



ORIGINAL ARTICLE

SELF-CARE OF THE CAREGIVER OF THE SICK IN ADEQUATE PALLIATIVE ONCOLOGICAL HOME CARE

AUTOCUIDADO DO CUIDADOR DE ADOECIDOS EM CUIDADOS PALIATIVOS ONCOLÓGICOS DOMICILIARES

AUTOCUIDADO DEL CUIDADOR DE ENFERMOS EN CUIDADOS PALIATIVOS ONCOLÓGICOS DOMICILIARIOS

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ABSTRACT

**Objective:** to know the self-care needs of family caregivers regarding the care of patients with palliative care at home and propose strategies to these caregivers for self-care. **Method:** this is a qualitative, descriptive study, the data was collected through an interview based on Dorothea Orem's self-care requirements. The generated materials were submitted to analytical processes recommended by Content Analysis in the Thematic Analysis modality. **Results:** two thematic categories were defined: Category 1 - Being a caregiver: overweight and quality of life and Category 2 - The need for care of the other as an obstacle to one's care. **Conclusion:** it was found that the caregiver's self-care needs are related to inadequate sleep and rest, ineffective feeding and hydration, impaired social interaction, health risk, socioeconomic vulnerabilities and lack of education. Strategies suggestive for the realization of self-care focused on these needs were considered as strong contributory factors for the advancement of studies focused on self-care.

**Descriptors:** Self-Care; Caregivers; Palliative Care; Neoplasms; Nursing; House Calls.

RESUMO

**Objetivo:** conhecer as necessidades de autocuidado de familiares cuidadores frente ao cuidado de adoecidos em cuidados paliativos oncológicos domiciliares e propor estratégias a esses cuidadores para a realização do autocuidado. **Método:** trata-se de um estudo qualitativo, descritivo, realizou-se a coleta de dados por meio de uma entrevista com base nos requisitos de autocuidado de Dorothea Orem. Submeteram-se os materiais gerados a processos analíticos preconizados pela Análise de Conteúdo na modalidade Análise Temática. **Resultados:** definiram-se duas categorias temáticas: Categoria 1 - Ser cuidador: sobrepeso e qualidade de vida e Categoria 2 - A necessidade de cuidado do outro como obstáculo para o próprio cuidado. **Conclusão:** constatou-se que as necessidades de autocuidado dos cuidadores estão ligadas ao sono e repouso inadequados, alimentação e hidratação ineficazes, interação social prejudicada, risco à saúde, vulnerabilidades socioeconômicas e falta de instrução. Traçaram-se estratégias sugestivas para a realização do autocuidado voltadas para essas necessidades consideradas como fortes fatores contributivos para o avanço dos estudos voltados para o autocuidado. **Descritores:** Autocuidado; Cuidadores; Cuidados Paliativos; Neoplasias; Enfermagem; Visita Domiciliar.

RESUMEN

**Objetivo:** conocer las necesidades de autocuidado de los familiares cuidadores frente al cuidado de enfermos em cuidados paliativos oncológicos domiciliares y proponer estrategias a los cuidadores para la realización del autocuidado. **Método:** se trata de un estudio cualitativo, descriptivo, se realizo la recolección de datos a través de una entrevista basada en los requisitos de autocuidado de Dorothea Orem. Se sometieron los materiales generados a procesos analíticos preconizados por el Análisis de Contenido en la modalidad Análisis Temático. **Resultados:** se definieron dos categorías temáticas: Categoría 1 - Ser cuidador: sobrepeso y calidad de vida y Categoría 2 - La necesidad de cuidado del otro como obstáculo para su propio. **Conclusión:** e verifico que las necesidades de autocuidado de los cuidadores están relacionadas al sueño y de descanso inadecuados, alimentación e hidratación ineficaces, interacción social perjudicada, riesgo a la salud, vulnerabilidades socioeconómicas y falta de instrucción. Se plantearon estrategias sugestivas para la realización del autocuidado dirigidas a la necesidades consideradas como fuertes factores contribuyentes para el avance de los estudios dirigidos al autocuidado. **Descriptor:** Autocuidado; Cuidadores; Cuidados Paliativos; Neoplasias; Enfermería; Visita Domiciliar.

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How to cite this article

Vale JMM do, Marques Neto AC, Santos LMS dos, Santana ME de. Self-care of the caregiver of the sick in adequate palliative oncological home care. J Nurs UFPE on line. 2019;13:e235923 DOI: <https://doi.org/10.5205/1981-8963.2019.235923>

## INTRODUCTION

Cancer is conceptualized as a set of more than 100 diseases that have in common the disordered growth of cells that invade the tissues and organs and can spread to other regions of the body.<sup>1</sup>

It is considered as a 'disease' of difficult acceptance that brings, for the subject who manifests it, physical and psychological changes and interferences in the social environment, since it is immersed in a context whose theme is socially understood as a synonym of suffering and death.<sup>2</sup>

It has been found that in the last decades, cancer has grown to become a global public health problem, being the second leading cause of death in the world, responsible for 9.6 million deaths in 2018. It is highlighted that, on a global level, one in six deaths is related to the disease;<sup>3</sup> as a result, patients are increasingly being referred to palliative care.<sup>4</sup>

In the National Policy for the Prevention and Control of Cancer in the Health Care Network of People with Chronic Diseases, within the scope of the Unified Health System (UHS), instituted by Ordinance N. 874, of May 16, 2013, global actions of promotion, protection and recovery of cancer patients in palliative care, and it is defined that the duty of the State is to offer and technically guide the palliative care with outpatient assistance, providing hospitalization, home care and pain control with the supply of drugs opiates.<sup>5</sup>

It is evidenced that the hospitalized patient wishes to be at home, this desire being a manifestation not only of the need of the sick person to feel more at ease in their environment and daily, but of the guarantee of a multiprofessional assistance that reaches it at home and projects on it a global look that goes beyond disease and contemplates the need to humanize death and care.<sup>6</sup>

It is emphasized that this desire is mainly related to the need to be with the family, however, the illness of an entity entails the restructuring of the family so that new roles are assumed; it is at this moment that the figure of the caregiver arises, which is usually an integral part of the family nucleus itself: the mother, who until then had been caring for the family, became ill and became cared for by her children; the father becomes care for his wife or children. Naturally, these new roles are assumed by family members, without questioning the caregiver's desire, availability and willingness, and there is often no explicit agreement among family members on who will provide care for the sick.<sup>7</sup>

It turns out that the family caregiver ends up giving up his own care to take care of his sick family member, and it is necessary to help him to find alternatives that aim to reduce the sense of stress. It is understood that this fact occurs

because the caregiver has to assume responsibility for care alone, when the other member of the family is only present in a sporadic and fragmented way. It is evaluated that this caregiver loses energy, is tired and emotionally exhausted, compromising the quality of care provided.<sup>2-8</sup>

In this perspective, Nursing, as a profession of care and health educator who acts directly in the prevention of injuries, is one of the great responsible for stimulating, in the caregiver, the need for self-care. It is pointed out that the role of Nursing, as a promoter of the restoration of the health of individuals, should be to encourage the implementation of care and educational practices that value self-care, providing assistance based on the multi-professional care of the team not only to the patient, but to the caregiver.<sup>9</sup>

Self-care is defined as a regulatory function, in which people are allowed to undertake life, health, development and well-being activities alone. It is understood that conceptualizing self-care and establishing related needs and activities are essential for understanding how people benefit from Nursing interventions.<sup>10</sup> It is known that self-care must be learned and applied in a deliberate and continuous way over time, always aligned with the regulation needs that individuals have in their growth and development phases, health status, health characteristics or phases of development, environmental factors and levels of energy consumption.<sup>11</sup>

In this sense, it is argued that, in Nursing, one should act with the family caregiver of the sick person in homeopathy oncological palliative care, among other attitudes, in the stimulation of the practice of self-care, since it is recommended, besides the search for the quality of life of the relatives of the sick, the support of these relatives in the period of coping with the disease and, if necessary, during the mourning phase.<sup>8</sup>

The family is discussed as a key player in the palliative care of cancer patients in various areas and social contexts, and in the health sector it is no different, and working with the family is one of the most significant strategies, since, besides being a space where protection is provided, where its members feel that they belong to a group united by bonds of love and affection, it is also defined as a health system for its members.<sup>12</sup> It is understood that, once this is recognized as a fundamental agent in the provision of palliative care, there is a need to intervene in improving the quality of life of the caregiver, teaching him to take care not only of his family member who is ill, but to carry out their self-care.

## OBJECTIVE

- To know the self-care needs of family caregivers regarding the care of the sick in

homeopathy and to propose strategies to these caregivers for self-care.

## METHOD

This is a qualitative, descriptive study carried out with ten family caregivers of cancer patients in homeopathic palliative care, linked to the Home Care Service (HCS) of Ophir Loyola Hospital (OLH), located in the city of Belém (PA), a reference in Oncology in the North region, which provides hospital and home care in palliative care.

The inclusion criteria of the study were as follows: family caregivers of patients with palliative care domiciliary domiciliary registered in the HCS of the OLH; older than 18 years; residing in the city of Belém and metropolitan region. The following were excluded from the study: caregivers whose family members who were ill were hospitalized or who died and contracted caregivers who did not belong to the family.

The research was carried out in three stages: in the first, a literature review was carried out on the key themes of this study, with the objective of deepening knowledge, specificities related to the thematic and defining possibilities in the approach of the categories raised through the interviews.

In the second stage, the home visits were carried out with the OLH palliative care team, from Monday to Thursday, from 9:00 a.m. to 12:00 p.m., according to the institutional protocol, with the subsequent return schedule for the interview semi-structured with family caregivers, this being the last moment of this stage.

A collection of questions was prepared for the caregivers to know their self-care needs in relation to the process of caring for patients with palliative care at home, in order to identify the self-care demands of these caregivers and strategies for self-care. Socioeconomic information about the participants, such as sex, age, marital status, educational level, occupation, income, number of residents in the residence, degree of kinship with the sick person and information were collected. related to the self-care deficits presented by these caregivers based on Orem's Theory. Following these procedures, the interviews were recorded and transcribed in their entirety, and the time of the interviews ranged from 29 minutes to one hour and 22 minutes.

The third step was a guiding instrument for self-care analysis orientation, whose data were grouped as follows: 1) socioeconomic factors; 2) self-care needs listed in the self-care requirements of Dorothea Orem, bypassing self-care deficits and Nursing systems.

Data was collected from September 2015 to March 2016. At the beginning of the collection, there were a total of 16 patients registered in the HCS of the hospital, receiving care from the home care team, each with a family self-declared

caregiver. Participants were admitted at first, according to the inclusion and exclusion criteria, but before the first contact with the same, six of the patients died, requiring the removal of the family caregivers of these patients from the research and finalizing the sample with a total of ten family caregivers.

The materials generated, from the collected data, were submitted to the analytical processes recommended by the Thematic Content Analysis. This method is part of the set of techniques used for the analysis of communication and content is understood as a means of understanding the meanings implicit in the messages.<sup>13</sup>

It should be emphasized that, in order to strengthen the aforementioned steps and to level the findings in Orem's Theory, the categories of this study were given the theoretical basis of several authors that relate to self-care, taking into consideration what Dorothea Orem advocated. that the last category was directly subject to the discussion based on the three requirements or requirements of this theory: Universal Self-Care requirements, Self-care Developmental requirements and Self-care requirements due to health diversities related to the Self-care Deficits approach. In this way, it was possible, after identifying the demands of self-care of the family caregivers, to propose strategies for self-care.

The ethical principles governing research involving human subjects were respected, and this study was submitted to the Research Ethics Committee of the Health Sciences Institute of the Federal University of Pará (REC / HSI / UFPA) and approved under opinion 518.778 / 2014.

## RESULTS

The family caregivers were identified by the letter E, "interviewee", and by sequential numbers, keeping the order of interviews: E1 to E10. It is pointed out that of the ten informants, all were female, aged between 18 and 61 years, five were single, four married and one was in a stable union, and the level of schooling ranged from incomplete elementary schooling to postgraduate studies. The income between one and eight minimum wages was understood, with an amount between two and eight people residing in the house. It should be noted that, in relation to the degree of kinship of caregivers with family members who are ill, eight were daughters, one wife and one sister, seven of whom are caring for their male relatives and three are female. It was obtained, with regard to the occupations, that three of the participants were from the home, one of them retired; two, students; one, operational assistant; a teacher; a nurse; a social worker and a restaurant manager.

It was found that, between these and other important data, after the exhaustive reading of

the transcriptions, from the analysis of the data, two thematic categories and their respective subcategories were listed, in which category 1, Being caretaker: overweight and quality of life, had two subcategories: Care synonyms: from love to pain and The role assumed and the change in the life trajectory, and category 2, The need to care for the other as an obstacle to one's care consisted of only one subcategory called Caregiver self-care demands: suggestive strategies for self-care.

#### ◆ Being a caregiver: overweight and quality of life

It has been observed, through the informants' reports, that caring for a family member suffering from palliative care requires a lot of willingness, commitment, love and commitment; however, the day-to-day burden of caregiving responsibilities, which, most of the time, is not restricted only to the sick person, but to the family in general, causes changes in the caregivers' life trajectory, in addition to a difficult overload by means of own means, without incentive and suitable orientations, what end up interfering directly in the quality of life.

#### ◆ Synonyms of care: from love to pain

It is understood that the act of caring for the family is marked by feelings and meanings that are configured in an attitude of permanent and inexhaustible love, where the feeling is the basis for the dispensation of a satisfactory care, independently of the other situations experienced. It is also considered as a way to protect the sick person, as well as an obligation associated with the feeling of gratitude before him, life and others, mainly because he is a fundamental part of the family nucleus.

*I take pleasure in caring for him because it has always been the love of my life and for me, caring for him is loving above all else. (Interviewee 1)*

*[...] sometimes I do not even like someone else to keep it. I already know how she likes things, so I'm already distressed when I have to leave and leave her with someone, there, I even avoid because I have the commitment to take care of her [...]. (Interviewee 8)*

*I always put it in my head: my mother changed my diaper, cleaned me, so now it's time for me to do for her what she did for me. (Interviewee 4)*

Care, however, is often experienced as a painful activity, resulting in an overload of stress and sadness; in this case, the obligation to care is expressed as an exhaustive function.

*There are times when I'm bursting, I can not even give a fuck, but I have to take care of her anyway. There are days that I do not think I'll take care of, but you have to find a way. (Interviewee 7)*

#### *The assumed role and the change in the life trajectory*

It is assessed that, once the caregivers found themselves in this condition, most of the time, without the support of other family members in the care of the sick person, changes in daily life began to occur and new adaptations were needed. It is observed that most of them abdicated activities that they previously did for themselves or with family and friends to dedicate themselves to the care of the sick person, a fact that directly influenced their quality of life. It was also registered the abandonment of employment to take care exclusively of the sick person, as reported in the statements below.

*Now, I do not have more time to leave home with before, I even went for a walk, sometimes with the girls at the mall, I went out with my sisters, but now I do not even ask anymore because, as I am only I who take care of him, I had to stop doing many things that I liked. (Interviewee 1)*

*I left my family and devoted myself totally to my mother to the point that they slept there alone and I slept with her here. It's a very difficult time for me because I left my job, I stopped being a housewife, mother, wife, to dedicate 24 hours to my mother. (Interviewee 4)*

It was also reported how this responsibility affected the interpersonal and social relations with family and friends, and the main conflict occurs because the other members of the family do not assist in the care. It is verified that all this triggered an evident physical and emotional overload in the caregivers, which caused the emergence of other problems related to stress, as shown below.

*My social life changed a lot. Because I sang, I left a lot, and had many friends, but, because of him, I had to stop, since I have nobody to help me, there, I was losing many things and many friends. (Interviewee 5)*

*The other siblings, too, should at least try to help me at the end of the week, but they never cared about Mom the way she was meant to be. They hardly come here, they only call from time to time. I pretend I do not care, but deep down, it makes me angry, you know? (Interviewee 7)*

*Sometimes I feel like I'm getting sick so there are several things at the same time, you do not need to just be well physically, right, that apparently all of us are well physically but, psychologically, that's the worst part. (Interviewee 7)*

#### ◆ The need to care for the other as an obstacle to one's own care

It is pointed out that, through the informants' reports, given that the care provided has become a priority in their lives, this care is an uninterrupted need that directly influences their ability to care; in this way, the need to care for the other has become an obstacle to the

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realization of self-care, as can be identified in the lines below.

*I'm practically not looking after myself, I'm taking better care of him. I know I have to take care of myself, but right now, it's the priority. Sometimes I'm very sad, wanting to cry, without strength, but I have to pass on to him that he's okay and that he'll be fine. (Interviewee 1)*

*I stopped taking care of myself, of my health. I do not go to the doctor anymore, I do not go out for walks, I do not study anymore, I do not work, I do not care, you know? There are days that the dedication is so great that I do not even sleep, I stay the whole dawn on her side. There are times when I arrive at the end of the day, I have not even showered, just taking care of her. (Interviewee 4)*

Therefore, the self-care needs of the caregivers are directly related to the self-care deficits presented by them and, therefore, Nursing must be willing to offer care to the caregivers, teaching self-care through health education. It is now identified the transversality of Nursing Systems theory in the whole process of self-care. It should be emphasized that when the caregivers were questioned about what they learned about caring for themselves and how they learned, they reported that they would like to give greater attention to caregivers because they often feel helpless by the health professionals.

*If the team took care of the patient, but also paid attention to the caregiver, it would be good for everyone. During the visit, when the team came to visit this patient, they also provided care for this caregiver. We sometimes need a lot of good guidance, a word of comfort, some tips, you know? So, this is the situation that many caregivers spend, sometimes, alone, without depending on anyone, with a lot of overhead on them. People do not stop to look that the caregiver also gets sick, physically and psychologically. We must understand that we caregivers also need care. (Interviewed 4)*

#### ◆ Caregiver's self-care demands: suggestive strategies for self-care

The self-care demands presented by the caregivers according to the Orem Theory, which brings, in its approach, the requirements or requirements for Universal, Developmental and Health Deviance self-care.

The Universal Self-Care Claims presented by the caregivers are related to sleep and rest, feeding / hydration, social interaction and health risk, in which, through their behavior, problems related to several factors that affect self-care have been generated. These factors associated with sleep and impaired rest and feeding / hydration were presented in eight of the ten caregivers, in situations such as: few hours of sleep / rest; weight loss; irregular and inadequate feeding (less than three meals a day) and poor water intake, as follows.

Self-care of the caregiver of the sick...

*I do not sleep well, I do not sleep very much. She wakes up often at dawn and calls my name. Then I always talk to her until she's asleep. When I fall asleep, she's calling me again. I eat badly, too, and drink little water. There are days I think I drink only a glass of water. Before, I fed better. Then I lost seven kilos with all that rush. (Interviewee 4)*

It should be pointed out that, in relation to social interaction, all respondents present with reduced or no leisure time, do not engage in activities such as talking and / or going out with family and friends, feel sad often, have low self-esteem and do not practice physical activity.

*I do not have time to leave, you know? Before, I still went out to talk and have fun with friends and some family members, I went for a walk, but now I can not. Sometimes I get sad because it's just me, she and the television here. There are days that make me sadder when I think of the day she leaves me [cry]. (Interviewee 10)*

In relation to the health risk, in four of the caregivers, some pathology due to the overload of care was developed, and in six, the pre-existing health problems were intensified, in addition to the ones that did not carry out consultations and examinations periodically.

*So there were several problems, I fell sick one after another, I caught infectious rheumatism; then I got stomach trouble, I got chronic migraine, I can not get too bored otherwise I fall bed because of the headache. (Interviewed 5)*

*I do not do exams as I should. I have not consulted in a while. And worse than that I have a proctological problem and I realize that it has gotten worse this whole time. (Interviewed 6)*

Developmental Self-Care Demands are mainly associated with the fact that caregivers develop the care of the sick person alone, because they are subjected to intense family conflicts and suffer physical and psychological stress frequently, such as the following caregiver's speech.

*I take care of him alone, I've always looked after him from the beginning. My brothers do not even show up here. I think they should at least call to find out how he is, you know? But I'm just here on the block. To tell you the truth, I feel angry at them. We fight a lot about it. I strain, I cry, even sick. Sometimes I do not think I'm going to give it a go and feel like giving up. (Interviewee 5)*

In relation to the Health Care Self-Care Claims, factors related to the fact that caregivers have health problems that affect their basic human needs (BHN), as well as factors related to their socioeconomic vulnerabilities.

*I do not care because I do not have time and my health problems are only increasing, increasing ... Not as right, I do not sleep well, I do not leave home to have fun, anyway. (Interviewee 10)*

*What really despairs me sometimes is when it feels bad. As she does not always have an*

*ambulance, I have to find a way to get her, but the financial condition is not enough and sometimes I can not afford a taxi. That makes me very sick, you know? (Interviewee 8)*

For each self-care demand that emerged, strategies were developed for the self-care of the caregivers focused on their reality, with the objective, through simple attitudes, to promote a change of behavior and the transformation of the form of take care of yourself and the other. As a basis for this suggestive strategies, the Notebook for Home Care of the Best at Home Program and the Practitioner's Guide of the Caretaker of the Ministry of Health.

#### ◆ Strategies for Universal Self-Care

It was suggested to the caregivers, for the demands of Universal Self-Care, regarding the factor of few hours of sleep / rest, measures to prevent insomnia such as: to perform relaxing activities before bedtime, including foot bath, massage of the muscles of the back, calf and feet; decrease the brightness of the environment before sleep and give preference to soft and comfortable beds.

It is necessary that the caregivers be guided on the tactics that can be developed to maintain the balance between activities and rest; for this, the caregiver needs to manage her time so that there is at least a rest interval between the heavier activities developed.

In relation to weight loss, irregular and inadequate diet (less than three meals a day) and poor water intake, increase and vary the consumption of fruits and vegetables, as well as reduce the consumption of foods with high lipid content, such as meats with apparent fat (many researched reported the consumption of these foods), canned, such as sausage and mortadella, as well as fried foods and snacks. You should do at least three meals and one snack per day, without 'skipping' the meals; this will help in reducing weight loss, since you will be ingesting what you need daily and with quality.

It is also necessary for caregivers to drink at least eight glasses of water per day; to ensure this water intake, caregivers can separate a container with water in the refrigerator that carries at least two liters of water, for their exclusive use, so that at the end of the day, if they are able to ingest the necessary amount of water.

The absence of moments such as talking and / or going out with family and friends, feeling of frequent sadness, low self-esteem and absence of the practice of physical activity, that the caregiver should participate in, at least, a monthly leisure activity, scheduling the best day for the same and trying not to interrupt; for this, it must have already obtained someone (family member, friend or neighbor of trust) to replace it in the care of his sick family member. This attitude is

characterized by the pursuit of activities and actions that promote social interaction and social development, aiming at the socio-educative, besides reducing the feeling of sadness and improving self-esteem.

It is important to stress that the caregiver should work harder to allow moments for talking with family, friends, neighbors and health professionals. After all, it is necessary to exchange experiences between family members and / or professionals and caregivers in order to the exercise of listening and speaking, as well as the elaboration of difficulties and recognition of potential.

Light walks, stretching and outdoor walks should also be performed frequently, stimulating the body to proper functioning, increasing the willingness to perform daily activities and producing health for themselves.

It was verified that, in relation to the fact that part of the caregivers developed some pathology due to the overload of the care and, in the majority of the cases, the preexisting health problems have intensified, besides not to make consultations and exams periodically, the caregiver should be guided to seek health care for the treatment of pathologies that have arisen as a result of the overload of care; To that end, health professionals, especially nurses, should pay attention to signs and symptoms presented by caregivers suggestive of organoleptic alterations, investigate whether they follow up on pre-existing pathologies before assuming the role of caregivers, and examinations periodically and guide them in decision-making regarding self-care. It is also defended that the nurse must forward / indicate referral services aiming at insertion into the social assistance network.

#### ◆ Strategies for Developmental Self-Care

It is noted that for the demands of Developmental Self-Care, in relation to the fact that the caregivers are the only ones in charge of the care of their family member who are ill, in addition to suffering intense family conflicts and being subjected to intense physical and psychological stresses, they ask the help of relatives, friends and neighbors of confidence for the accomplishment of the activities, dividing some tasks and balancing the actions developed daily, as well as, if possible, to define days and times so that they assume the functions for each one.

It is understood that in order to request assistance, mainly from a relative, in the dispensing of care, the caregiver will need to maintain a satisfactory dialogue with those who will assist her in the care and should expose her overload as the reason for requesting support. It is pointed out that an effective strategy in maintaining a good dialogue to request the help of

a family member who does not participate in the care is to avoid remembering situations in which he was not present or did not help when it was necessary, thus avoiding quarrels and arguments; if possible, caregivers may participate in family / community support groups aimed at reducing conflict.

It is necessary, for the reduction of physical and psychological stress, that a set of actions can be developed by caregivers. It is considered necessary that they know that the overload of care can culminate in acute and chronic diseases and, consequently, the use of various medications, making them as sick as the person who is cared for.

It should be emphasized that whenever the caregiver feels helpless or discouraged by a negative response, it is always a good thing to talk to another person, whether it is a family, a group of friends or a health team, and even if the latter does not is chosen by the caregiver for the dialogue, it is necessary to communicate to the team the anxieties, fears and difficulties that may be affecting the caregiver's health.

#### ◆ **Strategies for Self-Care for Health Deviations**

It is suggested, for the demands of Self-Care for Health Deviations, regarding the fact that caregivers have health problems with their basic human needs (BHN), as well as factors related to their socioeconomic vulnerabilities such as low financial condition, transport the family member to the hospital when necessary, as well as having little knowledge about the care provided, that some measures are taken.

Caregivers are required to have knowledge, through the health team, of general issues related to the pathological condition and specific about care, according to the types and degrees of dependency, to better care and to promote self-care. Self-care is impaired by the lack of simple actions or attitudes that harm the previously mentioned BHNs, such as inadequate feeding, impaired sleep and rest, social interaction affected, among other changes.

It has been found that socioeconomic vulnerability and difficulty in transporting family members who are ill with hospital are situations that require the help of people who can offer support; for this, caregivers can not lose the bond with family and friends who can help in these circumstances.

It is emphasized that the lack of knowledge about the care provided to the family member who is ill at home must be reverted to the multiprofessional team; and this, in turn, should clarify to the family the essential care and attention to the most common signs and symptoms, such as nausea and vomiting, constipation, diarrhea, bleeding and fainting. It is

also worth noting that basic guidelines should never be lacking in home visits, such as teaching the accommodation of the family member in bed, together with the instruction of measures to prevent pressure injuries, change of position and biosecurity measures, mainly with dressings, according to the need of each case. It complements that there must be harmony in the dialogue between the home care team and the family caregiver in the guidelines, clarification of doubts and moments of decision-making.

It is stated, through the results presented in this category, that the demands of self-care of the caregivers, coupled with strategies suggestive for self-care, need to be understood, taking into account the reality experienced by them, their biopsychosocial aspects and spiritual; however, the focus is only on the cancer patient who receives home care in palliative care.

It should be noted that the identification of the factors that affect the requirements of Universal, Developmental and Self-Care for Health Deviations, as well as the potentialities that the caregivers had for their self-care, with the support of the multiprofessional team, not only the elaboration of strategies for the realization of the caregiver's self-care, but also a critique in Nursing, through Orem's Nursing systems, for guidance during the home visit, based on national references on home care.

## DISCUSSION

It is emphasized that care as a mission sustains the caregivers' desire to protect and care for the loved one as they conceived of this act as something they were predestined to do, and not mind going back to the task imposed on them by life. It was evidenced in their languages that, when they worried about the future of the sick family member, each caregiver assumed.<sup>14</sup>

It was understood in this study that caring for a sick person at home is a great responsibility. It is revealed, from the speech of family caregivers, that some realize that home hospitalization provides some comfort and freedom, because they are in the patient's own space; on the other hand, feel that care at home generates feelings of guilt and greater responsibility, if the loved one passes away under their care.<sup>15</sup>

It is added that the family members understand the caregiver, in the exercise of caring, as if he were an orthodox priest and thus they treat him; in fact, it is the depository of all the yearnings and the responsibilities of the others, having, many times, to be accountable for the act of caring. It is understood that sometimes, even because of this, the guilt of the family as a whole is masked in relation to the patient; thus, abandonment by family members and the social protection network

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(health, care and welfare) makes the caregiver increasingly fragile in the task of caring.<sup>16</sup>

It is pointed out that, according to the Global Atlas of Palliative Care, the support of family and caregivers is very common and important for patients with palliative care needs, especially in the community. In the implementation of palliative care services, interventions to support caregivers should be considered in order to provide better evaluation and implementation of health care.<sup>17</sup>

Another important aspect to consider is the transformation of the routine: care causes the relationship to shake due to the fact that not all family members accept the new familiar clothing and the drop in attention and affection. The caregiver's relationship with the family is altered, and he will often feel lonely, afraid, sad for the sick family member, full of doubts and uncertainties, trying to do the best; the caregiver often suffers pressure from the family, who should share the tasks with him, when he sees him as the only responsible and with infinite availability and permanent tolerance, not considering him as a person with a life of his own, choices and desires - it is as if their identity is totally absorbed by the caregiver role.

In relation to another aspect to be analyzed, care with food, hygiene, administration of medications and patient health consultations increases their overload, but the suffering of caregivers is not only caused by the overload of work. It is known that the financial imbalance and the reduction of social activities also cause bad signs and symptoms for these caregivers.<sup>18</sup>

It is noted that the fact that caregivers abstain from their activities and vanities to care for their being is similar to another in which caregivers reported having difficulty practicing healthy habits, maintaining poor water intake and low consumption of dietary fiber, and they were sedentary due to the time limitation to worry about health and to carry out physical activities or leisure activities, thus minimizing social interaction practices and, thus, difficulty in socializing.<sup>19</sup> This difficulty is evident in their speeches and expressions in which they are saddened to have been deprived of personal care, such as sleeping, going to the bathroom or bathing, for they are easily impeded by the patient's constant calls.<sup>15</sup>

In this study data that is linked to the research carried out was obtained, highlighting the importance of using a structured approach to reflect on the challenges. A wide range of barriers to thinking and reflection have been described by caregivers: they feel overwhelmed, lack time, and engage in tasks that have become automatic and routine; in this way, health care team members can be a tool to encourage introspection among

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caregivers in providing a focused process to analyze problems and challenges.<sup>20</sup>

This data reveal the need to disseminate the strategies proposed here to overcome these difficulties, raising awareness and awakening to the need for self-care. A study carried out by the majority of caregivers reveals one or more information needs in personal psychosocial care, providing direct care and care management, while little more than four out of ten caregivers express the need for information about managing emotional and physical stress. It is emphasized that the need for personal psychosocial care contents was particularly evident among caregivers with high objective overload.<sup>21</sup>

It is necessary, therefore, to look at temporality, because, in caregivers, tensions, situations of stress and anxiety are permanent to the point of seeing the physical, mental, social and spiritual health affected, leading to a continuous and progressive deterioration of their quality of life, most of the time, unknown and unexplored by the multidisciplinary health team.

## CONCLUSION

It was found that the caregiver's self-care needs are linked to inadequate sleep and rest, ineffective feeding and hydration, impaired social interaction, health risk, socioeconomic vulnerabilities and lack of education. Strategies suggestive of self-care were designed to address these needs, taking into account their situational reality, considered as a strong contributory factor for the advancement of self-care studies.

It is evident that the barrier to support self-care is centered on the need to care for the sick person above anything, making it a priority of greater importance than any other personal need.

Dorothea Orem's Nursing Theory was used to identify the needs of Universal, Developmental and Health Deviant Self-Care for the planning of a Nursing action planning aimed at the caregiver and as close as possible to their real needs. It was explained, through this fact, the significant contribution of theory to restructure and improve Nursing care in the development of professional practice, seeking to respond to the basic needs of the individual, in this case, family care. It is necessary, however, for changes to occur throughout the health care process of individuals, permeating the logic of palliative care aimed at offering direct care to the patient and significant support to the caregiver, so that both are part of the care logic.

In this sense, it is emphasized that as a duty of Nursing, to guide self-care to any and all individuals that are included in the health care network, directly or indirectly. It should be characterized the home visit as an action aimed at the realization of education in continuous health

for the improvement of the abilities of the family caregiver in the care of the sick person and their self-care. It is suggested that the formation of support groups for caregivers be an excellent strategy, together with the use of educational technologies, as they provide spaces for the exchange of experiences, favoring a place for the free expression of emotions and feelings, so that the caregiver feels free the feeling of fear and repression, functioning as an escape valve for some of the feelings that overwhelm him, in addition to going for socialization, interaction with light technologies and collaboration with peer education.

It is hoped that this study will serve as a subsidy to sharpen the view of the palliative care professional, in the sense that, increasingly, part of the attention is directed towards the caregiver. It is necessary to create an indestructible bond between the multiprofessional team, the sick person and the caregiver, favoring the success of the planning of the actions and the accomplishment of a qualified assistance, with the attention, in fact, integral to the health of the individuals who make up this triad.

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Submission: 2019/04/01

Accepted: 2019/05/24

Publishing: 2019/05/09

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