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Coping strategies of caregivers of patients receiving palliative home care

Bruna Maffei¹

 <https://orcid.org/0000-0002-8793-189X>

Isabel Cristina de O. Arrieira²

 <https://orcid.org/0000-0003-4607-9255>

Renata A. Ferreira³

 <https://orcid.org/0000-0002-7623-0684>

Daniela H. Cardoso²

 <https://orcid.org/0000-0002-2226-1805>

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1 Federal University of Santa Catarina (UFSC), Florianópolis, SC, Brazil.

2 Federal University of Pelotas (UFPeL), Pelotas, RS, Brazil.

3 Nossa Senhora da Conceição Hospital, Tubarão, SC, Brazil.

Abstract

This research aimed to understand the coping strategies of caregivers of patients in palliative care. It is a qualitative, descriptive-exploratory study with nine caregivers of patients in palliative care of a home hospitalization program in the southern region of Brazil. A semistructured interview collected data and submitted to content analysis. The results showed strategies about personal resources before care and social support. Family, faith, and support from the home team were significant coping resources. The patient's clinical situation and caregiver-patient affection made it difficult for the caregiver's exposure to personal problems, devaluing health complaints. It is concluded that caring for a family member is a challenging task, which influences the caregiver's health and can lead to the illness of the caregiver, and the relay of care can reduce their overload. It is necessary to integrate the caregiver into the care of the team and implement educational actions to their health.

Keywords: coping behavior; caregivers; palliative care; psycho-oncology; home assistance.

ESTRATÉGIAS DE ENFRENTAMENTO DE CUIDADORES DE PACIENTES EM CUIDADOS PALIATIVOS NO DOMICÍLIO

Resumo

A pesquisa objetivou compreender as estratégias de enfrentamento de cuidadores de pacientes em cuidados paliativos. Estudo qualitativo, descritivo-exploratório, com nove cuidadores de pacientes em cuidados paliativos de um programa de internação domiciliar do Sul do Brasil. Os dados foram coletados por uma entrevista semiestruturada e submetidos à análise de conteúdo. Os resultados evidenciaram estratégias sobre recursos pessoais prévios ao cuidado e ao apoio social. A família, a fé e o apoio da equipe domiciliar foram importantes recursos. A situação clínica do paciente e o afeto entre cuidador e paciente dificultaram a exposição do cuidador sobre seus problemas pessoais, desvalorizando queixas de saúde. Conclui-se que cuidar de um familiar é uma tarefa desafiadora, que influencia a saúde do cuidador, podendo acarretar o adoecimento deste, e o revezamento do cuidado pode diminuir a sua sobrecarga. É necessário integrar o cuidador na assistência da equipe e implementar ações educativas à sua saúde.

Palavras-chave: enfrentamento; cuidadores; cuidados paliativos; psico-oncologia; assistência domiciliar.

ESTRATEGIAS DE ENFRENTAMIENTO DE LOS CUIDADORES DE PACIENTES EN CUIDADOS PALIATIVOS EN EL DOMICILIO

Resumen

La investigación objetivó comprender las estrategias de enfrentamiento de los cuidadores de pacientes en cuidados paliativos. Estudio cualitativo, descriptivo-exploratorio, con nueve cuidadores de pacientes en cuidados paliativos de un programa de internación domiciliaria de la región sur de Brasil. Datos recolectados por una entrevista semiestructurada y sometidos a análisis de contenido. Resultados evidenciaron estrategias sobre recursos personales previos al cuidado y al apoyo social. Familia, fe y el apoyo del equipo domiciliar, fueron importantes recursos. La situación clínica del paciente y el afecto entre cuidador-paciente, dificulta la exposición del cuidador sobre sus problemas, desvalorizando sus quejas de salud y descuidando el autocuidado. Se concluye que cuidar de un familiar es una tarea desafiante, que influye en la salud del cuidador, puede acarrear en su enfermedad, y el relevo del cuidado puede disminuir su sobrecarga. Necesario integrar al cuidador en la asistencia del equipo y implementar acciones educativas a su salud.

Palabras clave: enfrentamiento; cuidadores; cuidados paliativos; psicooncología; asistencia domiciliaria.

1. Introduction

The news of a serious illness impacts the entire context in which the individual is inserted. In the case of a diagnosis of cancer, it is linked to social representations and stigmas associated with the finitude of life. Cancer care includes comprehension about prevention, diagnosis, and treatment, and encompasses the understanding of palliative care for the patient and his/her family, including the caregiver. This person, like the sick family member, needs care and needs to be seen as a vulnerable individual faced with a stressful situation, which is having a sick family member with no prospect of a cure.

The main family caregiver is one who, within the family nucleus, takes primary responsibility for the care of a family member and is characterized as not having specific knowledge or receiving remuneration (Ferré-Grau, Rodero-Sánchez, Cid-Buera, Vives-Relats, & Aparicio-Casals, 2011). Caring goes beyond daily activities, since the caregiver invests attention in the physical, emotional, and social demands of the patient, serving as his/her support network (Fetsch et al., 2016). In

addition, the place of care for the patient receiving palliative care influences the life of the caregiver. In the case of the home context, this tends to be beneficial for family and friends, as well as for the patient, preserving the family contact (Oliveira, Quintana, Budó, Kruse, & Beuter, 2012a).

Therefore, many palliative care patients prefer to be cared for at home, although they fear overburdening their caregivers because of increased dependence due to the advanced disease (Mohammed et al., 2018). Accordingly, caregivers in the domestic environment can take on responsibilities and tasks, often without feeling prepared to perform them, resulting in suffering and worsening in the quality of life (Buck, Webb, Moth, Morgan, & Barclay, 2018).

Faced with responsibilities and proximity to the sick family member, the caregiver may encounter difficulties related to daily living, as well as exposure to the limitations and physical and emotional symptoms of the patient that can mobilize different feelings in the caregiver. When the caregiver-patient relationship involves family and affective bonds, the emotions may manifest even more intensely (Anjos & Zago, 2014; Araújo & Leitão, 2012).

Physical, emotional, financial, and social overload are some of the factors that affect the caregiver's health (Araújo & Leitão, 2012). In addition, worsening of the patient's clinical situation, the particularities related to the reality of home care, especially in the case of advanced diseases, and the possibility of death, can intensify the overload of the caregiver (Galatsch, Prigerson, Schnepf, Sayn-Wittgenstein, & Li, 2019; Oliveira et al., 2017).

Even so, the caregiver tends to seek strength, courage, and motivation in the sick family member to continue providing care (Oliveira et al., 2013). Therefore, faced with several stress enhancers, caregivers can use coping strategies that provide them with a stimulus to face the care and illness process of the patient.

Coping is understood as a set of cognitive and behavioral efforts used by individuals to manage specific external and/or internal demands that go beyond their resources (Lazarus & Folkman, 1984). The way each person will face a stressful situation occurs from a cognitive assessment of personal resources, beliefs, problem-solving skills, social support, and material resources available. Furthermore, the individual meaning attributed to the situation influences what strategies will be used (Lazarus & Folkman, 1984). These tend to be dynamic and change according to the actual needs (Fetsch et al., 2016).

Given the above and the understanding that stressful events may influence the caregiver's biopsychosocial health, the present study is justified due to the relevance of the development of studies on the factors that reinforce positive aspects of the period experienced by caregivers and support their coping in the home environment. Therefore, the study aimed to comprehend the coping strategies of caregivers of patients receiving palliative care in the home context.

2. Method

2.1 Study design and context

This was a qualitative, descriptive-exploratory study. This approach made it possible to deepen the phenomenon from the perspective of the participants according to their experiences and meanings related to their context. Descriptive-exploratory research seeks greater familiarity with the still-undecided topic (Sampieri, Colado, & Lucio, 2013), as is the case for coping strategies in caregivers specifically in the home context.

It should be mentioned that the present study sought to follow the recommendations of the Consolidated criteria for reporting qualitative research (COREQ), which presents a list of 32 items to be verified in qualitative studies, in order to help the researcher to report relevant aspects of the research (Tong, Sainsbury, & Craig, 2007). Among the items contemplated in this study are those related to the study team and reflexivity, those referring to the study design and some of the items related to data analysis and results.

The context in which the research was carried out was a home hospitalization program linked to a Teaching Hospital in the southern region of Brazil. The program was implemented in 2005 and is composed of two multidisciplinary teams that include doctors, nurses, nursing technicians, psychologists, nutritionists, social workers, physiotherapists, occupational therapists, dentists, and chaplains. Each team serves ten oncology patients receiving palliative home care.

2.2 Participants

Nine family caregivers of oncology patients receiving palliative care linked to a home hospitalization program were interviewed during the period from August to October 2016. The selection criteria were: 1. to be the main family caregiver of the

patient; 2. be aged 18 years or over. Caregivers who received remuneration for the exercise of care were excluded.

The caregivers were selected based on the convenience method, which takes into account the participants' accessibility, their willingness to participate in the study and the characteristics of the study (Sampieri et al., 2013). The theoretical saturation criterion supported the number of participants. This criterion is widely used in qualitative studies, since it makes it possible to identify when the number of interviews can be finalized. Even recognizing that each interview presents its particularities and specificities, the collection ends when the contents of the participants' reports begin to repeat themselves, and the inclusion of more data will not change the understanding of the subject studied (Fontanella, Ricas, & Turato, 2008).

2.3 Instrument and technique

To achieve the proposed goal, a semi-structured interview was used, composed of sociodemographic data and open questions to comprehend the coping strategies, such as: "Where do you seek the strength to face difficult situations throughout the care provided?" and "In these situations, whom or what do you turn to when you need to?". The semi-structured interview is a privileged space in which the participants can express their beliefs, emotions, and experiences (Moré, 2015). It is composed of a script of questions, and the interviewer can elaborate other questions to deepen the subject (Sampieri et al., 2013).

2.4 Procedures

Telephone contact with caregivers was carried out in order to make an initial approach and to identify their interest in participating in the study. For those who accepted, the place of the data collection was chosen according to the preference of the participants, having the School Hospital or the home of the caregiver as the possibilities, respecting the conditions of privacy. The collection began after the signing of the consent form, guaranteeing the freedom of refusal or withdrawal of consent at any time, without any prejudice. The duration of the interviews ranged from 45 to 90 minutes.

The interviews were stored on an audio recorder and transcribed in full. The data were organized using the thematic content analysis technique proposed by

Bardin (2011), through the three phases described by the author: 1. pre-analysis; 2. exploration of the material and 3. treatment of the results, inference, and interpretation. In the pre-analysis, the organization of the material, transcription of the recordings, and preparation of the obtained data took place. The exploration of the material consisted of an in-depth reading of the reports present in the transcripts in order to codify the contents identified and group them into units of meaning. The last phase made it possible to layout the results obtained and to propose inferences and possible interpretations (Bardin, 2011).

The categories were established according to the aim of the present study. Thus, through the analysis of the data, through successive readings of the caregiver reports, units of meaning were identified, which were grouped into categories according to their similarities, differences, and/or singularities. The names of the categories emerged from the statements of the participants and through the reading of the scientific materials related to the subject studied. The analysis revealed five categories related to the coping strategies used by home caregivers. These were: experiences of the practice of the family caregiver; the family as the care unit; faith as a therapeutic support; support from the home care team; and the home as a health care setting. Participants were identified by the code FC (family caregiver) followed by the number from 1 to 9 according to the order of the interviews. The Research Ethics Committee approved the study of the Federal University of Pelotas – authorization No. 1.558.688. The norms of Resolution No. 466/2012 of the National Health Council were respected.

3. Results and Discussion

3.1 Characterization of the participants

Nine family caregivers participated in this study, eight of them female and one male, aged between 49 and 72 years, with a prevalence of married caregivers (six caregivers), with incomplete elementary education (five caregivers) and exclusive dedication to the patient and activities of the house (eight caregivers). The time of care ranged from six months to 15 years and, concerning the degree of kinship of the caregiver, five were spouses and the others, mother, sister, niece, and sister-in-law.

3.2 Experiences of the practice of the family caregiver

Early care experiences are important forms of learning for future coping (Oliveira et al., 2013). These are consolidated in the function of the caregiver and are sources of knowledge, which can be configured as more security in the activities developed and can help in the elaboration of the resources that will be used in times of difficulty. Situations previously considered unknown now tend to be perceived with greater coping capacity by the caregiver (Cruzeiro et al., 2012), as identified in the reports below.

I already knew how to provide care because my mother had ischemia. We even learned how to insert the catheter (FC1).

My mother had lung cancer and I helped take care of her [...] I had the experience of looking after my grandmother and my father [...] I had to learn it because I had to provide the care and it helped me take care of him [caregiver's husband] now (FC5).

Coupled with previous care experiences, the affection involved between caregiver and family member tends to strengthen them in the face of the challenges (Oliveira et al., 2013). The patient plays an important role in the life of the caregiver, in which the caregiver seeks strength in the history experienced together and in the desire to stay with the loved one, as the following excerpts show:

The strength I find is in knowing that I have chosen it for myself. A physical problem cannot make me forget what I experienced with him, good and bad" (FC7). "That's exactly what she would do for me [...] we are finding strength because I want to continue living with that person" (FC8).

At the same time as the affection for the sick relative appears, the caregiver's narratives highlight the implications of the daily care, such as tiredness, discouragement, and fear, which led six participants to use psychoactive drugs to relieve the symptoms, as the statements reveal:

Emotionally I got really bad [...] in the beginning you are very strong, but then you weaken [...] I started taking medicine and feeling calmer (FC4).

I was down from depression [...] I take medicine, and it's helping me. It gives me courage (FC5).

There are times that I want to disappear, but then I think it will not solve the problems [...] I have medicine that the "doctor" prescribed for depression [...] I'm scared that he'll die (FC6).

The results reflect the feelings involved and the expressive number of caregivers using medication. Similar data were found in a study with home-caregivers of oncology patients who presented symptoms such as fatigue, anxiety, and depression, and used anxiolytics and anti-depressants to control psychic symptoms (Oliveira et al., 2013).

The wide variation of time in which the caregiver continues providing care should be noted, considering that it is a chronic disease, such as cancer. It is known that a long period of care for a patient in palliative care is associated with the physical and psychological overload of the caregiver (Fripp, 2012). In the present study, the time ranged from six months to 15 years, which may have intensified the responses obtained.

Along with the period of care, the caregiver must manage his/her time between the sick relative, the other family members, and the household activities, often giving up time for him/herself. Faced with the changes in the caregiver's roles and daily life, there is a reorganization of the daily household practices, plans, and routine in favor of providing the care (Anjos & Zago, 2014; Inocenti, Rodrigues, & Miasso, 2009).

During the interviews, it was identified that the caregivers presented difficulties in talking about themselves. The statements were focused on the clinical state of the patient, which presupposes that, for the caregivers, those who required more care were the sick family members. This result corroborates the results of the study by Yavo and Campos (2016), in which the home caregivers presented difficulties in verbalizing emotional contents, with their discourse being directed toward the daily tasks. Also, the authors pointed out that the fear the fear of losing the

person also makes it difficult for the caregiver to think about the future, considering the possibility of being without the sick family member. When such a thought emerges, it may be accompanied by a sense of guilt (Yavo & Campos, 2016).

3.3 The family as the care unit

The family represents an important source of support and protection for the patient during the hospitalization and treatment (Capello, Velosa, Salotti, & Guimaraães, 2012) and also plays a prominent role in the coping of the caregiver. All the statements showed the value attributed to the help received, either as dedicated help for the patient or the caregivers themselves, as illustrated by the participants:

God put her [the caregiver's daughter-in-law] in our lives. She is always with us [...] She is a nurse [...] So you feel more secure in everything [...] the family support is very important (FC4).

I always seek strength in my mother because she has experienced so much [...] We are clinging to who is close. I made a very good partnership with my son and daughter-in-law, who help me (FC8).

Accordingly, the family presents itself as an important support network for family caregivers (Cruzeiro et al., 2012) and the home environment is associated with the ease of care through the rotation of the care (Oliveira et al., 2012b). It also allows the proximity of living together among the family members and the exchange of experiences and feelings generated by the care practice (Inocenti et al., 2009). This approach favors closer bonds, reciprocal support, and the division of the care responsibilities among those involved. On the other hand, the absence of support from the family ends up overloading the person that assumes the responsibility, since it centralizes the needs of the patient in a single person, as shown by the statement of one caregiver:

I was very disappointed. I expected more partnership [...] I wanted them to talk to him [the caregiver's husband], to make time pass for him. That would help me because I would have more time to take care of the house (FC7).

In the report mentioned above, it can also be identified that the family's desire for support is linked to patient care and the ability of the caregiver to perform household tasks. However, the family may represent important support for caregivers by encouraging self-care activities, such as physical exercise, as in the following statement:

I really enjoy doing physical activity. Then, after he [the caregiver's husband] started to get worse and I could not go anymore. Time passed, my son said that I had to have some time for me to take care of myself. Then I started to go to Zumba classes. It's pretty good, but then he [caregiver's husband] had worse moments, then I had to leave (FC4).

The statement reinforces that the caregiver understood the patient's health as a priority and that she could give up her activities to provide support for the family member. In this sense, it is known that caregivers can also give up caring for their health. Changes in sleep, food, and a decrease in seeking medical care can be observed (Brasil, 2012), which tend to be understood as risk factors for their coping. In this way, the comprehension of the family members regarding the challenges and anxieties experienced by the caregiver, as well as the valorization of his/her well-being, potentiate the development of coping strategies that aim to encourage healthy habits and self-care, resulting in a better quality of life for the caregiver.

3.4 Faith as a therapeutic support

Faith was present in all the reports, with four participants saying they had a religion (Catholic) and five that they had no religion. Of the nine respondents, eight reported believing in God, and one believed that there was something, but was unable to describe it. The search for strength based on faith was presented through prayers and supplications to God, as expressed by the caregivers' reports:

Without God, what will become of us? If it was not for God [...] I'm very realistic. One day the person will die (FC1).

I think it's God Himself. I'm a Catholic, and so is he. I pray a lot [...] I ask what is best for him (FC2).

God is light. I think God is like a power line for us to hold on to. That lights up people to do nothing wrong (FC6).

The caregivers clung to spirituality and religiosity, through prayers and worship of God, also as a way of facing the threat of death. Accordingly, God appeared as a form of consolation and strengthening (Capello et al., 2012). The trust placed in this was also a source of comfort and security. The belief in a higher being is a form of support and protection related to the fact of not being alone caring for a loved one without the prospect of a cure.

When asked about the content of the prayers, the desires of the caregivers were directed towards the patient. These reports confirm the concern for the family member's health and reinforce the priority of the sick family member (Cruzeiro et al., 2012), as can be evidenced in the following statements:

I pray every day at night [...] When he is not well, I do not even ask for a cure, but that at least he gets a little better (FC7).

I ask God for help [...] May God enlighten his spirit, give him light (FC4).

Spirituality also involves the need to seek meaning, an explanation for the process experienced, or even a form of spiritual evolution, as portrayed in the narratives of the caregivers:

I have faith. I believe in god. The more you go through trouble and suffering, the stronger your spirit will be. Maybe that's the meaning (FC7).

Since I have read these [Spiritist] books, it seems that we have a hope of another life [...] a hope of continuity. If we do not believe in anything, it does not make sense to fight for everything (FC2).

Faith becomes a means of sustenance and security and expresses the understanding of situations as God's will (Inocenti et al., 2009). When dealing with caregivers of patients receiving palliative care, there exists the imminence of the finitude of life and the associated fear, which can reinforce the importance of the faith in this

process, considering that individuals facing difficult situations resort to spirituality as a coping strategy, going through this process less painfully due to the meaning assigned. Arrieira et al. (2017) add that through spirituality, new meanings can be attributed to the experience and that it can be a facilitator for the acceptance of death.

3.5 Support of the home care team

The security transmitted by the professionals passes credibility in the care for the patient and has repercussions in the sharing of the care. The presence of a home care team was highlighted by the participants as one of the main forms of support, as in the reports below:

After the PIDI (Interdisciplinary Home Hospitalization Program) appeared, the thing changed a lot [...] There is no way to explain the care. They come every day (FC9).

I turned my house over to them. I have confidence (FC3).

I feel calm. Even the dentist came (FC5).

Calmness. It brings a lot of peace of mind for people to know that they are well protected (FC8).

This possibility of home care, continuously, establishes a relationship of trust that results in greater peace of mind for the family members, often avoiding the need to travel to emergency services (Oliveira et al., 2012a) that are associated with long queues and unsatisfactory consultations.

Specialized home care is a source of gratitude and spending time together every day tends to strengthen the bonds between the caregiver and the health team. The good relationship, satisfaction and trust of the caregivers with the professionals in difficult situations makes the caregivers feel welcomed (Capello et al., 2012) and supported to continue their activities (Oliveira et al., 2012b).

Furthermore, facilitated and free access to materials such as medicine and diapers was another aspect highlighted since not all families would be able to afford them, as the participants pointed out:

Thankfully, we have this free treatment that comes with all the medication. Have you thought if we had to pay? There would be no way (FC2).

I think it's good because I didn't have to go out for him and do it. They bring medicine. Gloves, tape, gauze, everything you need (FC5).

Concomitant with the support with consumables, the guidance, by the professionals, conveys security to the caregivers faced with the care dedicated to the patient. For this, a team is required to invest in open and careful communication between caregiver, patient and other relatives about the health condition and prognosis of the person, providing dialogues that allow the treatment behaviors to be performed with the participation of the patient and family members (Alfaya et al. 2016; Gramling et al., 2015). Also, the constant intercommunication of these people with the health team allows a space of conversation and support for the clarification of doubts and the expression of anxieties (Gramling et al., 2015; Innocenti et al., 2009).

Accordingly, in addition to the technical and material support obtained, caregivers yearn for and appreciate affection, care, and attention to their emotional aspects, as the following statements demonstrate:

They are affectionate with me [...] A pastor comes too. It's good because he has a word that always brings comfort (FC5).

They talk. The affection that is transmitted to us. To help me and give that rise in the mood (FC6).

The "doctor" seems to feel together with us [...] She always finds something to say according to what we're experiencing (FC7).

The support offered through a welcoming environment provides the expression of feelings and helps the caregivers to allow themselves to feel and expose their thoughts, knowing that professionals are willing to provide support. This space permits the identification of the personal requirements of the caregiver, allowing the team to act in an interdisciplinary way, with professionals of different

areas of knowledge (Fripp, 2012) that can provide support according to the needs and particularities of each caregiver (Gramling et al., 2015). Therefore, the constant communication among the professionals of the team and between them and the caregiver favors the effectiveness of integrative care (Oliveira et al., 2017). Also, the support for the emotional conditions of the caregivers tends to facilitate their coping with the process of illness of a family member (Oliveira et al., 2012b).

3.6 The home as a health care setting

The different care spaces for the patient receiving palliative care have an impact on the life of the caregivers and can influence their coping. When feasible, an alternative is the permanence of the caregiver and patient at home, favoring the comfort and autonomy of both. All the caregivers cited the home as the best place to take care of the family member, as illustrated by the participants' reports:

It's better at home because you can take a shower. There [hospital] you can't take a shower (FC3).

At home, I think it's better because you can give better care. In the hospital, they have their schedule for everything [...] You can't even rest (FC4).

It's that concern to go to the hospital every day, but not here, here he lies in bed, and I can do my things (FC5).

The statements are corroborated by the results of the study by Cruzeiro et al. (2012), who highlighted the home as the best space for caregivers to provide support to patients, since it protects the autonomy, freedom, comfort, flexibility of feeding and hygiene schedules, and can be considered the best place for the caregivers to organize their daily activities. Also, home care may still be associated with hospital continuity, given the specialized care that remains when the family continues to be accompanied by the home health team.

In the case of hospitalization, the caregiver is exposed to noise, lack of privacy and comfort and standardized routines (Oliveira et al., 2012a). Also, the stimulation of public policies on home care in palliative care situations is justified by the reduction of costs in long hospital stays and by the valorization of the coexistence

between the patients and their family contexts in the comfort of their homes (Sanchez et al., 2010). In this way, it can be considered that being exposed to favorable environmental variables is a factor that positively influences the individual's coping strategies.

However, the desire to care for the family member at home is very much associated with the monitoring of the palliative care by the home care team, as revealed by the caregiver's statement: "The atmosphere of the house is better, and we are being attended by the PIDI" (FC8).

In the absence of the support provided by the home care team, feelings of loneliness and overload can emerge in the caregiver, and the home environment can generate insecurities. The caregiver starts to assume greater responsibility for the patient, which can lead to fear and guilt in the event of death (Oliveira et al., 2012a). Therefore, the caregiver's decision to continue home care is intrinsically linked to the psychological, technical, and social support received by health care providers (Sanchez et al., 2010).

4. Final considerations

The study made it possible to comprehend the coping strategies used by family caregivers of patients receiving palliative care in the home context, either through personal resources or social support. The home environment is seen by the caregiver as less complex to provide care compared to the hospital. This perception is linked to the presence of social support, especially by the home care team.

The act of caring for a relative receiving palliative care has been characterized as a challenging task, which tends to influence the health of the caregiver. An important alternative is rotating the care among family members, which may contribute to reducing the burden on the primary caregiver. Therefore, it is important to provide spaces for dialogue in order to allow the care of the patient to be shared by the other family members, as well as the responsibilities that permeate the care for a family member receiving palliative care. Faith was also highlighted as a coping strategy, since seeking meaning faced with the situation experienced and the understanding of it as God's will can provide comfort and better acceptance, given the imminence of the finitude of life.

The presence of the home care team was also presented as an important support, since it provided the caregivers with security and confidence in the care

process. These caregivers tend to prioritize care for the needs of the patient, which generates reflections on their quality of life and represents a hazard to their health. Therefore, the palliative home care team must be attentive to the needs of the caregiver in order to identify the coping strategies of the subjects, stimulating and strengthening the protective factors involved. Accordingly, the performance of an interdisciplinary team is prioritized, complementing the knowledge, offering integrative care to the caregivers and educational actions for their health.

Based on the results of this study, it is believed that future work and actions can be based and planned to promote health and strengthen protective factors that improve the quality of life of caregivers. The importance of groups of caregivers with regular meetings should be reinforced in order to provide a space for the exchange of experiences, making it possible to share the resources used.

As limitations of the study, it is highlighted that the study was carried out in a single home care service, as well as the exclusion of caregivers who were not family members or who received remuneration for the care provided. However, it is understood that these individuals have particularities that deserve to be researched in specific studies. Finally, the development of studies with caregivers in other contexts, such as in the hospital environment, is suggested, as this presents different characteristics that also need to be investigated. The importance of studies aimed at understanding the coping strategies of other caregivers, the patients themselves in palliative care, and the members of the home care team is also highlighted.

References

- Alfaya, G. M. M, Bueno, P. M. J., Hueso, M. C., Guardia, M. P., Montoya, J. R., & Garcia, C. M. P. (2016). Palliative care team visits. Qualitative study through participant observation. *Colombia Médica*, 47(1), 38–44. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4867515/>
- Anjos, A. C. Y., & Zago, M. M. F. (2014). Ressignificação da vida do cuidador do paciente idoso com câncer. *Revista Brasileira de Enfermagem*, 67(5), 752–758. doi:10.1590/0034-7167.2014670512
- Araújo, J. A., & Leitão, E. M. P. (2012). O cuidador do paciente em cuidados paliativos: Sobrecarga e desafios. *Revista do Hospital Universitário Pedro Ernesto*, 11(2), 77–81. Recuperado de: http://revista.hupe.uerj.br/detalhe_artigo.asp?id=330

- Arrieira, I. C. O., Thofehrn, M. B., Milbrath, V. M., Schwonke, C. R. G. B., Cardoso, D. H., & Fripp, J. C. (2017). O sentido da espiritualidade na transitoriedade da vida. *Escola Anna Nery*, 21(1). doi:10.5935/1414-8145.20170012
- Bardin, L. (2011). *Análise de conteúdo*. São Paulo: Edições 70.
- Brasil (2012). *Melhor em casa: A segurança do hospital no conforto do seu lar*. (Caderno de Atenção Domiciliar, v. 2). Brasília: Ministério da Saúde. Retrieved from http://189.28.128.100/dab/docs/geral/cap_6_vol_2_cuidados_paliativos_final.pdf
- Buck, J., Webb, L., Moth, L., Morgan, L., & Barclay, S. (2018). Persistent inequalities in hospice at home provision. *BMJ Support Palliative Care*, 8(Suppl.), 1–8. doi:10.1136/bmjspcare-2017-001367
- Capello, E. M. C. S., Velosa, M. V. M., Salotti, S. R. A., & Guimarães, H. C. Q. C. P. (2012). Enfrentamento do paciente oncológico e do familiar/cuidador frente à terminalidade de vida. *Journal of the Health Sciences Institute*, 30(3), 235–240. Retrieved from https://www.unip.br/presencial/comunicacao/publicacoes/ics/edicoes/2012/03_jul-set/V30_n3_2012_p235a240.pdf
- Cruzeiro, N. F., Pinto, M. H., Cesarino, C. B., & Pereira, A. P. S. (2012). Compreendendo a experiência do cuidador de um familiar com câncer fora de possibilidade de cura. *Revista Eletrônica de Enfermagem*, 14(4), 913–921. Retrieved from <https://www.fen.ufg.br/revista/v14/n4/pdf/v14n4a20.pdf>
- Ferré-Grau, C., Rodero-Sánchez, V., Cid-Buera, D., Vives-Relats, C., & Aparicio-Casals, M. R. (2011). *Guía de cuidados de enfermería: Cuidar al cuidador en atención primaria*. Tarragona: Publidisa. Retrieved from <http://www.urv.cat/dinfern/media/upload/arxius/guia%20cuidados%20infermeria.pdf>
- Fetsch, C. F. M., Portella, M. P., Kirchner, R. M., Gomes, J. S., Benetti, E. R. R., & Stumm, E. M. F. (2016). Estratégias de coping entre familiares de pacientes oncológicos. *Revista Brasileira de Cancerologia*, 62(1), 17–25. Retrieved from http://www1.inca.gov.br/rbc/n_62/v01/pdf/04-artigo-estrategias-de-coping-entre-familiares-de-pacientes-oncologicos.pdf
- Fontanella, B. J. B., Ricas, J., & Turato, E. R. (2008). Amostragem por saturação em pesquisas qualitativas em saúde: Contribuições teóricas. *Cadernos de Saúde Pública*, 24(1), 17–27. doi:10.1590/S0102-311X2008000100003
- Frupp, J. C. (2012). Ação prática do paliativista na continuidade dos cuidados em domicílio. In R. T. Carvalho & H. A. Parsons, *Manual de cuidados paliativos*. (pp. 375–391). São Paulo: Academia Nacional de Cuidados Paliativos.

- Galatsch, M., Prigerson, H. G., Schnepf, W., Sayn-Wittgenstein, F., & Li, J. (2019). Care-giver exposure to critical events and distress in home-based palliative care in Germany: a cross-sectional study using the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) scale. *BMC Palliative Care*, 18. doi:10.1186/s12904-019-0395-8
- Gramling, R., Gajary-Coots, E., Stanek, S., Dougoud, N., Pyke, H., Thomas, M., ... Norton, S. A. (2015). Design of, and enrollment in, the palliative care communication research initiative: a direct-observation cohort study. *BMC Palliative Care*, 14-40. doi:10.1186/s12904-015-0037-8
- Inocenti, A., Rodrigues, I. G., & Miaso, A. I. (2009). Vivências e sentimentos do cuidador familiar do paciente oncológico em cuidados paliativos. *Revista Eletrônica de Enfermagem*, 11(4), 858-865. Retrieved from <https://revistas.ufg.br/fen/article/view/5197/17570>
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Mohammed, S., Swami, N., Pope, A., Rodin, G., Hannon, B., Nissim, R., ... Zimmermann, C. (2018). "I didn't want to be in charge and yet I was": Bereaved caregivers' accounts of providing home care for family members with advanced cancer. *Psychooncology*, 27(1), 1229-1236. doi:10.1002/pon.4657
- More, C. L. O. O. (2015). A "entrevista em profundidade" ou "semiestruturada", no contexto da saúde: Dilemas epistemológicos e desafios de sua construção e aplicação. *4º Congresso Ibero-Americano em Investigação Qualitativa*. Aracaju: Universidade Tiradentes. Retrieved from <https://proceedings.ciaiq.org/index.php/ciaiq2015/article/view/158>
- Oliveira, S. G., Quintana, A. M., Budó, M. L. D., Kruse H. L., & Beuter, M. (2012a). Internação domiciliar e internação hospitalar: Semelhanças e diferenças no olhar do cuidador familiar. *Texto e Contexto Enfermagem*, 21(3), 591-599. doi:10.1590/S0104-07072012000300014
- Oliveira, S. G., Quintana, A. M., Denardin-Budó, M. L., Moraes, N. A., Lüdtke, M. F., & Cassel, P. A. (2012b). Internação domiciliar do paciente terminal: O olhar do cuidador familiar. *Revista Gaúcha de Enfermagem*, 33(3), 104-110. doi:10.1590/S1983-14472012000300014
- Oliveira, S. G., Quintana, A. M., Budó, M. L. D., Kruse, M. H. L., Garcia, R. P., & Simon, B. S. (2013). O enfrentamento da terminalidade pelos cuidadores familiares durante a internação domiciliar. *Revista da Rede de Enfermagem do Nordeste*, 14(3), 460-469. Retrieved from <http://periodicos.ufc.br/rene/article/view/3413>

- Oliveira, M. B. P., Souza, N. R., Bushatsky, M., Dâmaso, B. F. R., Bezerra, D. M., & Brito, J. A. (2017). Oncological homecare: Family and caregiver perception of palliative care. *Escola Anna Nery*, 21(2), e20170030. doi:10.5935/1414-8145.20170030
- Sampieri, R. H., Colado, C. F., & Lucio, M. P. B. (2013). *Metodologia de pesquisa* (5a ed.). (D. V. Moraes, Trad.). Porto Alegre: Penso.
- Sanchez, K. O. L., Ferreira, N. M. L. A., Dupas, G., & Costa, D. B. (2010). Apoio social à família do paciente com câncer: Identificando caminhos e direções. *Revista Brasileira de Enfermagem*, 63(2), 290–299. doi:10.1590/S0034-71672010000200019
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. doi:10.1093/intqhc/mzm042
- Yavo, I. S., & Campos, E. M. P. (2016). Cuidador e cuidado: O sujeito e suas relações no contexto da assistência domiciliar. *Revista Psicologia: Teoria e Prática*, 18(1), 20–32. doi:10.15348/1980-6906/psicologia.v18n1p20-32

Authors notes

Bruna Maffei, Postgraduate Program in Psychology, Federal University of Santa Catarina (UFSC); **Isabel Cristina de O. Arrieira**, Home Care Service, Federal University of Pelotas (UFPel); **Renata A. Ferreira**, Hospital Psychology Service, Nossa Senhora da Conceição Hospital; **Daniela H. Cardoso**, Nursing School, Federal University of Pelotas (UFPel).

Correspondence concerning this article should be addressed to Bruna Maffei – Rua Itália, 909, Bairro: Centro – Cidade: Boa Vista do Sul – CEP: 95727-000

E-mail: brunamaffei15@hotmail.com