

# On the way to look for care of people under palliative care

Aline da Cruz Cavalcante de Pinho<sup>a</sup> , Vanessa do Socorro Mendes da Silva<sup>b</sup> ,  
Airla Miranda de Souza<sup>c</sup> , Victor Augusto Cavaleiro Corrêa<sup>a</sup> 

<sup>a</sup> Universidade Federal do Pará – UFPA, Belém, PA, Brasil.

<sup>b</sup> Hospital Ophir Loyola, Belém, PA, Brasil.

<sup>c</sup> Universidade Estadual de Campinas – UNICAMP, Campinas, SP, Brasil.

**Abstract:** Introduction: Palliative care is a set of approaches to improve the quality of living for people who are out of the possibility of cure of a particular illness. Generally, they demand from family members the task of being caretakers, implying in their day-to-day occupations. The occupations are the various daily actions carried out by individuals, in groups and in the communities to which they belong, to fill the time and bring meanings and purposes to life. The occupational form understands what people do, how they do it, and in what circumstances they do. It is understood that caregivers of people who are in palliative care have a peculiar way of occupying themselves and with characteristic conditions. Objective: To understand the form of occupations of the main caregivers of people in oncological palliative care. Method: This is a qualitative research, carried out at a reference hospital in palliative care in the Northern Region of Brazil, at the Oncology Palliative Care Clinic (CCPO). An open interview was conducted with 20 family caregivers. Results: Outstanding changes in routine organization and dedication to caring for the loved one in palliative care. It also revealed that being a caregiver led to the difficult task of including, maintaining, and excluding day-to-day occupations. Conclusion: The study highlights the implications in the occupational repertoire in the condition of being a caregiver in palliative care and how the occupation is developed and drawing attention to the need for health professionals to direct their attention also to caregivers.

**Keywords:** *Oncology, Palliative Care, Caregivers, Occupation.*

## Sobre a forma de ocupar-se de cuidar de pessoas sob cuidados paliativos

**Resumo:** Introdução: Cuidados paliativos são um conjunto de abordagens para melhorar a qualidade de vida das pessoas, as quais estão fora da possibilidade de cura de uma determinada doença. Geralmente, exigem dos membros da família a tarefa de serem cuidadores, o que implica em suas ocupações do dia-a-dia. As ocupações são as várias ações diárias realizadas por indivíduos, em grupos e nas comunidades a que pertencem, que preenchem o tempo e trazem significados e propósitos à vida. A forma ocupacional entende o que as pessoas fazem, como elas fazem e em que circunstâncias elas fazem. Entende-se que os cuidadores de pessoas que estão em cuidados paliativos têm uma forma peculiar de ocupar-se e com condições características. Objetivo: Compreender a forma das ocupações de cuidadores principais de pessoas em cuidados paliativos oncológicos. Método: Trata-se de uma pesquisa de abordagem qualitativa, realizada em um hospital referência em cuidados paliativos da Região Norte do Brasil, na Clínica de Cuidados Paliativos Oncológicos (CCPO). Foi realizada entrevista aberta com 20 cuidadores familiares. Resultados: Destacam-se as mudanças na organização da rotina e a dedicação ao ocupar-se de cuidar do ente querido em cuidados paliativos. Também foi revelado que ocupar-se de ser cuidador conduziu a difícil tarefa de incluir,

**Corresponding author:** Aline da Cruz Cavalcante de Pinho, Universidade Federal do Pará – UFPA, Rua Augusto Corrêa, 1, Guamá, CEP 66075-110, Belém, PA, Brasil, e-mail: alinecavalcante2709@gmail.com

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manter e excluir ocupações do dia-a-dia. Conclusão: O estudo ressalta as implicações no repertório ocupacional, na condição de ser um cuidador em cuidado paliativos e como a ocupação é desenvolvida, chamando atenção para necessidade de que profissionais de saúde dirijam sua atenção também aos cuidadores.

**Palavras-chave:** *Oncologia, Cuidados Paliativos, Cuidadores, Ocupações.*

## 1 Introduction

Palliative Care is a set of multidisciplinary approaches to improve the quality of life of people and their families facing a life-threatening illness, through prevention and suffering relief, with early identification and treatment of pain and other physical, psychosocial and spiritual symptoms (WORLD..., 2007).

According to Silva (2013, p. 11),

palliative care is aimed at providing social, physical, psychic and spiritual comfort, alleviating suffering and improving the quality of life of people and family members/caregivers.

According to Floriani and Schramm (2008), palliative care offers a way of living and/or dying that shelter and observes the specificities of each person. Therapeutic actions are mainly sought for relieving stressful symptoms, such as pain, creating care that facilitates the recognition of the extremely fragile moment in which the person lives in these conditions, and establishing a host support and protection network.

For Palm (2007), in palliative care is important not to hasten or advance death, but to assert life and understand that death is a natural process. In this process, in addition to alleviating the pain and other symptoms that lead to distress, psychic and spiritual aspects should also be assisted, providing support for people to be active until death, and assisting the family in understanding the illness, or even in their grieving process.

According to the National Cancer Institute - INCA (INSTITUTO..., 2013), neoplasia is a set of more than one hundred diseases that have the disordered growth of cells as intercession that invade the tissues and organs and can spread to other parts of the body.

When neoplasia is in the early stages, the treatment is usually aggressive and has the goal of healing or remission of the disease. When it is already in a more advanced stage or evolving to this condition, even with the treatment of curative intention, the palliative approach should enter into play with the management of the symptoms of difficult control

and some psychosocial aspects associated with the disease (WORLD..., 2002).

Neoplasia is a disease that leads to several repercussions and is usually related to death. It can trigger several reactions such as fear, anguish, panic, despair, among others (SILVEIRA, 2002).

Cancer is a disease that has a major impact on a person's life and the family group, modifying the dynamics of the family; it can bring or remove members, especially when there is a great work overload due to the intensification of symptoms and the progression of the disease (REZENDE; ABREU, 2018).

Firstly, the family supports the sick person and is also the one who suffers from the changes that the disease causes (GALRIÇA, 2008). Besides being intense, the overload suffered by the family member causes psychic, physical and social consequences. Moments such as surgeries, chemotherapies, radiotherapies and when the patients is referred to a palliative care service, they may trigger reactions such as depression, fatigue, insomnia, shortness of breath, muscle tension, pain, impotence or other symptoms (VIANNA; SOUZA, 2014; AITKEN, 2014).

The emergence of family conflicts, concealment of the diagnosis to minimize undesirable comments, economic difficulties due to the costs of treatment, the need for adaptations and changes in living habits are also highlighted (FARINHAS et al., 2013).

According to Araújo and Leitão (2012), there is a relation between the psychic symptoms presented by the patient and the family, since the disease affects the family and the person in palliative care is influenced by the family dynamics. Silveira (2000) adds that as the person develops the disease, the family system can change, with changes in occupational roles among the family members, changing the structure and dynamics of this group.

The primary caregivers are those responsible for helping the sick person in a situation of dependency and they are usually close relatives. These caregivers usually assume this responsibility without financial compensation and often abdicate their own lives, restricting it primarily by caring

and being overburdened with care-related tasks (MCLEAN et al., 2013; MENEGUIN; RIBEIRO, 2016; OLIVEIRA, 2015).

The primary caregivers of a person in palliative care should be divided between their professional, marital, social, and family responsibilities. Caring involves extended periods of time given to the sick person, which may interfere with the quality of the caregivers' living (REZENDE et al., 2016; REZENDE; ABREU, 2018).

Facing new situations the unknown cause fear, especially when the impacts directly affect the quality of living of the sick person and of all those who surround him, involving emotional, physical, social, spiritual issues, among others.

The family member who assumes the role of caregiver of the sick person is also affected by the sufferings and significant changes of routine. Living with the other's suffering is exhausting because the person does not have time to take care of oneself by taking care of the other, generating ambiguous emotions and emotional conflicts (BIFULCO; CAPONERO, 2016).

The care of the family member in the process of becoming sick starts to incorporate the daily routine of the caregiver and this care in some cases is performed by a few or even by a single person who develops the most care and in the longest period of time, offering support to the sick person (SILVEIRA; CALDAS; CARNEIRO, 2006). In this sense, what are the occupations of those who take care of a loved one in palliative care? How is the routine of these people? Caring happened to be their main task?

The Sociedade Internacional de Ciência da Ocupação (2013) defines occupation as different daily actions carried out by individuals, families, and communities who occupy their time and bring meaning and purpose to life. Occupations include activities that people need, want, and are expected to do.

Occupations are fundamental to the identity and sense of competence of the individual. They are the daily life activities in which people are engaged, occurring in contexts and influenced by the interaction between client factors (values, belief, spirituality, functions, and structure of the body), performance skills (motor, process, and social interaction) and performance areas (ASSOCIAÇÃO..., 2015).

The Science of Occupation is shown as an academic discipline for the purpose of studying man as an occupational human being. The occupation is

characterized as all the daily activities that can be culturally recognized and that fill the time.

The Science of Occupation is described as the study of man as an occupational human being and aims to identify how human beings understand their occupations. It consists in elucidating the form, the function and the meaning of the occupation, resulting from the dynamic interaction between the person, the environment, and the activity (PIERCE et al., 2010; CARRASCO; OLIVARES, 2008).

This science includes knowledge focused on human behavior and is considered similar to other social sciences such as anthropology, psychology, and sociology. It carries out a study of human behavior, whose objective is to develop a systematic basis that describes and understands participation in occupations having a **form** (the observable), a **sense** (what it for) and a specific **meaning** known only to the individual engaged in it (ARAÚJO et al., 2011; LIMA, 2011).

Considering that the caregiver of people with Oncology Palliative Care faces several situations that may affect the occupational conditions, this research sought to understand how the caregivers' occupational forms of people assisted in an oncology palliative care service.

## 2 Methodology

### 2.1 Type of research

This is a qualitative research that, according to Mól (2017), it understands science as an area of knowledge constructed by social interactions in the sociocultural context. Therefore, its focus is to understand the meanings of the phenomena from those who experience them, considering times and spaces of actions and reflections.

This research approach provides the understanding, description, and analysis of the reality through the dynamics of social relationships. It addresses the universe of meanings, reasons, aspirations, beliefs, values, attitudes, perceptions, opinions, interpretations about how people live, build themselves and their artifacts, feel and think (MINAYO, 2013).

Thus, it was observed that the qualitative method was the essential way to carry out this research because it needed a great knowledge of the subject to understand the human being its complexity of the care. This study needed to enter into the subjectivity of the participants to seek understandings, relationships, roles and meanings of caregivers' occupations of people in cancer palliative care.

## 2.2 Research location

The research was carried out in a reference hospital in the Oncologic Palliative Care in the Northern Region of Brazil.

## 2.3 Research participants

Twenty main caregivers of people hospitalized at the Oncology Palliative Care Clinic - OPCC in the terminal phase of the referred hospital participated in the study, as shown in Table 1.

As the inclusion criteria, it was important to be the main caregiver of hospitalized patients undergoing palliative oncology care of both genders and who accepted to participate in the study and signed the Informed Consent Form (ICF). As exclusion criteria, it was important to be under 18, be a formal caregiver, with a benefit for the care provided.

## 2.4 Procedures for collecting and analyzing data

The research was carried out in compliance with the Research Guidelines Involving Human Beings (Res. CNS 466/12) of the National Health Council. It began after approval of the Research Ethics Committee Involving Human Beings, approved by number 1,955,568 and authorized by the management of the hospital, by the participants and/or by their legal caregivers, through the signing of the Informed Consent Form - ICF.

**Table 1.** Demographic distribution of main caregivers of people hospitalized at the Oncology Palliative Care Clinic - OPCC in the terminal phase.

Variables	Patients
	n(%)
<b>Age</b>	48.35
<b>Gender</b>	
Male/Female	04(20%)/16(80%)
<b>Marital Status</b>	
Single/Married	06(30%)/14(70%)
<b>Origin</b>	
Metropolitan Region/ Interior or other state	14(70%)/06(30%)
<b>Retirement</b>	
No/Yes	17(85%)/03(15%)
<b>Religion</b>	
Catholic/Evangelic/No Religion informed	12(60%)/06(30%)/2(10%)

Age expressed as mean. (n): frequency in absolute number. (%) frequency in percentage.

The data of the study were obtained from the application of a semi-directed interview, and recording in the field diary. The research had a single meeting with an interview divided into two parts. The first part of identification was containing information such as name, age, gender, date of birth, place of birth, address, people they live with, profession, marital status, education level, religion, family composition, interaction time in palliative care, time as caregiver. The other part was containing questions about the occupational form, using the following guiding questions: 1- "Tell me about your relationship with the hospitalized person?", 2- "How are your occupations organized at this point in your life?", 3- "What about the person you care for?".

All questions were recorded in audio, transcribed in full and then analyzed. The research was held in a period of 6 months, in the morning and/or evening shifts.

The Bardin content analysis technique was used to analyze the data, which is defined as a method and a set of methodological tools that seeks to know what lies behind the meaning of words, focuses on the message, that is, in the communication that occurs between the researcher and the participant. The objective is to organize the message to confirm the indicators that allow inferring about realities that are not in the message (BARDIN, 2011; MOZZATO; GRZYBOVSKI, 2011).

According to Silva (2017, p. 3), the content analysis

encompasses both the rigor of scientific objectivity as the fecundity of the researcher's subjectivity, as well as not neglecting socio-spatial influences and the context in which textual material is embedded.

The content analysis could be called as the analysis technique of the communications since it analyzes what was said in the interviews or what was observed by the researcher, and to carry out the analysis of the material, the classification of the topics or categories to understand what is implicit in the discourses (SILVA; FOSSÁ, 2015).

## 2.5 Risks and benefits

During the research, the risks regarding the identity of the participants were minimal since the researcher used random proper names and did not report any personal data.

This research had the benefit of new knowledge about the attention to the needs of the caregivers of

people in palliative care, as well as possibilities about occupations and the practice of the palliative care.

### 3 The Way of Caring for People under Palliative Care

This research is focused on the occupational dimension of people who are caregivers of loved ones in palliative care situations about the way of being a caregiver in these conditions. The understanding of human occupation and its social, economic, cultural, and political determinants is the main object of the recently created Occupational Science (MAGALHÃES, 2013).

When occupational scientists study the occupation form, they focus on directly observable aspects of how people organize and develop their activities (CLARK; WOOD; LARSON, 2002; DRUMOND; REZENDE, 2008). Thus, this research looked at aspects of the way of caring for people hospitalized in oncological palliative care.

Considering that the occupation form is directed to what, how and under what conditions people do, and the relationship of personal conception adjusted to the structural and environmental characteristics. In this sense, it was sought to understand the occupational form of caregivers, a condition in which they need to have the skills to harmonize contexts that can be changed when caring for someone.

In this moment of life in which the person becomes a caregiver, he has other experiences of routines, environments, people and, mainly, contact with new sensations and emotions.

*[...] it is learning... an experience that we acquire and will take for the rest of our lives, right? Not only with her, but with other people who give support as well, that at that moment of pain, we become, [...], we get closer to people and we come together to endure this situation, right? That we get, like this [...], because each patient has a different case, but it is a difficult situation for everyone within each patient picture, so get closer to each other... (Antônia).*

The need of these people to feel comforted and supported, either by gestures, attitudes, prayers or material things are observed. The feeling that they are not alone in those times that they need so badly gives them strength, encouragement, and courage.

Social support is critical for caregivers to feel comforted. Some of them have friends and neighbors as their own family, so it is like family support. According to Marchi (2012), the role of the caregiver

is reflected in this relationship of social recognition. By taking on this burden, the caregiver expects attitudes of complacency from the surrounding community.

The occupational form has a considerable impact on the way people participate and engage in daily life due to the great dedication to this occupation, as seen in the following report:

*It's sooo complicated, right [...] my time is for her [...] (Antônia).*

*I left a lot of things my love... a lot of things... I don't regret it, okay? I don't regret it, I am doing what my heart told me to do, and I go until the end, whatever the end is (Tereza).*

Care has been an occupation chosen by these people who are with their loved ones hospitalized in oncological palliative care, as seen as follows:

*So, at the moment I chose to stay with her, I dedicate myself a lot at that point, [...] I thought the other sisters would have more consideration, but no... there is one that helps me, but I am overwhelmed [...] (Santana).*

*Because I was the eldest daughter I wanted to take care of him [...] i have this mission in my life, with the help of God, He [...] God is guiding me in what I have to do, everything is going to give me strength [...] (Maria).*

Aitken (2014) says that caring for a loved one can be one of life's most painful experiences, but at the same time he discovers previously unknown skills such as strengths and weaknesses, but at the same time he feels pride and well-being for being doing what he really should do.

Caring for the elderly involves extended periods of time that are not available to the sick person, and may interfere with the quality of caregivers' living (REZENDE et al., 2016; REZENDE; ABREU, 2018), as shown in the following report:

*I'm like... tired, right? I've already been a long time away from home, right? But we go like this.. living... it's going the way we think we should take it. God holding my body, my soul [...] (Maria).*

In some situations, the caregiver does not play this role only to the family member who is hospitalized. At home, there are things that involve other caring tasks, such as taking care of the children, the husband, the organization of the house, or even someone else who is sick at home, thus the responsibility of being a caregiver is bigger.

*It's not organized, I can't help the way it can, that she needs [...]. I also need to stay with her children who study, right? [...]* (Marta).

*I have a daughter [...] so [...] who says 'she has a daughter, stay here', but I even talked to her, 'but I will', 'I argued with her, she said 'I'm here sick and you only live there in the hospital', I said, 'Hey, my daughter, stop it. You're 25, I'm not aware of you, she's your grandmother, she's with a disease that has no cure, you do not know what is a disease like this, you just have a flu, if you want milk, I do I' [...]* (Bernadette).

The routine has become suffocating when there is no other option than to be a caregiver. According to Aitken (2014), the activities previously performed by the caregivers are in the background. The stress situations can bring family conflicts, pressures, charges that can modify the relationships.

During the interviews, there was the need of these caregivers to report their routine, their difficulties, their fears and their yearnings, and all the strategies they used in exercising such occupation. When asked about how their occupations were organized, they reported them in detail.

*So... as I almost have a job, I'm being helped by my husband, but, the bills... my work is being more to keep it, employee ... yes ... rent ... phone, energy bills, these things, I do everything to not get involved in this part... for the company to stay, the one who is supplying me is my husband, right, my brothers, they come and help me, the bus tickets, these things, you know? [...]* (Conceição).

The occupational routine is going on in such a way that there is not even time to think about how the ways of being a caregiver were being constituted. According to Bifulco and Caponero (2016), it is fundamental that caregivers have a space to verbalize emotions and work them. They live a very intense moment, they need to understand the normal reactions in these situations of chronic stress. In general, the reports reveal that this occurred at a moment in the caregivers' lives, as follows:

*I left everything there [...], and I went away [...]. I left my job, I left my house, my children everything and I came to care, you know* (Conceição).

When there was a possibility to talk about being a caregiver, this research helped to express what these caregivers felt about what they did, helping them to reflect and organize what they did and wanted or did not want, keep doing.

*[...] I try to rest a little and then I return to stay here, right, which is to stay with him, take care of him, right... because the nurses do their job on the medication, right? But the rest is with us, right? Because they spend most of their time with us than with themselves, right? My sister helps me, takes care of things too, we have a kind of relay, when I'm here, she takes care of things, when she is there, I take care, you know [...]* (Tereza).

*Well, before when daddy operated I was already prepared because I didn't know when I could come to take care of him, right? So, when.. now that I needed to drop, the girl gives my classes, I help her through my cell phone, and so... when there are those clients that do not accept to do with anyone I go one day and I go back, but there... I... for example I had not been there for more than 20 days [...] you know... I went on Sunday now, my husband came and I went to work, I worked Monday and Tuesday and I came back today (Wednesday) at dawn and I came straight to the hospital [...]* (Conceição).

In this moment of the caregivers' lives, they lived intensely this doing. The more they cared, the more they looked for ways to organize their daily life for the best care. At some moments in life, choices were needed, more meaningful activities were prioritized, and others, even though they were very important, they needed to be left for later, even if the quality of life was threatened or reduced.

Oliveira et al. (2011) also confirm the need for the family member to describe their reality and their daily life as a caregiver, which facilitated an understanding of how this task and its difficulties are performed.

The time spent on other occupations is compromised, as many other occupational forms became secondary, referring to the difficult task of choosing occupational priorities, including work.

*I'm staying here straight, in the morning someone stays here for me while I go home to take a shower and go to work. I leave work and come straight here. Today I didn't go to work* (Josefa).

*I can't do my job perfectly, when I'm there at work, I'm thinking all the time in the hospital* (Josefa).

Although the act of caring for a loved one is also a matter of choice, both affective or value matters, among others, it does not fail to impose an overload, especially on the main caregiver. In this sense, when the person is in palliative care, the burden on the caregivers tends to generate even more worries, requiring that the caregivers/family members need

to change the routine of family or professional life and put some or all needs and desires in the background (REZENDE et al., 2016; REZENDE; ABREU, 2018).

Due to changes in their routine, the caregiver's life went through a reorganization of the tasks, not being easy, changing schedules, environments, occupations, and hindering those who were in a situation that demanded the everyday reorganization.

For example, one day the person is in the hospital as a caregiver, the other day he needed to go home to handle the tasks such as cooking, cleaning and taking care of the children, or even solving personal demands and problems like going to the bank, supermarket, then he need to return to the hospital to be again taking care of the patient, but not always can solve everything, leaving pending occupations that would be solved in another opportunity when get out of the hospital and organize a new day. This is an experience that very much alters the caregiver's occupations and life.

In other situations, the caregiver is unable to take turns with another family member and stays for a long time accompanying the loved one in the hospital without leaving, and then seeks to solve the demands through the cell phone and/or asking for favors to third parties. It is a race against time and space, as observed in the following speech:

*I spend all day in here [...], I can organize even though I'm already here, on the phone, I say to my son, to my sister-in-law "Come here, I need you", even here I've been able to solve it" (Raimunda).*

*My life is like this if someone gets ill, I stay [...] I spent the month of April with my brother in the emergency room for 17 days... she came and left 20 days later, she came to do surgery but it didn't work, she left but come back again, now she has been 15 days here (Auxília).*

According to Rezende and Abreu (2018), the caregiver assumes the role of caring for the sick family member. Such a condition can lead to several changes in training, as well as new occupations assumed by him, as he will be responsible for the main care of the patient who may present a decline in physical and/or psychic capacity and maybe for transitional or permanent periods.

From these findings, it was possible to know the various factors that influenced the organization of the care occupation form for the participants of this research. The change and need for routine organization, too much dedication that affects the quality of life, taking care of the caregiver on more

than one occasion, the need to tell about how to take care of caregiver, and other occupations in the background are highlighted among them.

## 4 Final Considerations

This research was of great relevance because it had a look back at those who gave up their lives and their chores to be with the other, offering their care by choosing this new occupation of caring and that had their routine changed. It gave the participants the opportunity to express how to take care occupation.

Caregivers of people assisted in palliative care have shown a need for urgent care and donation since the imminence of death contributes to the desire to care more intensely.

This study is a great contribution in palliative care research since most of research is directed to patients in palliative care and, very little, to caregivers.

This research extends the knowledge about the caregiver and the occupational dimension, highlighting what they think and feel about being caregivers. In this sense, it contributes with the other professionals for this field of action, being able to impel new researches and observation.

## References

- AITKEN, E. V. P. *Um dia de cada vez*. São Paulo: Cultura Cristã, 2014.
- ARAÚJO, J.; LEITÃO, E. M. O cuidador do paciente em cuidados paliativos: sobrecarga e desafios. *Revista Hospital Universitário Pedro Ernesto*, Rio de Janeiro, v. 11, n. 2, p. 77-81, 2012.
- ARAÚJO, L. D. S. et al. Ciencia de la Ocupación y Terapia Ocupacional: sus relaciones y aplicaciones a la práctica clínica. *Revista Chilena de Terapia Ocupacional*, Chile, v. 11, n. 1, p. 1-12, 2011.
- ASSOCIAÇÃO AMERICANA DE TERAPIA OCUPACIONAL – AOTA. Estrutura da prática da Terapia Ocupacional: domínio e processo - Tradução. *Revista de Terapia Ocupacional da Universidade de São Paulo*, São Paulo, v. 26, p. 1-49, 2015. Edição Especial.
- BARDIN, L. *Análise de conteúdo*. São Paulo: Edições 70, 2011.
- BIFULCO, V. A.; CAPONERO, R. *Cuidados Paliativos: conversas sobre a vida e a morte na saúde*. Barueri: Manole, 2016.
- CARRASCO, M. J.; OLIVARES, A. D. Haciendo camino al andar: construcción y comprensión de la Ocupación para la investigación y práctica de la Terapia Ocupacional. *Revista Chilena de Terapia Ocupacional*, Chile, n. 8, p. 5-16, 2008.

- CLARK, F.; WOOD, W.; LARSON, E. A. Ciência Ocupacional: legado da Terapia Ocupacional para o século XXI. In: NEISTADT, M. E.; CREPEAU, E. B. *Willard & Spackman - Terapia Ocupacional*. Rio de Janeiro: Guanabara & Koogan, 2002. p. 10-15.
- DRUMOND, A.; REZENDE, M. (Org.). *Intervenções da Terapia Ocupacional*. Belo Horizonte: Editora UFMG, 2008.
- FARINHAS, G. et al. Impacto psicológico do diagnóstico de câncer na família: um estudo de caso a partir da percepção do cuidador. *Pensando famílias*, Porto Alegre, v. 17, n. 2, p. 111-129, 2013.
- FLORIANI, C. A.; SCHRAMM, F. R. Cuidados paliativos: interfaces, conflitos e necessidades. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 13, n. 2, p. 2123-2132, 2008.
- GALRIÇA, I. N. *As conferências familiares como estratégia de intervenção e apoio à família em cuidados*. Portugal: APED, 2008.
- INSTITUTO NACIONAL DE CÂNCER – INCA. *O que é o câncer?* Brasil, 2013. Disponível em: <[http://www1.inca.gov.br/conteudo\\_view.asp?id=322](http://www1.inca.gov.br/conteudo_view.asp?id=322)>. Acesso em: 07 dez. 2013.
- LIMA, M. A. X. C. *Ócio e trabalho redesenhando significados na longevidade*. São Paulo: PUC São Paulo, 2011.
- MAGALHÃES, L. Ocupação e atividade: tendências e tensões conceituais na literatura anglófona da terapia ocupacional e da ciência ocupacional. *Cadernos de Terapia Ocupacional da UFSCar*, São Carlos, v. 21, n. 2, p. 255-263, 2013.
- MARCHI, A. P. *Desempenho ocupacional e habilidades sociais de cuidadores: grupo de suporte com foco educativo*. Curitiba: UFPR, 2012.
- MCLEAN, L. M. et al. A couple-based intervention for patients and caregivers facing end-stage cancer: outcomes of a randomized controlled trial. *Psychooncology*, Chichester, v. 22, n. 1, p. 28-38, 2013.
- MENEGUIN, S.; RIBEIRO, R. Dificuldades de cuidadores de pacientes em cuidados paliativos na estratégia da saúde da família. *Texto & Contexto – Enfermagem*, Florianópolis, v. 25, n. 1, p. 1-7, 2016.
- MINAYO, M. C. S. *O Desafio do Conhecimento: pesquisa qualitativa em saúde*. São Paulo: Hucitec, 2013.
- MÓL, G. S. Pesquisa qualitativa em ensino de química. *Revista Pesquisa Qualitativa*, São Paulo, v. 5, n. 9, p. 495-513, 2017.
- MOZZATO, A. R.; GRZYBOVSKI, D. Análise de conteúdo como técnica de análise de dados qualitativos no campo da Administração: potencial e desafios. *Revista de Administração Contemporânea*, Rio de Janeiro, v. 15, n. 4, p. 731-747, 2011.
- OLIVEIRA, D. C. et al. Qualidade de vida e sobrecarga de trabalho em cuidadores de idosos em seguimento ambulatorial. *Texto & Contexto - Enfermagem*, Florianópolis, v. 20, n. 2, p. 234-40, 2011.
- OLIVEIRA, R. A. A. Tensão do papel de cuidador principal diante do cuidado prestado a crianças com câncer. *Revista Cubana de Enfermería*, Habana, v. 31, n. 2, p. 1-7, 2015.
- PALM, R. C. M. Oncologia. In: CAVALCANTI, A.; GALVÃO, C. *Terapia Ocupacional: fundamentação e prática*. Rio de Janeiro: Guanabara Koogan, 2007. p. 487-492.
- PIERCE, D. et al. Occupational science: a data-based American perspective. *Journal of Occupational Science*, Austrália, v. 17, n. 4, p. 204-215, 2010.
- REZENDE, G. et al. Sobrecarga de cuidadores de pessoas em cuidados paliativos. *Medicina*, Ribeirão Preto, v. 49, n. 4, p. 344-354, 2016.
- REZENDE, G.; ABREU, C. B. B. Condições de envelhecimento e cuidadores de idosos em contextos hospitalares e cuidados paliativos. In: DE CARLO, M. M. P.; KUDO, A. M. *Terapia Ocupacional em contextos hospitalares e cuidados paliativos*. São Paulo: Editora Payá, 2018. p. 289-310.
- SILVA, A. C. C. *Diferentes Intervenções de Terapia Ocupacional em Cuidados Paliativos: Revisão Sistemática de Literatura*. 2013. 54 f. Monografia (Aprimoramento Profissional em Terapia Ocupacional Hospitalar) – Universidade de São Paulo, Ribeirão Preto, 2013.
- SILVA, A. H.; FOSSÁ, M. I. T. Análise de conteúdo: exemplo de aplicação da técnica para análise de dados qualitativos. *Qualit@ Rev. Eletrônica*, Santa Catarina, v. 17, n. 1, p. 1-14, 2015.
- SILVA, D. C. A análise de conteúdo como método analítico no campo da política externa. In: CONGRESSO LATINO-AMERICANO DE CIÊNCIA POLÍTICA, 9., 2017, Montevideu. *Anais...* Montevideu, 2017. Disponível em: <<http://www.congressoalacip2017.org/arquivo/downloadpublic?q=YToyOntzOjY6InBhcmFtcyI7czoNToiYT0xOntzOjEwOiJRRF9BUiFVSVZPIjtzOjQ6IjI4NzgiO30iO3M6MT0iaCI7czozMjoiNGVjOGI2M2I4ZGVmNzZINjRIYzE0OTA4ZmZlNDRkMmIiO30%3D>>. Acesso em: 04 jun. 2018.
- SILVEIRA, N. H. Câncer e Morte. *Revista Brasileira de Sociologia da Emoção*, João Pessoa, v. 1, n. 3, p. 406-416, 2002.
- SILVEIRA, T. M. O sistema familiar e os cuidados com pacientes idosos portadores de distúrbios cognitivos. *Textos Envelhecimento*, Rio de Janeiro, v. 3, n. 4, p. 23-31, 2000.
- SILVEIRA, T. M.; CALDAS, C. P.; CARNEIRO, T. F. Cuidando de idosos altamente dependentes na comunidade: um estudo sobre cuidadores familiares principias. *Cadernos de Saúde Pública*, Rio de Janeiro, v. 22, n. 8, p. 1629-1638, 2006.
- SOCIEDADE INTERNACIONAL DE CIÊNCIA DA OCUPAÇÃO – ISOS. 2013. Disponível em: <<http://www.isocsci.org>>. Acesso em: 25 mar. 2013.



VIANNA, M. L.; SOUZA, W. Qualidade de vida em cuidadores de pacientes em cuidados paliativos. In: JORNADA DE ESTUDO E PESQUISA EM BIOÉTICA, 1., 2014, Curitiba. *Anais...* Pontifícia Universidade Católica do Paraná, 2014. Disponível em: <<http://jorneb.pucpr.br/wp-content/uploads/sites/7/2015/02/QUALIDADE-DE-VIDA-EM-CUIDADORES-DE-PACIENTES-EM-CUIDADOS-PALIATIVOS2.pdf>>. Acesso em: 19 fev. 2018.

WORLD HEALTH ORGANIZATION - WHO. Cancer. 2002. Disponível em: <<http://www.who.int/mediacentre/factsheets/fs297/en/>>. Acesso em: 28 abr 2014.

WORLD HEALTH ORGANIZATION – WHO. *Cuidados Paliativos*. Cancer control: knowledge in action: WHO guide to effective programs. Geneva: OMS, 2007.

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### **Author's Contributions**

Aline da Cruz Cavalcante de Pinho participated in the elaboration of the project, obtaining, analyzing and discussing the data, besides the text preparation and review. Vanessa do Socorro Mendes da Silva and Airle Miranda de Souza participated in the text elaboration and review. Victor Augusto Cavaleiro Corrêa coordinated and guided the research, participating in the analysis, discussion, and interpretation of the data, besides the text preparation and review. All authors approved the final version of the text.