

**Original Article** 

# Approach to grief: exploratory aspects about the assistance of occupational therapists<sup>1</sup>

Abordagem ao luto: aspectos exploratórios sobre a assistência de terapeutas ocupacionais

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#### Abstract

Introduction: Grief consists of a natural and expected reaction upon a loss, and is understood as a process experienced in a unique way, in which emotional, physical, behavioral, and social responses are manifested differently according to each individual. Comprehensive care for the bereaved should include understanding the individuals as biopsychosocial and occupational beings; however, the impacts on the occupational dimension during bereavement are still little explored in the literature. Objective: To characterize the practices carried out by Brazilian occupational therapists with bereaved people. Method: This is a cross-sectional, exploratory, qualitative study. Data were collected through virtual forms aimed at surveying potential participants and, subsequently, through interviews with occupational therapists who claimed to have assisted grief. Data evaluation was performed by content analysis. Results: It was found that only one occupational therapist reported the use of theoretical references on grief as a basis for interventions, as well as the predominance of assistance to the adult and older populations. The demands reported by occupational therapists in assisting the bereaved culminated in three categories: occupational deficits, emotional demand, and restriction of spaces for exchanges. Conclusion: Occupational therapists participating in this study expressed a perception of the repercussions of grief in occupations; however, practices in this area emerged mainly from care flows that are not specifically structured for this assistance, which may justify the distancing from theoretical references on grief reported by the professionals.

Keywords: Bereavement, Activities of daily living, Occupational therapy.

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#### <u>Resumo</u>

Introdução: O luto consiste em uma reação natural e esperada diante do rompimento de um vínculo, sendo compreendido como um processo vivenciado de modo singular, em que são manifestadas respostas emocionais, físicas, comportamentais e sociais que se diversificam de indivíduo para indivíduo. O cuidado integral ao enlutado deve perpassar pela compreensão do sujeito como um ser biopsicossocial e ocupacional; contudo, impactos sobre a dimensão ocupacional do luto ainda são pouco explorados na literatura. Objetivo: Caracterizar as práticas de terapeutas ocupacionais brasileiros com pessoas enlutadas. Método: Pesquisa transversal, exploratória, de abordagem qualitativa. Os dados foram coletados através de um formulário virtual voltado a levantar os potenciais participantes e, posteriormente, de entrevistas com os terapeutas ocupacionais que afirmaram realizar atenção ao luto. Os dados foram avaliados por análise de conteúdo temática. Resultados: Constatou-se que apenas um terapeuta ocupacional usou referenciais teóricos do luto como base para as intervenções, bem como a predominância de assistência ao público adulto e idoso. As demandas relatadas pelos terapeutas ocupacionais na assistência aos enlutados culminaram em três categorias: prejuízos ocupacionais, demanda emocional e restrição de espaços para trocas. Conclusão: Os terapeutas ocupacionais participantes deste estudo manifestaram percepções das repercussões do luto nas ocupações; contudo, práticas nessa vertente emergiram principalmente a partir de fluxos de atendimento não estruturados especificamente para essa assistência, o que pode justificar o distanciamento de referenciais teóricos sobre luto relatado pelos profissionais.

Palavras-chave: Luto, Atividades cotidianas, Terapia ocupacional.

## Introduction

Grief, one of the study areas of Thanatology, is understood as a natural and expected reaction to the rupture of a bond, referring to a process of elaborating a significant loss. It consists of a dynamic, individualized, and multidimensional process, surrounded by intense emotional suffering and deep sadness (Bousso, 2011).

Pires (2010) defines grief as a cognitive process in which, faced with a loss, the person begins the search for meaning, triggering memories associated with the deceased person, as a way of adapting to a new reality. In addition, Franqueira et al. (2015) and Parkes (1998) state that grief is experienced in a unique way where there is no pattern to follow, with variations in intensity and period, influenced by principles such as the circumstance of death and the characteristics of the bereaved.

Considering the premises of the study on grief, it is essential to highlight Freud, who, through his studies, gave rise to the Theory of Grief Work, with the production of the article "Mourning and Melancholia". In this work, published in 1917, mourning is referred to as a process of gradual reduction of energy in which the individual has the task of breaking ties with the deceased person, with the expression of feelings being the main way of elaboration (Freud, 1996).

John Bowlby, an author also recognized for the studies developed on this topic, considers that after the breakup of the bond, the grieving process occurs in four phases,

which are not necessarily presented in an orderly manner: phase of numbness or shock, which may accompany manifestations of anger and despair; phase of the search for the lost figure; phase of disorganization and despair, with feelings such as sadness, apathy, and anguish in a more intense way; and phase of reorganization (Bowlby, 1985).

For Worden (1998), grief is processed through tasks that the bereaved must perform to adapt to the loss. The author presents four tasks: accepting the reality of the loss, processing the pain of grief, adjusting (internally and externally) to the world without the deceased, and finding a lasting connection with the deceased during the beginning of a new life.

Among the existing theories, the Dual Process Model of Grief, created in the late 1990s by Stroebe & Schut, is one of the most contemporary theories, and one of the most guiding models of current international research (Stroebe & Schut, 2010; Bennett et al., 2010).

This model presents a dual understanding of events by individuals in the face of losses, where they will deal, in their way, with the adequacy of the process of coping and adaptation to grief. Three perspectives are addressed: loss orientation, restoration orientation, and oscillation.

In loss orientation strategies, the person in the grieving process focuses his mentality on points such as affective bonds and relationships, paying attention to the conditions of death, that is, there is rumination related to the deceased person and thoughts about the context of the death (Hansson & Stroebe, 2007; Stroebe & Schut, 1999). In the orientation strategies for restoration, there is a load of sources of stress with which the bereaved person needs to deal, seeking the exercise of new roles, and relationships, reconstruction of the routine and their own identity, with the relocation of the lost figure to a new level. symbolic and spiritual. Oscillation, on the other hand, marks the dynamism of this process, which is characterized by the alternation between strategies oriented towards loss and those oriented towards restoration, is a regulatory process of confrontation and avoidance (Stroebe & Schut, 1999).

For Stroebe & Schut (2010, p.280), "while the bereaved experience pain and feelings of loss, there is a need to reorganize life in the face of the absence of the deceased, in a constant and cyclical experience of stressful events that destabilize life".

Although grief is understood as a reaction to loss and has been studied for many decades; researches that focus on the theme, based on occupational paradigms, are still scarce in the literature.

For Corrêa (2009), grief impacts the occupational dimension since the tendency to engage in activities carried out until then with or by the deceased person becomes something no longer desirable. These daily activities are presented as ways of relationships, affection, and meanings, becoming meaningless in the absence of the deceased, promoting an occupational void.

Souza & Corrêa (2009) found that bereavement implies several damages to global health. Thus, these authors defend the importance of evaluating occupational aspects in assisting the bereaved as a way to provide holistic care that understands the person as a biopsychosocial and occupational human being.

The study by Batista (2017), which aimed to understand the daily occupations of 14 widows in the first six months after the death of their husbands, found that aspects such as suffering associated with the absence of the husband in daily life, the performance of

the role of caregiver, perception of negative about the quality of the previous relationship with the spouse, participation in the decision-making processes of treatment and death, support from an informal network and spirituality, are factors that influence the meaning attributed to daily activities. We found that everyday occupations and their meanings can change considerably during widowhood and that activities aimed at restoration-oriented coping are potentially beneficial for bereaved widows (Batista, 2017; Batista et al., 2019).

According to the World Federation of Occupational Therapists (2010), occupations are understood as day-to-day activities that people perform for themselves, within their families, or in the community, that give meaning to life. The occupations comprise, therefore, necessary tasks, desired, or that need to be done.

In this aspect, Dahdah et al. (2019), based on a systematic review, found that occupations are valuable tools, to be used as a means or end in intervention with the bereaved. The authors express that occupational therapists must assess the influence of grief on occupations, as a way of helping the bereaved in the coping process.

Given the above, we believe that occupational therapists have expertise that can favor the care provided to people in mourning. However, according to Dahdah et al. (2019), investments in research on this topic are necessary to produce evidence that may strengthen the work of occupational therapists with bereaved people. In line with this statement, this study aims to characterize the practices of occupational therapists with the bereaved population.

#### Method

This is a cross-sectional, exploratory study with a qualitative approach carried out with Brazilian occupational therapists.

To identify occupational therapists who carry out actions aimed at mourning, a form was created on a virtual platform (Google forms) covering questions of personal characterization (name, age, training time, and contact email) and identification of practices with bereaved (time of work with people in mourning, place of work, level of health care provided, city/state of work, interest in participating in the interview).

The occupational therapists were invited to fill in the form in two ways: 1) the Regional Councils of Physiotherapy and Occupational Therapy (*Conselhos Regionais de Fisioterapia e Terapia Ocupacional* -CREFITOs) were asked to disclose the form link to occupational therapists; 2) the form link was disseminated in social media groups linked to the profession.

Based on the data on the form, occupational therapists who met the inclusion criteria and expressed their willingness to participate in the interview were invited via email.

As inclusion criteria we considered occupational therapists in practice, who develop interventions with people in mourning for at least three months, excluding professionals who work with the theme exclusively within the scope of the research.

The interviews took place individually, at a single previously scheduled time, and were carried out virtually synchronously through the Google Meet platform.

The interviews lasted an average of 45 minutes and followed a semi-structured script created by the researchers. Before the beginning of the interview, we explained to the participants that the focus of the research consisted of exploring the occupational

therapist's approach to mourning death and its repercussions on the occupation. The script questions involved information such as the causes of death that promote mourning, characteristics of the interventions carried out, and theoretical references that guide care. The instrument developed was sent for evaluation by three judges with expertise in the area of grief, and the invitation was made to experienced occupational therapists responsible for care actions and/or scientific production in the area.

After feedback from the judges, a pre-test was carried out that showed the need for changes in the structure of the questions to facilitate the achievement of the proposed objectives.

Data collection took place between November 2020 and March 2021. The data were analyzed by thematic content analysis to verify the repetition of themes in the content of the material analyzed in three stages: pre-analysis (floating reading of the transcripts and review of the material), exploration of the material (organization of collected information, and analysis of reports into thematic categories) and treatment of results (interpretation of data based on references) (Bardin, 2011).

This study was approved by the Ethics Committee for Research on Human Beings of the Federal University of São Carlos (UFSCar) according to opinion number 4,192,360. The Informed Consent Term (ICF) was presented before the questions asked, both regarding the application of the screening form and the interview script. To sign the term, the participant only had to, after reading it, mark the alternative "accepted" to agree. To express a refusal, the participant closed the browser tab.

#### Results

From the questionnaire, we obtained 23 records from occupational therapists who self-identified as professionals who develop actions aimed at mourning.

One person did not fit the established criteria because he had been working with the bereaved for less than three months; three participants indicated their unavailability to participate in the interview and two professionals participated in the pre-test. We had a total of 17 professionals considered as the intended sample for conducting the interviews.

We contacted 17 professionals, but we only got seven feedback. Ten participants did not respond to any of the emails sent. Thus, the final sample of the study consisted of seven occupational therapists.

Regarding the characterization of the sample, there was the participation of five women and two men, with a mean age of 36 years (minimum of 25 years and maximum of 46 years). The average time of training was 11 years, with the shortest time corresponding to 1 year and the longest to 23 years. On average, the time of practice with bereaved people was 2 years.

Regarding the place of work, we found that three occupational therapists work in hospitals and four in the primary care network; two professionals from the southern region of Brazil (Curitiba-PR and Santa Maria-RS) and five from the southeast region (Ribeirão Preto-SP, São Paulo-SP, Betim-MG, Pouso Alegre-MG, and Vitória-ES).

The concept of grief explained by the participants gave rise to four categories: grief as a process linked to losses; individualized process; experience of ruptures and moments of internal and external disorganization. The category mourning as a process linked to losses involved manifestations referring to the understanding that mourning is a process triggered not only by the death of someone but by situations such as the end of a relationship, loss of job, or functions, among others:

I understand grief in many ways, [...] such as the end of a relationship, the loss of a job [...] So I think grief is a process of intense suffering that comes along with it. a very unfavorable situation in that person's life, which she did not expect she would go through [...] (E.1).

Grief is a state of loss [...] it is a process [...] I think of it as a much more comprehensive way [...] you will work with a stroke patient, for example, who had a functional loss or a mother with an autistic child, she sometimes has a loss of a project, of an idealization that she had concerning the child (E.5).

For me, mourning is a moment of understanding the affection we felt for something, for someone who left. It could be due to death, it could be due to separation, so for me, it's experiencing that feeling (E.4).

In the individualized process category, expressions of grief were considered as something singular, experienced uniquely:

[...] so I think that for each person, for each subject, it happens in a way (E.3).

[...] it is a whirlwind of things and for everyone, it can be something (E.7).

In the rupture experience category, the participants expressed the idea of mourning as a moment of breaking expectations:

[...] I see it as a difficulty in dealing with an expectation, it is often a sudden rupture of something that the person expected (E.2).

[...] in life we have losses, right, so failures or distance from what we idealize, from what we sometimes face in reality (E.5).

In the category of the moment of internal and external disorganization, alterations that permeate emotional and routine aspects were reported:

I see grief as a process of emotional readjustment... it is an internal, emotional readjustment and it is also an external readjustment, which affects daily life, in the life of the bereaved person so that they can readapt, elaborate that loss and being able to get on with your life, with your routine (E.6).

It is important to highlight that, although the concept of mourning was presented by the participants as a process linked to different types of losses, the process of assistance to mourning due to the death of a loved one was considered in the interview. Thus, occupational therapists were asked about the causes of deaths in the grieving processes attended, and it was found that the action takes place in the face of losses related to health-disease processes (cancer, heart disease, COVID-19, lung and neurodegenerative diseases), situations of violence (homicides, disasters, and accidents) and losses associated with suicide.

Specifically, regarding the profile of the bereaved assisted by occupational therapists, there was a predominance of adult and elderly people, with interventions with children and adolescents bereaved by two occupational therapists who work in the hospital context.

Regarding the use of theoretical frameworks used as a basis for interventions, five categories were found: thanatology and palliative care; fundamentals of occupational therapy; theoretical models of grief; national humanization policy, and lack of use of theoretical models.

In the thanatology and palliative care category, the expressions that mentioned professionals popularly recognized for their work in the area were considered:

[...] Cicely Saunders [...] developed the issue of Palliative Care (E.2).

[...] in this process we ended up studying a lot of psychology [...] Maria Julia Kovács has worked with the issue of grief and also has several works on suicide. [...] Kübler-Ross, who is going to look, obviously to study grief itself [...], that doctor, Ana Cláudia, she talks a lot about this approach with the family... (E.3).

Kübler-Ross model, of the stages of grief, [...] we work more with the idea of meaning itself (E.5).

[...] I really like Kovács [...] I really like Aroldo Escudeiro, [...] his trajectory (E.6).

In the category called fundamentals of occupational therapy, explanations about references linked to occupation were considered, as expressed below:

[...] a model that I really like [...] is the ecological model of human performance [...] an activity analysis technique, was created by Jô Benetton and is the associative trails, that the patient goes through the analysis together with you, [...] that goes well with the ecological model [...] another model that I use a lot [...] because of the grief that was the Kaua model [...] sometimes I use the model of human occupation [...] in some cases too, the model of competence in the environment, that model of Rangedor also [...] the model of occupational integrity [...] the framework of spiritual reference [...] a chapter from Spackman's book on narrative, of the use of narratives in occupational therapy (E.5).

[...] my line of work within occupational therapy, I work from a psychodynamic perspective [...] (E.3).

Já na categoria modelos teóricos, referenciais foram mencionados por um único profissional:

In the theoretical model category, references were mentioned by a single professional:

I use Worden's tasks [...] of grief a lot, which for me [...] relate better to my work as an occupational therapist [...] I really like grief mediators too, because I think that this issue of the profession also comes into play, our knowledge, you know, skills [...] I really like Parkes; [...] I really like Bowlby's attachment theory (E.6).

The same occupational therapist who said to base his interventions with the bereaved on theoretical models of grief was also the only participant to report a purposeful action to the bereaved public.

Continuing with the categories referring to the theoretical frameworks, the category called humanization policy comprised the manifestation of the expanded clinic as the basis of the assistance given to the bereaved by the occupational therapist, as reported below:

Look, I don't have a background in mental health [...] but I was studying for a contest on... humanization, on primary care, and there was a booklet on the extended clinic, so I relied a lot on the concepts of the expanded clinic, which speaks a lot about you seeing the subject beyond the disease, [...] it is part of the humanization policy [...] of the SUS (E.1).

Finally, there was a manifestation of the non-use of theoretical benchmarks for promoted assistance:

[...] not really (E.7).

In the evaluation process carried out by occupational therapists with the bereaved, all participants stated that they do not use standardized instruments. The reports show that the assessment considers information about changes in occupational, emotional, physical, and spiritual aspects.

In the category of changes in occupational aspects, manifestations of the exploration of daily activities and roles performed were considered:

Oh, of course, the family context, how was the routine related to the entity [...] what were the leisure practices, practices that on the day they did together so that the person has experienced, we can link some experiences and give a new meaning to these feelings through a practice (E.2).

[...] I think it is important to welcome, and listen to the story [...] even individualized at first. Me, I think it is important for us to have, for example, a list of occupational roles [...] death played a fundamental role at a given moment and today it managed to rescue some things, it managed to resume mainly the issue of social participation, the issue of care there with the house because this appears a lot in daily disorganization [...] So I think we need to have a lot of this knowledge of this occupational performance from before, from now and if there is a projection of the future (E.3).

[...] mainly to see how this grieving process is presenting in everyday life [...] I start the service trying to know how the routine of these bereaved people is, what they bring me, what the main complaint they have at that moment and I ask [...] then the care begins based on that, on what the person is experiencing difficulties, on the parts of grief that they are finding more complicated (E.6).

The analysis of physical components was also mentioned as a strategy to start the dialogue in the evaluation:

[...] so I start a lot with the physical issue [...] because from that [...] we can get hooks so that it's more inside [...] you go unraveling, you get the person to talk more, because if you go straight, oh tell me about your loss, [...] you can't go straight to the emotional [...] (E.7).

The emotional dimension was also mentioned as a component to be considered in the evaluation:

[...] to check how the emotional state of this patient is, [...] to know what kind of support we need to give to this patient and if our support will be enough, if I need to use medication, from other professionals, such as psychologists [...] (E.1).

It is worth mentioning that spirituality also emerged as an aspect to be investigated:

[...] an issue that appears a lot when talking about bereaved people is spirituality and this is something that many people do not have well resolved [...] (E.5).

The main demands reported by occupational therapists in assisting the bereaved went through three categories: occupational losses, emotional demand, and restriction of spaces for exchanges.

In the category of occupational losses, changes in occupational activities and difficulties in routine adaptation were expressed:

[...] it interferes in people's routine and daily life [...] so you see that they are losing occupations related to leisure, social participation, activities of daily living, [...] this process is very devastating in everyday life, in this day-to-day [...] So the biggest demand I see is this restructuring, first of a routine, and then resuming everyday life (E.3).

[...] the issue of papers that are being lost [...] (E.5).

The main demand is this [...] people say they sometimes have difficulty moving forward [...] And I see this a lot, something from T.O. of trying to find ways for the person to move on and have this emotional readjustment and this practical readjustment in her life [...] I always try to facilitate the organization of her routine, her occupational roles [...] for her to understand that in the everyday life, [...] she will be able to adapt, she will be able to live despite this pain, despite this loss (E.6).

[...] there is great difficulty for the bereaved person to think of strategies alone [...] either with leisure or with the routine itself (E.7).

In the emotional demand category, the need to favor the expression of emotions to welcome the feelings raised by the loss was mentioned, considering the latency of feelings present:

[...] these are patients who are in an impaired emotional state, we see fear, sadness, melancholy, so there is an important demand [...] for an emotional change [...] (E.1).

The biggest demand that I see is trying to get them to express what they are feeling, to allow them to bring it and for them to put it out, whether it is anger or a weight on their conscience [...] that it was not enough, who didn't do everything he could (E.4).

The category called restriction of exchange spaces involved expressions about the lack of social openness in death and dying, which entails the need to offer qualified listening as a way of building spaces for dialogue on topics that are still socially prohibited:

> [...] people do not have a space to talk even among friends, among family members, and it is very related to cancer too, it is still very difficult to talk [...] there is no space for the person puts himself up and it's through an activity, a group... I really notice the space for the person... to expose himself, exchange ideas, put it out, let off steam (E.2).

Considering the aforementioned demands, we sought to understand the occupational therapist's therapeutic goals with the bereaved public. In this aspect, three categories were identified: favoring quality of life, helping to cope with and (re)constructing meanings, and promoting comfort.

In the category called favoring quality of life, the qualification of living based on a more focused look at occupational issues modified by grief was mentioned:

[...] I think that seeking quality of life, improving [...] the person's routine, and this goes in all ways [...] will directly or indirectly affect my patients, [...] the person decreases productivity in self-care (E.2).

In fact [...] it was welcoming [...] it was giving a space of support and ventilation and [...] thinking about these losses of occupational roles and these daily changes, [...] to rescue [...] but I think it was thinking a lot about it, [...] to help restructure this routine and this daily life in grief (E.3).

Helping to face and (re)construct meanings was also a mentioned objective:

Welcoming these people and creating a meaning in it, a meaning [...] would even promote this transition between the stages of grief [...] to try to make it as stable a process as possible (E.5).

The main objective [...] is to guide and accompany the person in the grief tasks [...] to try to direct them to these tasks and monitor how they are performing these grief tasks (E.6).

Promoting comfort also emerged as an objective:

[...] I play that [...] whatever I can do to relieve this pain and that is it, it is wellbeing anyway, and that until today I managed to do it with everyone who I attended to the issue of mourning [...] (E.7).

[...] welcome, [...] bring comfort, security to that person (E.5).

The following therapeutic resources were used by occupational therapists in grief assistance: active listening, occupations, groups, artistic, expressive, and social activities, and integrative practices.

Active listening was expressed by some participants as a central resource and primary basis of care for the bereaved:

We do this welcoming, this active listening (E.1).

Usually we do not use resources other than listening, listening and speaking to the body [...] (E.4).

[...] Listening [...] conversation [...] more listening than anything (E.7).

The use of occupations was also mentioned as a therapeutic resource:

Look [...] basically in the focus of grief, they are guidelines... schedule some routine, recommend some activities [...] I also raise the person's context and seek leisure practices to support (E.2).

The resources, [...] there are some cases where I take a clipboard with a sheet of sulfite and I map the daily life of that person, the routine, [...] and I see what is happening and I go discussing each of the things that appear, seeing what meaning it has in life if that is being maintained, [...] and reestablishing possible connections [...] (E.5).

[...] We usually organize after a while [...] this issue is that in the house she has found many things about the person who died [...] So, let's work together and see how you can organize it [...] what does the person want to keep? [...] I think it is a very affective and very respectful way of elaborating mourning (E.6).

The groups also appeared as a resource used and valued by occupational therapists:

[...] I think that the issue of the group [...] was a nice way [...] we planned the groups very much according to the need for what they brought [...] it ended up that we worked a lot on the demand of what they brought, you know, the proposal, right... many questions, some wanted to read about grief (E.3).

[...] We also organized [...] the group of mourners by Covid [...] As they couldn't say goodbye, we organized a memorial. Each person in the group, I wrote the life

story of that person who died, [...] and they told what that person represented to him [...] (E.6).

Artistic, expressive, and social activities were also cited:

[...] cognitive games, handicraft practices that are closely linked to art therapy [...] sometimes [...] physical activity, sometimes cooking, chat, depending a lot on what the person was looking for, but most were cognitive games (E.2).

[...] more expressive activities, [...] even conversation, verbal, but we use a lot of films, [...] sometimes some excerpts that people, [...] wrote, [...] letters to themselves, what did they mean [...] They sometimes brought poetry, several brought funeral saints, and we worked a little on why they had chosen that, [...] photo album [...] they rescued photos with people, [...] we also had some moments [...] of practical incursions in the market, in the square... thinking it was a resource to make contact [...] with that world again (E.3).

Finally, one of the integrative practices was also mentioned as an alternative resource used in the occupational therapist's assistance with the bereaved:

[...] I use auriculotherapy (E.7).

When asked whether the grieving process compromises occupations, all participants stated that grief directly impacts occupations.

Based on this understanding, the participating occupational therapists were asked which occupations are most compromised in the bereavement process. The answers originated from seven categories: self-care, work, activities of daily living (ADLs) and instrumental activities of daily living (IADLs); social participation, sleep, and rest; general changes in occupational performance, studying, and playing.

The category called self-care encompassed expressions about losses in self-care:

[...] decreases commitment, self-care (E.2).

[...] difficulties in taking actions to benefit oneself to take care of oneself, for selfcare (E.3).

[...] self-care (E.4).

[...] the self-care activities (E.6).

Self-care, especially, [...] self-care is one of the most common (E.7).

The work category included expressions about changes in productivity and linked to domestic services recognized as a job function for many women:

*decreases productivity* [...] (E.2).

[...] I think that work and these everyday routine issues (E.3).

[...] compromises the work (E.4).

[...] I think that because they are women in this age group, this issue of home care appears a lot [...] (E.7).

ADLs and IADLs were also mentioned as the main occupations impacted by grief, especially about food:

[...] the quality of life, in activities of daily living (E.2).

[...] the ADLs, IADLs... thinking about these... in our daily lives [...] difficulties in eating, cooking [...] practical things, bank (E.3).

[...] compromises food [...] hygiene (E.4).

[...] the issue of food, [...] of compulsive eating or [...] non-eating, [...] the person avoids eating (E.6).

In social relationships and participation, occupational therapists understand that there is a decrease in the act of attending different spaces and in the motivation to interact with other people:

[...] the person feels less desire to be in more pleasurable activities, to be in a social environment that was positive for her (E.2).

If I were to list I think they are interpersonal relationships (E.3).

[...] *it compromises family ties* (E.4).

In addition, sleep and rest were also expressed as commonly affected understood occupations:

[...] I think people have a lot of difficulty sleeping and waking up (E.3).

[...] compromises sleep (E.4).

As, the question of sleep, of rest (E.6).

Some participants expressed an understanding that grief affects occupational performance in general:

[...] completely decreases occupational performance (E.2).

Thinking at the level of tasks, activities, [...] sometimes you lose a performance capacity [...] So, [...] this commitment starts to reach [...] the roles, [...] how these are performed [...] So it affects occupations in many ways, [...] I see it as an umbrella for various occupational experiences, thinking from the most basic components to everyday life that would be a broader thing (E.5).

Finally, studying and playing were also cited as altered occupations in the grieving process when considering the children:

[...] it depends on the age group, children with a lot of school activities, their school routine ends up being compromised, even their development, playing, these occupations (E.6).

From the perspective of the participating occupational therapists, the grieving process has a comprehensive impact on occupations, and, for this reason, it is configured as an object of intervention for occupational therapy.

## Discussion

The data obtained showed that the occupational therapists participating in this study showed an understanding of grief as a process linked to losses, that is, they denote an understanding of grief as a moment of disorganization experienced in a particular way by each individual, caused by the lack of something or someone significant.

According to Franco (2021), the experience of loss occurs from the breakup of a known and significant situation, and the manifestations of grief may be related to different types of losses such as marital separations, in which there is the symbolic death of the couple and dreams and shared projects; illness or accidents, which cause loss of part of the body or specific functions, requiring the construction of positive meaning for that experience, retirement and/or dismissal from work, which causes impacts in the presumed world, for example. In this aspect, the conceptual vision of mourning presented by the participants is in line with literary productions that explain mourning as a process associated with concrete and symbolic losses.

This study investigated occupational therapists' actions specifically produced in situations related to loss resulting from someone's death. Initially, we found that the practice of the participating occupational therapists is centered on the adult and elderly population, mentioning the development of mourning assistance with the child and youth population.

It is important to note that mourning assistance is a clinic of care and subtleties, considering that the experience of the death of significant people can indicate the crossing of experiences inhabited by intense suffering and pain, which is no different in the child sphere. It is understood that the child, after the loss of someone affective, will need to rebuild their perception of the world and relationships, instituting a new form of existence and meaning (Bianchi et al., 2019).

It is essential to understand that grief is a complex and multidimensional process, experienced uniquely and influenced by aspects of the biographical trajectory. One of the points that differentiate the child's mourning process from that of the adult is the fact that the child's bereavement permeates its development (Bianchi et al., 2019), denoting the need to create spaces for assistance also directed to the youth people.

Still referring to the profile assisted by occupational therapists, we identified that the adult/elderly population attended experienced grief associated with the death of a loved one in three different situations: death resulting from the process of illness, suicide, and

violence. It is important to understand that how the deaths occurred are potential influencers of the experience of bereavement.

According to Parkes (2009), factors such as the bereaved's vulnerability, their relationship to the deceased, the events and circumstances that led to that death, the death itself, and social support, as well as other circumstances after the death, are fundamental in the evaluation, since they are risk predictors.

When death is associated with illness processes, there are situations in which family members take on tasks that require a great deal of time and energy in the provision of care, a factor that can trigger situations of exhaustion and emotional instability during the illness, arousing feelings of guilt after the death of the patient linked to possible hostile reactions they had (Franco, 2021). On the other hand, in these processes, the family, caregivers, or close people can follow the evolution of the clinical condition gradually, which often incites manifestations of anticipatory grief (Neto & De Macedo Lisboa, 2017), which is a facilitating factor in coping.

Suicide situations trigger a variety of emotions in the bereaved that transit through anger, sadness, grief, guilt, and shame, among other feelings, exposing the bereaved subject to the same risk and increasing their chances of developing complicated grief, a factor that demands measures of postvention to suicide due to the risk that this type of death represents (Franco, 2021; Cândido, 2011).

Death by violence, in this study, manifested by the participants in situations of accidents, murders, and disasters, are unexpected deaths, which are outside the natural order of life. They are deaths that occur without any prior notice, causing a great shock to family members, without them having time to process what happened (Carnaúba et al., 2016).

Given the above-mentioned particularities, mourning assistance must be based on a process of sensitive and qualified listening, where existing bonds, specific contexts, and assigned meanings must be considered, which requires a theoretical foundation associated with sensitivity from the professional (Franco, 2021).

We noted that only one of the participating occupational therapists bases his practice on knowledge of grief theories, a factor that was perceived to be associated with the fact that he is the only participant who reports having purposeful actions aimed at the bereaved public specifically. In the practice of the other participants, the demands linked to mourning assistance end up emerging secondarily, that is, being carried out during the therapeutic process previously initiated by other demands in which the occupational therapist observes, from the care trajectory, the experience of the grief as a stressful process that needs support and embracement.

Regardless of whether the attention is designed for people in mourning or this assistance to the bereaved emerges during an intervention process that initially did not have this focus, it is necessary to consider that professional training for this approach is of paramount importance. However, data referring to the absence of foundations on the theories of grief show tension in the profession, indicating the need to improve the attention of occupational therapy in this field.

Nevertheless, the data from this study show that the incorporation of these occupational therapists in mourning care was driven, in some cases, by their work in palliative care.

In palliative care, assistance to the patient-family binomial is advocated, with attention to grief being exposed among its guiding principles. As described in art. 4, items VIII and IX, of resolution 41 October 2018, in the organization of palliative care, it is essential to consider offering a support system to help the family deal with the patient's illness and bereavement; as well as developing multiprofessional and interdisciplinary teamwork to address the needs of the patient and their families, including grief counseling whenever indicated (Brasil, 2018), reinforcing the maintenance of the team's bond with the family member and the sense of continuity of caution.

According to Pallottino et al. (2021), within the scope of palliative care, assistance to mourning must be planned in its preventive dimension and may involve post-death telephone calls, condolence letters, face-to-face consultations in the weeks following death - actions that tend to reinforce the maintenance of the team's bond with the family member and the sense of continuity of care.

Specifically, on the assistance of occupational therapists with the bereaved, Dahdah et al. (2019), Hoppes & Segal (2010), and Souza & Corrêa (2009) report that there is a lack of scientific production in this area, and that this practice is still recent in the scope of occupational therapy, a factor that is perceived in line with the average of 2 years of professional experience with the bereaved reported by the participants of this study.

It is important to consider that mourning has repercussions on daily life, being a process that can cause withdrawal and isolation, with demotivation of the bereaved person to perform occupational activities (Frizzo & Corrêa, 2018), a factor that denotes the importance of occupational therapists to qualify for the carrying out actions in this area.

The participants' responses show that the occupational therapist's evaluation process with the bereaved has as its main focus the modifications of the occupational aspects, but with an also expanded look at the evaluation of the emotional, physical and spiritual aspects, however, without the use of standardized evaluations.

As a central element of the evaluation, it is essential to understand the occupational experiences before and after the loss, investigating the routine of the bereaved after the death of the loved one, seeking to understand who the person lost, under what circumstances, the occupations they performed together and the meanings attributed, to identify the changes that have occurred or that may occur associated with the loss experienced (Frizzo & Corrêa, 2018).

The main demands found by professionals in the evaluations with the bereaved include occupational damage, emotional fragility, and restriction of spaces for exchanges, which is directly related to the therapeutic objectives expressed regarding favoring the quality of life, promoting comfort, and helping to cope and (re)construction of meanings.

To address the aforementioned demand for occupational losses, it is first necessary to point out that occupations are understood as necessary, desired, or tasks that need to be done (World Federation of Occupational Therapists, 2010) and permeate ADLs, IADLs, health management, rest and sleep, education, work, play, leisure and social participation (American Occupational Therapy Association, 2020). In this direction, occupational therapists claimed to observe in their practices that the grieving process directly affects occupations, expressing observations of changes in self-care, work, ADLs, IADLs, social relationships and participation, sleep and rest, studying, and playing.

For Hoppes (2005), for example, the individual may experience stages of occupation during the grieving process, which are called occupational maintenance (when the occupation is carried out while denying the severity of the loss); occupational dissolution (when family and daily occupations become devalued and may lose meaning); occupational ambivalence (when negative feelings are experienced in formerly routine occupations) and occupational restoration and adaptation (when occupations are restored and adapted to the new condition after the loss).

Considering that grief changes the bereaved's occupations, the occupational therapist presents as a professional with the expertise to offer support in this process (Batista et al., 2018). For Frizzo & Corrêa (2018):

In bereavement situations, through the person-occupation-therapist relationship, the professional open a space for the expression of mourning and promotes actions that can enhance human action, seeking to promote satisfactory actions. Its function is to favor the well-being of people in the development of their occupations, in the (re)signification of what was lost, and in the elaboration of the demand(s) that are interfering in the development, realization, and participation of occupations... (Frizzo & Corrêa, 2018, p. 397).

According to Dahdah et al. (2019), occupations are potential tools for intervention with bereaved people and can be used as a means or an end, with the occupational therapist having the competence to enable spaces for speech and resignification to reduce occupational losses triggered by the experience of grief.

Thus, it is necessary to overcome barriers to expand and consolidate the practice of occupational therapists with the bereaved, which permeates the need to expand scientific studies that offer evidence that boost the theoretical-practical construction of occupational therapy with the bereaved (Dahdah et al., 2019), as well as encouraging the approach of content linked to finitude, death, and mourning within the scope of initial and continuing education.

#### Conclusion

Through this study, we could perceive a greater direction of the assistance of occupational therapists with bereaved belonging to the adult and elderly life cycle, as well as initially understand how such practices are carried out in terms of guiding theoretical references, evaluation, demands and, in particular, how grief affects occupations from the perspective of occupational therapists.

We understood that the sample of this study provides assistance to mourners from a flow that is not specifically structured for this assistance. That is, in most cases, occupational therapists are faced with the experience of the client's grief during the trajectory. assistance initiated by another demand, a factor that evidences a sensitive professional look at emotional changes and an adjustment movement in the therapeutic plan from the identification of the suffering instituted by the loss and its relationship with the performance of occupations. However, devoid of theoretical foundations of grief, which is a tension presented.

The data obtained reinforce that the emptiness of loss is associated not only with the absence of the other but also with shared occupations directed to the deceased person (Souza & Corrêa, 2009), with the occupational therapist being a professional with the expertise to act with the bereaved people with responsibilities to invest in the foundation of this practice.

As a limitation of this study, the reduced number of participants and the lack of representation of occupational therapists from different regions of the country are pointed out. However, these results point to ways for new studies with methodological designs that allow both the observation of such practices for greater detailing of therapeutic approaches, with research clippings by health equipment, with methodologies that lead to reaching the meanings attributed to occupations that change.

## References

American Occupational Therapy Association – AOTA. (2020). Occupational therapy practice framework: domain et process. The American Journal of Occupational Therapy, 74(Suppl. 2), 1-87.

- Bardin, L. (2011). Análise de conteúdo. São Paulo: Edições 70.
- Batista, M. P. P. (2017). Significados atribuídos às atividades cotidianas de mulheres após a morte em até seis meses do cônjuge idoso (Tese de doutorado). Universidade de São Paulo, São Paulo. Recuperado em 27 de julho de 2022, de https://www.teses.usp.br/teses/disponiveis/5/5170/tde-04082017-095747/publico/MarinaPicazzioPerezBatista.pdf
- Batista, M. P. P., Rebelo, J. E., Carvalho, R. T., Almeida, M. H. M., & Lancman, S. (2019). Widow's perception of their marital relationship and its influence on their restoration-oriented everyday occupations in the first six months after the death of the spouse: a thematic analysis. *Australian Occupational Therapy Journal*, 66(6), 700-710.
- Batista, M. P. P., Rebelo, J. E., Carvalho, R. T., Almeida, M. H. M., & Lancman, S. (2018). Reflexões sobre a realização de entrevistas com viúvas enlutadas em pesquisas qualitativas. *Cadernos Brasileiros de Terapia Ocupacional*, 26(4), 797-808. http://dx.doi.org/10.4322/2526-8910.ctoAO1571.
- Bennett, K. M., Gibbons, K., & Mackenzie-Smith, S. (2010). Loss and restoration in later life: an examination of dual process model of coping with bereavement. *Omega*, 61(4), 315-332.
- Bianchi, D. P. B., Kublikowsk, I., Camps, P. B., & Franco, M. H. P. (2019). Possibilidades da clínica gestáltica no atendimento de crianças enlutadas. *Estudos e Pesquisas em Psicologia*, 19(4), 1018-1035.
- Bousso, R. S. (2011). A complexidade e a simplicidade da experiência do luto. Acta Paulista de Enfermagem, 24(3), VII-VIII.
- Bowlby, J. (1985). Perda: tristeza e depressão. Apego e perda. São Paulo: Martins Fontes Editora.
- Brasil. (2018, 31 de outubro). Resolução Nº 41, de 31 de outubro de 2018. Dispõe sobre as diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito Sistema Único de Saúde (SUS). *Diário Oficial da União*, Brasília, seção 1, p. 276.
- Cândido, A. M. (2011). *O enlutamento por suicídio: elementos de compreensão na clínica da perda* (Dissertação de mestrado). Universidade de Brasília, Brasília.
- Carnaúba, R. A., Pelizza, C. C. A. S., & Cunha, S. A. (2016). Luto em situações de morte inesperada. *PSIQUE*, 1(2), 43-51.
- Corrêa, V. A. (2009). A expressão do pesar nas atividades ocupacionais quando alguém querido morrer (Dissertação de mestrado). Universidade Federal do Pará, Belém.

- Dahdah, D. F., Bombarda, T. B., Frizzo, H. C. F., & Joaquim, R. H. V. T. (2019). Revisão sistemática sobre luto e terapia ocupacional/Systematic review about bereavement and occupational therapy. *Cadernos Brasileiros de Terapia Ocupacional*, 27(1), 186-196.
- Franco, M. H. P. (2021). O luto no século 21: uma compreensão abrangente do fenômeno. São Paulo: Summus Editorial.
- Franqueira, A. M. R., Magalháes, A. S., & Féres-Carneiro, T. (2015). O luto pelo filho adulto sob a ótica das máes. *Estudos de Psicologia*, 32(3), 487-497.
- Freud, S. (1996). Luto e Melancolia. In S. Freud (Ed.), A história do movimento psicanalítico: artigos sobre metapsicologia e outros trabalhos (pp. 249-263). Rio de Janeiro: Imago Editora.
- Frizzo, H. C. F., & Corrêa, V. A. C. (2018). Perdas e luto em terapia ocupacional nos contextos hospitalares e cuidados paliativos. In M. M. R. P. De Carlo & A. M. Kudo (Orgs.), *Terapia* ocupacional em contextos hospitalares e cuidados paliativos (pp. 387-398). São Paulo: Payá.
- Hansson, O. R., & Stroebe, M. S. (2007). Bereavement in late life. Coping, adaptation, and developmental Influences. Washington: American Psychological Association.
- Hoppes, S. W. (2005). When a child dies the world should stop spinning: an autoethnography exploring the impact of family loss on occupation. *The American Journal of Occupational Therapy*, 59(1), 78-87.
- Hoppes, S., & Segal, R. (2010). Reconstructing meaning through occupation after the death of a family member: accommodation, assimilation, and continuing bonds. *The American Journal of Occupational Therapy*, 64(1), 133-141.
- Neto, J. O., & De Macedo Lisboa, C. S. (2017). Doenças associadas ao luto antecipatório: uma revisão da literatura. *Psicologia, Saúde & Doenças, 18*(2), 308-321.
- Pallottino, E., Rezende, C., & Dantas, J. C. S. (2021) Assistência ao luto. In R. T. Carvalho & H. A. Parsons (Orgs.), *Manual de cuidados paliativos da Academia Nacional de Cuidados Paliativos* (pp. 546-549). São Paulo: Academia Nacional de Cuidados Paliativos.
- Parkes, C. M. (1998). Luto: estudos sobre a perda na vida adulta. São Paulo: Summus.
- Parkes, C. M. (2009). Amor e perda: as raízes do luto e suas complicações. São Paulo: Summus.
- Pires, C. (2010). Luto: processo de viver a morte. In Corrente Dinâmica (Org.). Emoções em Saúde (pp. 142-151). Vila Real: Corrnite Dinâmica.
- Souza, A. M., & Corrêa, V. A. C. (2009). Compreendendo o pesar do luto nas atividades ocupacionais. *Revista do NUFEN*, 1(2), 131-148.
- Stroebe, M. S., & Schut, H. (1999). The dual process model of coping with bereavement: rationale and description. *Death Studies*, 23(3), 197-224.
- Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: a decade on. Omega, 61(4), 273-289. http://dx.doi.org/10.2190/OM.61.4.b.
- Worden, J. W. (1998). Terapia do luto: um manual para o profissional de saúde mental. Porto Alegre: Ed. Artes Médicas.
- World Federation of Occupational Therapists WFOT. (2010). Definition "Ocupation". Recuperado em 6 de julho de 2022, em https://wfot.org/about/about-occupational-therapy.

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Isabelle Paris Saciloti: study design, data collection, and analysis, organization of sources, and writing of the text. Tatiana Barbieri Bombarda: study design, data analysis, writing, and text review. All authors approved the final version of the text. **Corresponding author** Tatiana Barbieri Bombarda e-mail: tbbombarda@ufscar.br

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