criteria were used: Inclusion - aged 18 years and older; be an "informal family caregiver" of a cancer patient without possibility of therapeutic cure, i.e., without technical training in nursing and/or receiving remuneration as a caretaker; of either gender; have a family cancer patient without therapeutic possibility of cure assisted in the hospitals; be physically, emotionally, and psychologically able to participate in the interview; Exclusion - be a family member of cancer patients already deceased.

Telephone contact was initially

established with 17 families assisted in the hospital A, where two interviews were conducted (one residential and one in the hospital); three families could not be reached through the phone, one refused to participate, and eleven patients died, and therefore, their family members were excluded from the study. In a second step, 10 families who were accompanying the inpatients in the Palliative Care sector were interviewed in the hospital B. Thus, a total of 12 interviews were conducted. The family members were identified by the letter F and a subsequent number according to the order of interviews.

The analysis was based on the textual discursive analysis of Moraes.¹¹ This methodology can be understood as a self-organizing process for building and understanding new insights that emerge from a recursive sequence of three components: deconstruction of the corpus texts, unitarization; establishment of relationships between individual elements, the categorization; capturing of the new emergent that results in a metatext in which the new understanding is communicated and validated.

Concerns with ethical issues were present in all stages of the study and according to Resolution 466/12 of the National Health Council. The study was approved by the Research Ethics Committee under CAAE in 16689513.1.0000.0039. The study was presented to study subjects in the first meeting with the researchers when its purpose was explained, and doubts were clarified. Those who agreed to voluntarily participate signed the Informed Consent form (TCLE). The participants were notified of the possibility of withdrawal during the study.

RESULTS

The family caregivers were mostly females (67%), aged 31-40 years (42%), married (50%), and followed by single (17%) or in stable relationships (17%). As for religion, most reported being Catholic (83%), and the highest level of education was complete middle school level (50%).

As for the kinship degree with the patient, half of the caregivers were children (50%) and a small percentage was spouses (25%). Regarding the type of cancer, the most prevalent were breast cancer (25%), and others cited were: ethmoidal breast, larynx, spine, lung, spleen, intestine, cervix, penis, and prostate cancer, each accounting for 8%. The time since diagnosis was reported

between 01 and 03 years in most families (84%). The average time providing family care was 01-02 years (50%); the shortest period was 04 months and the longest was 04 years.

Three categories were identified after the analysis of interviews: 1) the family caregiver perception of death: impotence, denial, acceptance, and spirituality; 2) Reflecting on the location of the terminal illness: death at home or in the hospital on the perception of the family caregiver; and 3) Subsidies to support family caregivers who care for patients under palliative care.

♦ Category 1 - The perception of the family caregiver about death: impotence, denial, acceptance, and spirituality.

One of the weaknesses in human beings is dealing with death. Feelings of fear, fearfulness, and helplessness, when faced with the possibility of increasingly present death, were evident in the speeches of family caregivers.

One family caregiver points out that the process of dying and the death of a loved one awakens a feeling of impotence because though the caregiver is dedicated 24 hours every day, she does not see improvement in the patient. This implies in recognizing that the family caregiver cannot do anything to prevent or minimize suffering in the patient.

He is the person that we love, it is a moment of suffering and you cannot do anything. (F.5).

Some family caregivers tend to deny death, even knowing that this is a natural process of life and that all shall pass someday. Others, however, report the process of acceptance in the terminal illness, viewing death as a form of rest and a passage to another world that will happen to everyone at some point in life.

At this point I do not see, we do not want to accept, but deep down it is the reality of life, we will all go, it is a journey, but no one wants to accept. [...] I am aware of what can happen about this. (F.1).

It is a difficult time, not only for me but for all family members, but if the time comes to happen we have to accept, we all have to go one day and leave this earth where we live. [...] (F.8).

It is possible to identify in their speeches that caregivers suffer a lot with the pain in patients. To overcome it, faith in God appears as one of the pillars of strength, security, and support to families coping with the situation, contributing to the acceptance of the terminal process. Thus, the testimonies that portray healing through faith and death as God's will are revealed.

[...] I have God, I already placed this in his hand and know that he can do everything. I just want the best for him. God knows that in our heart we do not want him to go, that's the truth. (F.5).

It is bad, who is going to find this good, but if it is the will of God, one has to accept. (F.11).

♦ **Category 2 - Reflecting on the location of the terminal illness: death at home or in the hospital on the perception of the family caregiver.**

In the perception of family caregivers, the ideal place for the process of death varied between at home and in the hospital. Some caregivers believe that the occurrence of death in the house is more comforting for both patient and family, but others consider the hospital the best place because it has trained professionals to assist in coping with the feeling of loss and pain, as evidenced the following excerpts:

The comfortable for her would be at home because her family, things, and everything is here. It does not compare being at home and in the hospital. (F.1).

It is sad, I think the occurrence of death at home is better, all the family will be gathered [...] (F.7). [...] Regardless of the location, at home or in the hospital as long as it happens by my side. (F.11).

Regardless of the preference on the location for the terminal moment, one family caregiver underscores the importance of being next to the patient at the time of death. The fear of the occurrence of death at home seems to result from a lack of support, care, and technical assistance monitoring from health professionals to the family, as described by some respondents in the following:

It has not been in my mind to be at home, I prefer in the hospital. (F.2).

I prefer it to be in the hospital because there will be better care and monitoring. (F.8).

Death at home is a very difficult situation because it will happen suddenly and the family is not prepared for that hour, we will not get the support we need from professionals to help us at that moment. Death at home is a very painful death, and the family caregiver will be very worried, distressed, she will not have the mind to solve all the required procedures when a person dies, for now, I think it should happen in the hospital, but if we had assisting professionals at home just as those in the hospital, such as nurses, psychologists, and social workers, certainly the situation would be different, but only with family members is difficult. (F.12).

The option of terminality in the hospital seems to be related to the support offered by the health service because the family caregiver indicates that death could be at

home but with the necessary assistance. He points out the presence of a multidisciplinary team in the residence and list the support of professionals from different areas of healthcare such as nursing, psychology, and social work.

♦ **Category 3 - Subsidies to support family members who care for patients under palliative care.**

The subsidies to support family members who care for patients under palliative care are associated with three aspects: the professional support in the hospital; training for family members; and patient compliance.

Family caregivers highlighted the support they found in hospital professionals, feeling embraced by them. They add having received training for the appropriate care for the oncological family member and assistance from a multidisciplinary team (nurses, doctors, psychologists, physiotherapists, speech therapists, and social workers).

When she came and was admitted here [...], the staff gave us a little book with the care that should be conducted and everything right. Here is wonderful, she is well treated here and has everything, psychologist, physiotherapist. She was lucky to be with a good doctor who works here and treat patients well. Here the social worker helps me and gives me advice. (F.6).

The nurse explained the care of colostomy to me. (F.4).

At the moment it is here at the hospital because at home she does not have the assistance she has here, she has a psychologist, physical therapist, social worker, doctor on call, and nurse. And at home, she does not have this facility, if she feels pain, begins vomiting, we do not know what to do and have to rush her to the hospital and try to get her in, which is difficult. (F.4).

The lack of support from health professionals to family members providing care to the patient at home was identified as generating feelings of inadequacy, insecurity, and despair in the family, as evidenced by the following speech:

I think there should have training for us at home, often we do not know how to do it right (specific procedures), and we have to do it [...] (F.12).

The fact of not knowing how to perform patient care, including procedures that are necessary, considering the difficulty of access to health services, could be minimized by the training family caregivers.

Most family caregivers reported the collaboration of patients in palliative care as a good relationship, demonstration of love and affection, behaving as enablers of care

despite being in a terminal process, as shown in the following excerpts:

She accepted that I take care of her, all that I provide for her, with little ways, I always try to please. (F.1).

The ease that I have to take care of her is because she accepts everything I say. (F.11).

He helps a lot, even being weak he turns by himself and helps when I change his diaper, raise his legs and back. (F.12).

We have a good relationship; she accepts that I take care of her. (F.4).

Faced with numerous difficulties experienced by family members and patients under palliative care, the aid of patients within their means facilitates the care provided by caregivers.

DISCUSSION

The family is usually the main source of caregiving and adult and elderly women prevail in these types of care,¹² however, in this study, there are also records of male caregivers. The analysis of the speeches of family members shows that facing the disease involve several factors that underlie the emotional, socioeconomic, cultural, and spiritual conditions of patients and their loved ones. The family structure should be considered in the attention to palliative care because family support is of extreme importance to experience this moment the best way possible¹³.

Cancer is a disease difficult to face for both patient and his family because the patient starts to require attention from those around him and his family ends up being affected by feelings and stressful reactions. This shows that a humanized support and assistance is necessary not only for the cancer patient but also to the family caregiver.¹⁴ It is important to note that the recent redefinition of palliative care by the OMS¹⁵ also incorporates the support to family caregivers during the coping period of the disease and during the mourning phase.

The analysis of feelings of family members shows two moments, the first one as negativist and confirmed in the study¹⁶, which characterizes the denial of death as the first phase of the dying process through which the family members and patients pass. The second moment is of acceptance¹⁷, as the diagnosis is confirmed and it is necessary to assimilate and understand what is happening to possibly face the situation and adhere to treatment.

In this process, resignation and absolute faith are resources used by people when they experience difficult situations as a way of

trying to face adversities with the help of a higher being. This generates a feeling of embracement and helps to rescue the strength to fight and overcome difficulties¹⁸.

There specific hospitals to treat cancer and as they take the charge of treatment or death and the dying process, this keeps the family with the possibilities to distance themselves from the member who is dying.¹⁷ However, it was found in this research that family members choose to be present at all times in the life of the cancer patient, even in the dying process.

When the home care cannot meet the needs of the patient, and the family caregiver experiences situations in which she does not know how to handle it, she tends to seek hospitalization, even contradicting the patient's wishes. This situation arouses a sense of guilt in the family caregiver by failing to meet the desire of the cancer patient to remain at home, which highlights the lack of support from a multidisciplinary team in palliative home care.¹⁹

Despite advances in proposals for palliative care during the terminal illness aimed to be at home, there is a predominance of institutionalized death. This situation stems from several factors, among which is the low health team support to patients and caregivers in the home care, inadequate physical infrastructure, and technical and emotional lack of training in caregivers to deal with the needs of the terminal patient care. Thus, the support of a multidisciplinary team is essential to the maintenance of terminal patients in the home environment, which could bring more comfort as the individual remains in the comfort of her home. This support of this team also enables family caregivers to feel supported and safe in the performance of home care.²⁰

In this study, the satisfaction from family caregivers about the service during hospitalization was revealed, however, the aggravating difficulty of access to hospital care was also revealed. This fact emerges from the reflection on the importance of guidance, monitoring, and training by a multidisciplinary team in relation to home care since the municipality where this study was conducted is not aware of home care projects in cancer palliative care.

The acceptance of care and collaboration by the cancer patient represented satisfactory results referred to as facilitating elements for the provision of care in the palliative phase.

CONCLUSION

Cancer is a disease that causes intense physical and emotional stress in the patient, who over time becomes unable to perform independent activities, and need help from his family. It was observed that family members suffer with the patient's symptoms and are subjected to feelings of: cancer denial, helplessness in the face of the patient's status, and acceptance of the disease; they have the spirituality as a source of support.

The results found in this study reaffirm the perspective of fear and fear of dealing with the death of a loved one, regardless of where that might happen; the need for follow-up by a multidisciplinary team is stressed. It is up to the nursing staff as the professional category that constantly remains with clients and family members during 24 hours a day in the hospital, to assist patients and their family caregivers, offering them support, training, and emotional comfort in coping with these changes in their lives.

In addition to the nursing staff, other subsidies to support family caregivers of cancer patients without the possibility of cure were identified as faith and spirituality, always issued in times of pain and sorrow such as in the process of death and dying. It was also noted that there is still a lack of assistance to home care, which was heavily reported by the family caregivers as a source of support.

In short, although home care under the SUS has progressed, greater efforts are needed to make it effective in practice. It is, therefore, to the nursing/health professionals and users of SUS to conquer this right and improve the quality of care to cancer patients under palliative care at home and their families.

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