



## APPREHENSIONS OF THE FAMILY WHO TAKES CARE OF THEIR FAMILY MEMBER WITH CANCER AT HOME

### APRENSÕES DA FAMÍLIA QUE CUIDA DO SEU FAMILIAR COM CÂNCER NO DOMICÍLIO APREHENSIONES DE LA FAMILIA QUE CUIDA DE SU FAMILIAR CON CÁNCER EN EL DOMICILIO

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#### ABSTRACT

**Objectives:** to identify whether families who take care of their family member with cancer at home have apprehensions about this process and analyze which are within the scope of nursing. **Method:** descriptive exploratory study with a qualitative approach, carried out with ten caregivers. The production of the data was from semi-structured interview, then analyzed by thematic analysis and discussed with the theory of basic human needs. The research project was submitted approved by the Research Ethics Committee, CAAE 021236/2011-91. **Results:** apprehensions were related to the severity of the diagnosis; possibility of suffering and loss of the family member; unfavorable evolution of the disease and its manifestations; lack of resources for funding the needs of the patient, the care that the family could need and its preparation to provide them. **Conclusion:** all caregivers reported apprehensions being located within the nursing. **Descriptors:** Nursing; Family; Oncology.

#### RESUMO

**Objetivos:** identificar se famílias que cuidam de seu familiar com câncer em domicílio apresentam apreensões em relação a este processo e analisar quais estão no âmbito da enfermagem. **Método:** estudo descritivo exploratório com abordagem qualitativa, realizada com dez cuidadores. A produção dos dados foi a partir de entrevista semiestruturada, em seguida, analisados pela Análise temática e discutidos à luz da Teoria das necessidades humanas básicas. O projeto de pesquisa foi submetido aprovado pelo Comitê de Ética em Pesquisa, CAAE 021236/2011-91. **Resultados:** apreensões foram relacionadas à gravidade do diagnóstico; possibilidade de sofrimento e perda do familiar; evolução desfavorável da doença e suas manifestações; falta de recursos para custeio das necessidades do doente, dos cuidados que o familiar poderia necessitar e ao seu preparo para prestá-los. **Conclusão:** todos os cuidadores referiram apreensões, sendo estas situadas no âmbito da Enfermagem. **Descritores:** Enfermagem; Família; Oncologia.

#### RESUMEN

**Objetivos:** identificar si familias que cuidan de su familiar con cáncer en domicilio presentan apreensiones en relación a este proceso y analizar cuales están en el ámbito de la enfermería. **Método:** estudio descriptivo exploratorio con enfoque cualitativo, realizado con diez cuidadores. La producción de los datos fue a partir de entrevista semiestructurada, en seguida, analizados por el Análisis temático y discutidos a la luz de la Teoría de las necesidades humanas básicas. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación, CAAE 021236/2011-91. **Resultados:** apreensiones fueron relacionadas a la gravedad del diagnóstico; posibilidad de sufrimiento y pérdida del familiar; evolución desfavorable de la enfermedad y sus manifestaciones; falta de recursos para costeo de las necesidades del enfermo, de los cuidados que el familiar podría necesitar y a su preparo para prestarlos. **Conclusión:** todos los cuidadores refirieron apreensiones, siendo estas situadas en el ámbito da Enfermería. **Descriptor:** Enfermería; Familia; Oncología.

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## INTRODUCTION

This study deals with the apprehensions of the family who takes care of their family member with cancer at home. From the concerns of the people it allows us to glimpse and grasp what else touch them, enabling thus subsidize effective actions of nursing. It is understood as apprehension the family concerns of any nature, whether they are: physical, psychological, social and/or spiritual. We consider the family, as the main caregiver and their direct family and substitutes, the patient at any stage of cancer seen in outpatient level, the hospital or at home.<sup>1</sup>

The idea of holding such an investigation arose from the experience of the authors in the Extension Project named Care of the School of Nursing and Pharmacy-ESENFAR of the Federal University of Alagoas-UFAL, which aims to empower families to care for their family members with cancer without therapeutic possibilities at home.

The family, interpersonal system formed by people that maintains binding by varied reasons, promotes dynamics social relationship that, throughout its development process, assume forms and tasks that are formulated from a system of beliefs, values and norms, generating thus influence in the environment in which they inhabit and social class to which they belong.<sup>2</sup> Because they have their own views on health and disease, they create their own attitudes and modes of care, generating group and individual needs, whose attendance is conditioned to the resources at their disposal.<sup>3</sup>

In this study, the greatest experience was with patients in palliative care, because six of the ten families who participated in the survey were already with the family member at this stage. In these circumstances, the care do not have the purpose of healing, since the disease is already in a progressive, irreversible stage and not responsive to curative treatment, and therefore the goal of providing quality of life in the closing stages.<sup>4</sup>

When a patient is out of therapeutic possibilities, he is sent home with no oncological support service and the family receives superficial information on the disease and on the degree of care needs at home, making it difficult to carry out the activities by family caregivers. Among the tasks of the caregiver, there are maintaining the well-being, health, food, personal hygiene, education, culture, recreation and leisure of the assisted person.<sup>5</sup>

The permanence of the sick at home has advantages for him, essentially, with respect to a greater control over the situation, more opportunity for affective and emotional exchanges, comfort and familiarity of the environment, greater autonomy in choosing activities. However, the family, in most situations, is not prepared to accompany the sick at home, especially if he is in a terminal phase. Special attention should be focused on the problems of the family, essentially the accompanying family and takes care of the sick, which passes by the fear of causing unnecessary suffering, afraid to find him dead, difficulties in answering questions for the sick and how to confront them with the anticipation of loss.<sup>6</sup>

Like other researchers, the care relationship is marked by perplexities and doubts and in this way, the family members who care them are confronted with various feelings and concerns. The work of nursing at her parents' caregivers must contemplate information and reflection, and it is necessary to instruct the relatives in nursing practice, as well as to observe the feelings that arise in relation to the patient. This situation is also an opportunity for the families to reflect on their personal possibilities of illness and in their own finitude.<sup>7-9</sup>

The objectives of this study are:

- To identify whether families who take care of their family member with cancer at home have apprehensions;
- To analyze which are within the scope of nursing.

## METHODOLOGY

Descriptive-exploratory study with a qualitative approach. In this approach, the purpose is to allow, to a greater degree of depth, the interpretation of the particularities of the behaviors or attitudes of the individuals. It was also a descriptive research, because it sought to observe, record and analyze the facts we presented the way the are.

The study subjects were ten families caring at home for a patient with cancer. The interest was not to select subjects according to the criteria related to the disease itself, but rather, the relevance of the concerns of relatives about the care performed. The criteria for inclusion consisted in the fact of the participant be the primary caregiver or direct substitute, while the criteria for exclusion eliminated the family who was with the patient in a very critical moment.

The scenario chosen was the domicile of the subjects and the highly complex Oncology Center (CACON) Professor Ulpio Miranda of the University Hospital Professor Alberto Antunes (HUPAA), health Institution at the Federal University of Alagoas (UFAL), located in the neighborhood of Tabuleiro of the Martins, city of Maceio, Northeast of Brazil.

For the production of information, it was adopted the semi-structured interview, elaborated in order to obtain information about the profile and nature of apprehensions of the family member as well as to find out if these are the purview of nursing. The collection of information happened between February 2012 and August of the same year, respecting the saturation of information as advocates the qualitative research methodology.

The study used content analysis in its thematic mode. As a way of uncovering the themes that stand out in relation to the concerns of daily care, it was chosen to work with the basic human needs theory, classifying the findings within the issues pertaining to it.

The project was submitted to the Committee of Ethics in Research-CEP at the Federal University and Alagoas - UFAL, having been approved by the CAAE Protocol 021236/2011-91. Before the day of the interview study subjects, they were clear about the ethical aspects involving the research with human beings. We affirm that they were carried out in accordance with the provisions of resolution 196/96 of the National Health Council.

## RESULTS

The study was conducted with adults, with ages ranging between 22 and 74 years old, being the median of 44 years old. In relation to the degree of relationship, it was observed direct kinship (mother, sons and brothers) and collateral (spouse, daughter-in-law and son-in-law). The degree of education, the higher education was complete university and the lowest incomplete elementary school. In terms of household income, in three situations, there was not any monthly income where the family with better financial condition had an income of up to four minimum wages. Despite the education of the sample, the income has remained low. Gender-related data point participants of both sexes, with a predominance of women.

Several apprehensions emerged however, those who have been approached for practically all the participants were: the apprehension related to the severity of the

diagnosis; the possibility of loss of the family member; the unfavorable development of the disease and its manifestations; the suffering of the family member; the lack of financial resources to cover the needs of the patient as well as the care that the family could need and its preparation to provide them.

We observe that those apprehensions related to the severity of the diagnosis meant to the subject concerns arising from the discovery of cancer. In the design of the participants, as well as culturally, the disease is understood as a synonym of aggravation that entails suffering, pain and death. It represents both for the patient and his family, feelings such as sadness, anguish and uncertainty.

When it comes to a sick old man, this diagnosis is even more difficult for the family because they receive the news as an end-of-life sentence to their family member, believing that him, weak already, will not support such aggressive treatment.

*I worried that someone with her age, how would she react. (Daisy)*

*The first thing that worries me is knowing that it is a ' C. ', That is worrying. (Sunflower)*

From the moment in which a person assumes that may have cancer, is created as much for her as for any environment that surrounds them, a great uncertainty; there is a sense of uncertainty and helplessness in families, being constantly worried about the health of the sick, his prognosis, the result of treatments, relapses and death.<sup>10</sup>

Apprehensions related to possibility of family loss, were related to the fear of death of the loved one, that he did not resist disease and his aggressive treatment. The concern was unanimous among respondents and demonstrates that cancer is still seen as the early expression of finitude.

The feeling of powerlessness on this devastating disease reaches both the familiar as the family, generating a feeling of being impossible to change the course of things. The caregiver begins to imagine what would be the impact to the group if the family member were to die. He put in a position of wanting to avoid suffering and fear the worse, death.

*The concern that I have with him is he died [...] I worry how it will be after he dies, because he was a very good man and I'm afraid of how my family is going to react. (Carnation)*

*We know he was born and one day he will die, but we care about that final part huh? (Bromeliad)*

Fear is the most common psychological response in the face of death. The fear of death is universal and affects all human beings, regardless of age, gender, socioeconomic status and religious creed. It presents itself with various facets and comprises several dimensions. No human being is free of fear of death and all the fears that we have, they are somehow related to it.<sup>11</sup>

It is so ingrained is the association between finiteness and cancer that, even while continuing to live, the hallmark of early death remains forever in the people who stumble upon this situation of illness. There are many diseases besides cancer fatal, but the impression we have is that the other diseases kill, destroy cancer.<sup>12</sup>

The apprehension related to the unfavorable development of the disease and its manifestations correspond to the fear that the treatment does not have the desired result of cure, causing the disease evolve negatively causing a decline in the general condition of the familiar, bringing unwanted symptoms and causing suffering to the patient as the weakness, and may reach the inability and the dreaded end of life.

It becomes incapable on caregiver's vision, it would be a state of embarrassment and distress to the familiar, and even generate a condition of disinterest for life. This feeling is more pronounced when it comes to a working man and his family's livelihood provider or that woman whose life was donated to child-rearing.

*Some things worried about that will hit him on the inside [...] a doctor told him he had cancer on her thighs and in the organs, he said he could not respond to radiotherapy. (Carnation)*

*The concern is what's going to happen from now on when she starts getting impaired, when she starts feeling a lot of pain, not knowing what to do. (Bromeliad)*

*[future] concern is that it is really weak and the worst to happen. (Girasol)*

*One of the respondents went so far as to blame for the condition of illness that is passing, fearing including that it does not support the treatment and that there is more to be done to seek a cure, since the disease was discovered belatedly.*

*She did a cytology for four years or so, when she came to live with me. I should have insisted more for her to do more, but I couldn't, I didn't do that [crying]. (Bromeliad)*

To imagine their family member dependent on their care, without autonomy or even

powerless to keep only, because the caregiver a feeling of sadness and loss. Loss of that person strong, independent, and happy. Brings a sense of unpreparedness to deal with such emotional suffering and limitations. The lack of positive feedback to treatment, the incredulity of their effectiveness, the advancement of the complications and the effects of illness on the family can bring physical, emotional and interactional consequences, leading the family to undergo more sufferings.<sup>13</sup>

In many instances, the relatives expressed that concern is part of ignorance about the disease and its evolution. Maybe the difficulty is in knowing how professional give unpleasant news or find the familiar more emotionally prepared to receive them. However, the nurses and other professionals, guaranteeing the right of the family to know the condition of the patient, explain why the new signs and symptoms that the familiar is showing and how the caregiver may be able to help him.

The apprehension related to the lack of financial resources to cover the needs of the patient was another concern too. It meant for people of this study the unrest for failing to financially support the treatment of the sick, as well as the maintenance of the family, since, in many cases, providers of family livelihoods are the patient and/or caregiver.

Although financial changes occur due to increased expenditure on direct care to dependent family, there are difficulties in reconciling the caregiver role with work outside the home, making the subjects also have to leave the job. Thus, due to this limitation, the family spends only relying on help from friends, neighbors or some kind of government aid.<sup>14</sup>

*At home he takes medicine for pain, the medicine from us, because the doctor gave an expensive medicine than there had no conditions to buy. (Carnation)*

*What worried me was that I have to leave my work to take care of her [...] now we lost the ambulance and have to pay. And if we don't have any money to go, we have to do anything to take her. (Geranium)*

The nurses and all healthcare professionals, while connoisseur's oncology patients' rights, should guide them to seek financial support from the government, which, although small, will help keep some of the costs of the disease. It must still be sought a way to help the family with regard to the provision of medications and transport for treatment. Lack of financial resources is mentioned as a big problem in the family. With a lower income, the family suffers from the lack of money.<sup>15</sup>

Apprehensions related to family's suffering refers to the fear of seeing the familiar suffer and not be able to help you. Is wanting in any way to promote the patient well-being and avoid suffering and its possible causes, coming to feel powerless when unable to do so. In this work, was very evident the relationship made by caregivers between the pain, suffering and a possible sign of death.

*It worries me because I know that cancer is a lot of pain, there are some screaming of pain. (Azalea) The doctor has already made it clear that she has metastasized into the rectum and she will use that bag, which can be temporarily or forever, and that worries me a lot. (Daisy)*

*Sometimes she complains of pain in the rectum, I'm worried because they said that the cancer won't hurt, and when it starts to hurt is because it's near to the end. (Bromeliad)*

The caretaker is an observer of the pain, the suffering, the disrepute on healing and all the emotions that surround the patient. It is he who goes hand to hand, trying to make sense of the life of the loved one to continue fighting against the death with no escape from the difficult task of treatment. The one who takes care, inevitably suffers more than one who is affected by the disease, as it accumulates a very large load of responsibility, anguish with his own anguish and angst on the other. As a human being, he is involved him sympathetically in other's pain, feels his own limitation, suffers for not having the healing power over the other.<sup>16</sup>

The apprehension related to the care that the family could need and its preparation to provide them relate to concerns from new demands that cause a greater need for care on the patient, which causes the carer feel, at times, unable to remedy.

The words portray a sense of unpreparedness and afraid to be alone in the care and do not have an access to professional who could help him. They refer to the will of wanting to take care, accompanied by the fear of not knowing how to perform properly care and end up damaging the family's condition.

*What's worrying me is the question of food, why didn't she is adapting, not enjoying it. (Daisy)*

*Once he put a probe and asked to take it and I had no one else to ask for. (Azalea)*

*I worried to her go into depression. (Jasmine)*

The demands of patient care at home can be of direct care, when they concern the administration of medication, wound care and

dressings, or they can be indirect care, when transiting in the universe of obtaining medications, scheduling consultations or coordination of care; administration of symptoms and comfort. In both cases, the ethos approaches are involved that generate the need for information about the disease, treatment strategies for problem solving and community resources.<sup>17</sup>

Nursing has the search function to keep the individual in perfect balance and health, prevent and try to reverse any mismatches. To identify some of the basic human needs in cancer patients helps in preparation of a care plan compatible the reality of each patient and stimulate/highlight of these the important that self-care represents to the evolution of their treatment.<sup>17</sup>

It is necessary to keep a family support, in which access to a Professional Nursing is guaranteed and facilitated. Many of the physiological changes presented by the sick person flee the jurisdiction of the caretaker, who in turn finds himself desperate for not understanding what happens and how he can help. The nurse then plans an appropriate assistance to that sick and that family, in order to remedy or reduce the needs presented.

## CONCLUSION

Caregivers revealed that caring for a cancer patient at home is to suffer in advance with the diagnosis, fear the evolution of the disease and weakness of the loved one, is disappointed not to be able to take care of the way they would like, by not being able to meet the financial needs that treatment spends, and even worse, to be in constant suffering with the fear of loss. Feelings are exposed to the truth that is being focused on tracing a journey into the unknown.

It was clear that all of these apprehensions were the scope of nursing actions and that assistance should be made based on the understanding of what they experience and what they need. The pain often cannot be avoided, however, with the support of health professionals, it can mitigate it by performing appropriate advice, looking for simple ways to relieve pain through religious support, support groups and psychological follow-up if possible.

Nursing professionals were the longest remained with the client and family, constituting real links, enabling the promotion of interaction and, consequently, a search for resources that promote the quality of life of the sick person and his family. Nursing professionals who work in the area of

Oncology, in particular nursing, must pay attention to the fact that the family should also be subject of their care, taking into account the uniqueness of each experience for individuals.

As seen previously, the apprehensions could be avoided or resolved with simple active listening actions and appropriate advice. We must be available to the patient and his family understand that they are not alone and that they have to turn to when they need to take their questions or alleviate their concerns.

Given the above, there is still much to be done by the oncological patient and his family, in order to promote a comprehensive and quality assistance. It must be remembered that due to the nature of the illness, the patient and his family need an integral care given the impact on biopsychosocial waits.

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