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Occupational therapists' perceptions of intervention with caregivers of older people with Alzheimer's disease: a qualitative analysis

Percepções de terapeutas ocupacionais sobre a intervenção com cuidadores de pessoas idosas com doença de Alzheimer: uma análise qualitativa

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Abstract

Introduction: Occupational therapists are crucial in dementia care, which includes working with older adults, intervening in the environment, and providing support to caregivers. However, there are few studies in the field specifically focused on caregiver support. **Objective:** To analyze occupational therapists' perceptions of interventions with caregivers of community-dwelling older persons with AD and the main difficulties encountered in this process. **Method:** This is a cross-sectional qualitative study, conducted in two stages, with 31 occupational therapists from different regions of the country. In stage 1, an online questionnaire was applied to collect sociodemographic and professional data, as well as information about interventions with caregivers. In the second stage, seven participants from the initial phase were subdivided into two focus groups to deepen the understanding of the interventions. Data analysis combined frequencies with inductive analysis. **Results:** The participants, professionals who had graduated on average 17 years ago, developed comprehensive interventions to reduce the impact of physical, psycho-emotional, and social demands on caregivers' occupational areas. However, the interventions were influenced by factors such as family conflicts, high caregiver turnover, limited knowledge about the disease, and caregivers' financial difficulties. **Conclusion:** The intervention proves relevant in promoting caregivers' wellbeing and, consequently, the quality of care provided to older adults with dementia.

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Therefore, it is necessary to increase recognition of the importance of specific care for caregivers and to develop strategies to expand interventions and overcome the difficulties in their implementation.

Keywords: Alzheimer Disease, Caregivers, Occupational Therapy, Dementia, Neurocognitive Disorders, Qualitative Research.

Resumo

Introdução: Terapeutas ocupacionais desempenham um papel crucial no cuidado em demência, que contempla a atuação com a pessoa idosa, intervenções no ambiente e suporte aos cuidadores. No entanto, há poucos estudos na área focados especificamente no cuidado ao cuidador. **Objetivo:** Analisar a percepção de terapeutas ocupacionais sobre as intervenções realizadas com cuidadores de pessoas idosas com doença de Alzheimer que vivem na comunidade, bem como as principais dificuldades encontradas nesse processo. **Método:** Trata-se de uma pesquisa transversal qualitativa, realizada em duas etapas, com 31 terapeutas ocupacionais de diferentes regiões do país. Na etapa 1 aplicou-se um questionário on-line para coletar dados sociodemográficos, profissionais e informações sobre a intervenção com cuidadores. Na segunda etapa, sete participantes da fase inicial foram subdivididos em dois grupos focais para aprofundar o conhecimento sobre a intervenção. A análise dos dados combinou frequências com análise indutiva. **Resultados:** Os participantes, profissionais graduados, em média, há 17 anos, desenvolviam intervenções abrangentes para reduzir o impacto das demandas físicas, psicoemocionais e sociais nas áreas ocupacionais dos cuidadores. Entretanto, a atuação foi influenciada por fatores como conflitos familiares, alta rotatividade de cuidadores, limitado conhecimento sobre a doença e dificuldades financeiras dos cuidadores. **Conclusão:** A intervenção mostra-se relevante para promover o bem-estar dos cuidadores e, consequentemente, a qualidade do cuidado prestado à pessoa idosa com demência. Assim é necessário ampliar o reconhecimento da importância do cuidado específico ao cuidador e desenvolver estratégias para expandir as intervenções e superar as dificuldades para a sua implementação.

Palavras-chave: Doença de Alzheimer, Cuidadores, Terapia Ocupacional, Demência, Transtornos Neurocognitivos, Pesquisa Qualitativa.

Introduction

Aging does not necessarily imply disease; however, there is a global increase in the incidence of neurodegenerative disorders with advancing age, particularly in dementia syndromes (Nichols et al., 2022). These are characterized by the progressive deterioration of cognitive functions and behavioral changes, resulting in functional decline (Martínez-Campos et al., 2022).

Among dementia syndromes, Alzheimer disease (AD) stands out as the most common, accounting for between 50% and 75% of all cases (Brasil, 2024). In Brazil, specifically for AD, a significant increase is projected: from 927,000 cases in 2010 (3.1% of the population) to 3.7 million in 2050 (12.4%) (Oliveira et al., 2019). Given this growing trend and its impact on the healthcare system and families, AD was defined as the focus of this research.

As AD progresses and irreversible, progressive cognitive decline occurs, the need for care arises, an important role fulfilled by informal and/or formal caregivers. Informal caregivers are mostly family members, friends, or neighbors who provide unpaid care, motivated by emotional bonds or necessity, often without specific technical training (Oh et al., 2024). In contrast, formal caregivers are paid professionals, generally with qualifications in the health field, hired to provide direct and continuous assistance (Oh et al., 2024). Both perform a fundamental role in maintaining the health and wellbeing of older adults. However, informal caregivers often face challenges due to a lack of technical preparation and appropriate support, in addition to changes in their routine and in the way they perform their own activities, which can often result in distancing from their personal lives, especially as AD advances (Mattos et al., 2020; Oh et al., 2024).

Occupational therapists have a fundamental role in the care of people with AD, acting integratively in managing the challenges that affect occupational performance, through preventive actions, symptom mitigation, and treatment of physical, cognitive, and psychosocial limitations. The central objective is to promote autonomy, functionality, and greater engagement in occupations. In addition, the occupational therapist makes environmental adaptations and provides support to caregivers, contributing to more comprehensive and person-centered care (Bernardo & Raymundo, 2018; Bennett et al., 2019).

Regarding caregivers, the focus of this study, the professional implements educational actions that include guidance on simplifying activities and making environmental adaptations, with the aim of optimizing the functional abilities of the older adult with AD and reducing their behavioral and psychological symptoms, while also providing caregivers with tools for managing stress and encouraging participation in meaningful activities for their own wellbeing (Thinnes & Padilla, 2011). Furthermore, training fosters a better understanding of the disease's progression, assists in coping strategies to deal with cognitive and behavioral changes, and provides guidance to strengthen emotional bonds among family members (Bernardo & Raymundo, 2018).

The international scientific literature documents the role of occupational therapists with caregivers through various types of studies – observational, controlled clinical trials, practical guides, and evaluations. These studies mainly investigate the effects of interventions with older adults with dementia on caregivers, focusing on aspects such as reduction of burden and depression, improvement in quality of life, strengthening the sense of control over life, and engagement in meaningful activities, in addition to evaluating the impact of the educational and support strategies provided (Graff et al., 2007; Thinnes & Padilla, 2011; Bennett et al., 2019; Wenborn et al., 2021; Gitlin et al., 2021).

Similarly, national research on the subject focuses mainly on evaluating the effects of occupational therapists' interventions with older adults and their physical and social environments, as well as on educational and support actions directed at caregivers (Bernardo & Raymundo, 2018; Bernardo, 2018b; Novelli et al., 2018; Mattos et al., 2020). However, few studies investigate the direct work of occupational therapists with caregivers of older adults with AD, especially those centered on the occupational changes experienced by caregivers, including the impact on their routines, self-care activities, occupational roles, mental health, and quality of life (Bernardo, 2018b; Mattos et al., 2020).

Given the above, and considering the significant increase in AD cases in developing countries such as Brazil, it becomes essential to expand research at the national level, including caregivers. Thus, the objective of this study was to analyze occupational therapists' perceptions of interventions with caregivers of community-dwelling older persons with AD and the main difficulties encountered in this process.

Method

This is an exploratory, cross-sectional, qualitative study conducted with occupational therapists from different regions of the country who worked with community-dwelling older adults of both sexes with a probable diagnosis of AD. The focus on AD is justified by its being the most common form of dementia worldwide, accounting for between 50% and 75% of all cases (Brasil, 2024). Standardizing the type of dementia aimed to ensure greater homogeneity in the sample, allowing for a more in-depth analysis of the occupational therapists' practice in relation to the specific demands associated with the clinical and functional profile of these individuals.

Professionals who worked exclusively with older adults with other types of dementia or distinct neurological conditions were excluded from the study. Participants were recruited through national instant messaging groups composed of occupational therapists, as well as through social media posts and email messages. The invitations clearly specified the eligibility criteria for participating in the study.

Data collection was conducted virtually and divided into two stages. The first stage consisted of a questionnaire created on the *Google Forms* platform, composed of open- and closed-ended questions, and remained available for nearly 30 days (from 02/26 to 03/21/2024).

The closed-ended questions addressed sociodemographic characteristics (such as gender, age, income, state, and city of residence) and professional profile (such as training time and institution, additional education, place and type of service), in addition to aspects of the intervention with people with AD and, especially, with their caregivers (such as length and mode of practice, main goals and strategies used, key signs and symptoms observed in the caregiver, and their occupational repercussions). Regarding the open-ended questions, occupational therapists were able to write about their objectives and main aspects of occupational therapy practice with caregivers. These questions sought to explore how occupational therapists address the needs of caregivers in their interventions. A total of 31 professionals participated in this stage.

The second stage of the study involved conducting two focus groups with participants from the first stage. Participants were selected based on the following criteria, in this order: expressing interest in participating in the second stage during completion of the online questionnaire; providing a means of contact (e-mail or phone) for the invitation; and providing complete and relevant responses to the open-ended questions in the online questionnaire.

The focus groups aimed to deepen understanding of the challenges and potential of occupational therapy interventions with caregivers of older adults with AD. The sessions were held separately, with different groups, on April 15 and 18, 2024, via *Google Meet*.

Each meeting lasted 1 h and 30 min and was conducted based on a semi-structured guide of questions developed by the researchers based on the literature in the field and preliminary analysis of the data collected in the first stage (Table 1).

Table 1. Question guide.

1. Are there differences in the work of occupational therapists with family (informal) and non-family (formal) caregivers of older adults with AD? Explain.
2. What are the main needs of these caregivers? Are there differences?
3. What would be the main objectives of occupational therapy with these caregivers?
4. What is the intervention like? Do you use any specific models, resources, techniques, or materials? Which ones?
5. What are the main difficulties faced in the care process with family (informal) and non-family (formal) caregivers? Are there differences?
6. Have you ever been called upon as occupational therapists to provide specific care for caregivers of people with AD? Under what circumstances, context, and objective?
7. Have you ever worked with these caregivers in partnership with other professionals? What was the experience like?
8. In analyzing the previously completed questionnaire, participants highlighted several aspects, including the lack of professional training for caregivers and the caregiver's use of occupational therapy appointments with the older person as a time for rest. How do you evaluate these two issues?

The analysis of the data regarding the characterization of participants in the first stage of the study was carried out using absolute and relative frequencies, based on the spreadsheet automatically generated by *Google Forms*. The open-ended questions from the first stage and the data from the focus groups, which were recorded and transcribed, were analyzed inductively by two researchers using the content analysis methodology, divided into the following stages: pre-analysis, material exploration, and treatment of results, inference, and interpretation (Bardin, 2016).

This process made it possible to identify and quantify the occurrence of terms and words, as well as themes related to interventions with caregivers, allowing for the extraction of three main categories, namely: 1) Demands presented by caregivers and occupational repercussions; 2) Occupational therapy goals and interventions; and 3) Main difficulties encountered by occupational therapists in caregiver support. The first category included data from the first stage (two closed questions, namely: What are the main signs and symptoms you observe in the caregiver? and What are the main occupational repercussions you observe in the caregiver?) and from the second stage of the study. The same occurred with the second category. However, this category included only two open-ended questions from the first stage, which were directly related to the theme (What are the main goals and strategies carried out in your direct work with the caregiver? and How do you work to minimize the signs/symptoms and occupational repercussions identified in caregivers?). The third category included only the responses from the second stage of the study.

To preserve confidentiality, the names of the focus group participants were replaced with P1, P2, P3, P4, P5, P6, and P7, according to the order of response. Participants digitally signed the Informed Consent Form. The study was approved by the Ethics

Committee of the Clementino Fraga Filho University Hospital of the Federal University of Rio de Janeiro, under CAAE Nº.76819723.2.0000.5257.

Results

Participant characterization

The study included 31 participants (30 cisgender women and one cisgender man), with a mean age of 41 years (SD±12.0), from eight Brazilian states, and with an income of 5 to 10 minimum wages (38.7%).

The average time since completing undergraduate education was 17 years (SD=12.3; ranging from 3 to 43 years). Most participants reported graduating from a public institution (70.9%). Regarding further education, 25 participants (80.6%) had some type of specialization, mainly in the fields of Gerontology, Older Person's Health, Palliative Care, and Family Health. In terms of professional practice, 10 participants (32%) worked exclusively in public institutions, while 19 (61.3%) worked with older adults, and 17 (54.8%) had been working with older adults with AD for 9 years or more (Table 2).

In addition to the sociodemographic and professional profile data of the participants presented previously, it is noteworthy that all occupational therapists reported working with older adults at different stages of the disease. Since it was possible to select more than one option, it was observed that all participants worked with individuals in the moderate stage (*n* = 31; 100%), while most also reported assisting individuals in the mild (*n* = 22; 74.2%) and severe (*n* = 21; 83.9%) stages.

Regarding occupational therapy care for these individuals, referrals generally came from geriatricians (*n* = 11; 35.5%), physicians from other specialties (*n* = 7; 22.6%), and other professionals from the interdisciplinary team (*n* = 6; 19.4%). As for the place of practice, most pointed to three main settings: home-based (*n* = 24; 77.4%), outpatient (*n* = 10; 32.3%), and hospital (*n* = 6; 19.4%).

Furthermore, except for one participant, all occupational therapists reported considering the caregiver as an integral part of their care. This implies recognizing the caregiver as a subject with their own needs, requiring specific occupational therapy follow-up and interventions. Most provided assistance to both informal and formal caregivers (*n* = 27; 87.1%), and 23 (74.2%) stated that the caregivers had no specific training in the area of care for people with AD. More than half reported developing specific intervention plans for caregivers (*n* = 17; 55.6%).

Specific actions with caregivers involved assistance (*n* = 22; 71%), followed by education (*n* = 8; 25.8%); one person (3.2%) mentioned management, and no one mentioned research. Regarding self-assessment of the effectiveness of their interventions with caregivers, 12 (38.7%) and 11 (35.5%) participants gave scores of 4 and 3, respectively (on a scale from 0 to 5; the higher, the better), indicating that the interventions were evaluated as effective and moderately effective, respectively.

Table 2. Characterization of participants in stage 1 of the study (*n* = 31).

Characteristics		**N**	**%**
Gender	Woman	30	96.8
	Man	1	3.2
Age (Years)	20 to 29	8	25.8
	30 to 39	10	32.2
	40 to 49	7	22.7
	50 to 59	2	6.4
	60 to 69	4	12.9
State	Rio de Janeiro	11	35.5
	São Paulo	9	29
	Minas Gerais	4	12.9
	Pernambuco	3	9.7
	Distrito Federal	1	3.2
	Pará	1	3.2
	Rio Grande do Sul	1	3.2
	Santa Catarina	1	3.2
Income (minimum wages)	2 to 5	11	35.5
	More than 5 to 10	12	38.7
	More than 10 to 20	6	19.4
	More than 20	1	3.2
	Prefer not to say	1	3.2
Type of undergraduate institution	Public	22	70.9
	Private	9	29.1
Time since graduation (years)	1 to 5	4	12.9
	6 to 10	7	22.5
	11 to 20	10	32.2
	21 to 30	4	12.9
	31 to 40	3	9.6
	41 to 50	3	9.6
Additional training*	Specialization	25	80.6
	Residency	9	29
	Master's	8	25.8
	Advanced	7	22.6
Main institution of professional activity	Public	10	32.2
	Private	9	29
	Autonomous	7	22.6
	Mixed	3	9.7
	Philanthropic	1	3.2
	Other	1	3.2
Time working with older people (years)	Less than 4	3	9.7
	4 to 8	9	29
	9 or more	19	61.3
Time working with people with AD (years)	Less than 4	8	25.8
	4 to 8	7	19.4
	9 or more	17	54.8

Caption: *Multiple answer options. AD - Alzheimer disease.
Source: Elaborated by the authors.

Interventions with caregivers were mainly conducted on an individual basis (*n* = 25; 80.6%), followed by group strategies (*n* = 6; 19.4%) or in a multidisciplinary format (*n* = 5; 16.1%), that is, alongside other health professionals, including geriatricians.

It is noteworthy that in 18.4% of cases, the occupational therapist dedicated themselves exclusively to addressing specific demands of the caregiver.

The data regarding the profile of participants in stage 2 of the study were compiled in Table 3. It is worth noting that, of the 31 participants, 26 expressed willingness to participate in the second stage of the research, but only 14 provided e-mail or phone contact. Of these, 4 did not complete the open-ended questions from stage 1. Thus, 10 occupational therapists were invited to take part in the focus groups, but only seven attended.

Table 3. Characterization of participants in stage 2 of the research (*n* = 7).

Focus group	P	Age (Years)	State	Training time (years)	Length of experience working with older people with AD (years)
1	1	33	São Paulo	12	7-8 years
	2	42	São Paulo	11	Over 10 years
	3	28	Minas Gerais	6	5-6 years
2	4	44	Minas Gerais	22	9-10 years
	5	36	Rio de Janeiro	14	Over 10 years
	6	27	Rio de Janeiro	5	3-4 years
	7	44	São Paulo	24	Over 10 years

Source: Elaborated by the authors.

Caregiver demands and occupational impacts

In the first stage of the research, participants indicated that caregivers may present with various physical, psycho-emotional, and social signs and symptoms. The most frequently cited symptoms were: overload (*n* = 29, 93.5%), stress (*n* = 25, 80.6%), fatigue (*n* = 24, 77.4%), anxiety (*n* = 21, 67.7%), anticipatory grief (*n* = 14, 45.2%), sadness (*n* = 13, 41.9%), insomnia (*n* = 12, 38.7%), depressive symptoms (*n* = 11, 35.5%), and excessive worry about the future (*n* = 11, 35.5%). Furthermore, participants reported that caregivers experienced feelings such as guilt (*n* = 10, 32.3%), complaints of pain (*n* = 9, 29.0%), regret (*n* = 8, 25.8%), anger (*n* = 7, 22.6%), and loneliness (*n* = 7, 22.6%). Less frequent feelings and perceptions were also mentioned, such as denial about the situation (*n* = 2, 6.5%), concern about finances (*n* = 1, 3.2%), feelings of disability (*n* = 1, 3.2%), and insensitivity to the suffering of others (*n* = 1, 3.2%). During the focus groups, participants validated the presence of burden, stress, anxiety, depressive symptoms, anticipatory grief, and denial, especially on the part of informal caregivers.

> *When an informal caregiver arrives, whether it's a child or a wife or husband, most of the time, people are overwhelmed. It's such an overload that, at times, the person loses control. (P3)*

> *There's usually an issue of overload, of stress. I see this, symptoms of anxiety, and sometimes even depression. It's not a rule, obviously, but I pay close attention to these issues. (P5)*

> *The family was actually experiencing the stages of grief and was in that phase of denial. At that moment, you can give a thousand and one pieces of advice that doesn't work and doesn't help. (P4)*

Furthermore, they highlighted that the demands placed on informal and formal caregivers can vary. For example, informal caregivers tend to experience higher levels of stress and a greater need for educational and psychosocial support.

> *An informal caregiver experiences much higher stress levels than a formal caregiver, precisely because of the emotional burden. (P4).*

> *The biggest problem for families with Alzheimer's is a lack of knowledge. They lack knowledge about the disease, the triggers for behavioral changes, or the importance of routine. (P3)*

The statements also highlight the difficulties faced by both caregivers in balancing the needs of older people who are caring for their own needs, with possible influences on occupations.

> *And it ended up bringing a lot of self-care demands. The family caregiver needed to go to the doctor, needed so many things for their own care, for the care of their children or other family members, but they couldn't do it when they were with the older person. (P1)*

> *I encounter psychological issues, sometimes so difficult to manage, where it's not possible to have time for leisure activities, psychotherapy, or physical activity. And then, of course, this care becomes severely compromised, because the person increasingly internalizes all those needs: I need to care, I need to care, I need to care. (P7)*

> *In fact, caregivers in general – both family and informal – I notice that they have a hard time when we think about occupation. This issue of managing self-care and health. (P5)*

> *Often, it's not uncommon, that lady who took care of the house, was a maid, cooked the meals, and then the older person became a widower, and she started taking care of the house and of the older person, fulfilling roles for which she wasn't hired. (P2)*

These results corroborate the findings from the first stage of the study. Thirty participants in the first stage of the study – out of a total of 31 – identified 170 impacts on caregivers' daily lives, which are subdivided into different occupational areas, such as leisure (*n* = 25), social participation (*n* = 19), health management (*n* = 16), work (*n* = 11), ADL (*n* = 10), IADL (*n* = 9), and education (*n* = 8). Furthermore, they mentioned that caregivers may experience difficulties engaging in meaningful activities (*n* = 23), achieving occupational balance (*n* = 25), and managing time (*n* = 23). One participant also mentioned that caregivers may prioritize care for the older person over self-care.

Regarding occupational therapy interventions, occupational therapists can incorporate these specific caregiver demands into their care process, fostering a positive impact on their occupations and the care provided to the older person.

> *The caregiving relationship a formal caregiver offers has a lot to do with personality traits, listening skills, technical preparation, and, of course, on the informal caregiver's side, there are many emotional issues. So, it ranges from truly affectionate caregiving to overwhelmed caregiving, often filled with anger. [...] So, adopting this approach – with each caregiver, whether formal or informal, is very important. (P7)*

> *When I think I have an intervention that won't educate the caregiver on specific tasks for my patient, I ask if they'd like to leave the room to do something pleasurable for them. I do this in consultation with key professionals on the rehabilitation team to find spaces for rest during the older person's stay with the professional. (P2)*

Regarding the possibility of specific interventions with the caregiver, it was observed that, frequently, care for the caregiver occurs indirectly, based on a demand that arises from caring for the older person.

> *Sometimes, along with the older person's intervention, I include that family member, that child, that wife, or husband, and I begin to conduct small interventions with them. [...] In many cases, my services are only with caregivers. (P3)*

> *I've never received (a referral). Generally, caregivers, in my practice, are referred to psychiatrists and psychologists. I've never received a referral for occupational therapy. (P2)*

> *I've never received a referral from colleagues directing them to the caregiver. That's never happened. Usually, it comes to the older person, and then we end up extending our services to the caregiver (P4).*

Occupational therapy objectives and intervention

In the first stage of the research, participants highlighted a comprehensive set of objectives and intervention strategies for caregivers of people with dementia, articulating complementary actions aimed at both caregivers and patients. These include: psychoeducation, support, routine organization and practical implementation of care, guidance on behavioral management and communication, optimization of the older person's occupational performance, strengthening the support network, and promoting safety and self-care, many of which simultaneously integrate more than one process. In total, 178 mentions were made of possibilities for occupational therapy interventions.

Specifically regarding psychoeducation, participants made 35 mentions highlighting the importance of promoting knowledge about the disease, its signs and symptoms, as well as about the prognosis and progression of dementia, which can occur individually or in groups. The role of the occupational therapist in the psychoeducation process was also pointed out by participants during the second stage of the study, both with informal and formal caregivers.

> *Whenever possible, I work with psychoeducation in a very relevant way with the caregiver. I believe that this care for the caregiver has a great impact on the older person. (P7)*

> *Families sought us out for guidance. At that time, there were also formal caregivers who joined me. They had this need to know what they could do beyond hygiene care, how they could promote better quality of life. (P1)*

Additionally, there was a statement pointing to the role of the occupational therapist in the process of raising awareness about patients' rights.

> *[...] raising awareness also about rights, which many times people have no idea about. The Statute of the Elderly, what your municipality provides, etc. I also see this as part of the job. I'm talking maybe about more specific groups, anyway, I see this less in home settings, [...] I also see this as a possible task for the occupational therapist, which can be powerful, maybe even more with occupational justice. (P5)*

Regarding emotional support (30 mentions), in response to the questionnaire, participants highlighted goals and strategies aimed at active listening, validating feelings, addressing emotional demands, and developing coping strategies as key actions carried out by occupational therapy professionals with caregivers of people with dementia. The role of the occupational therapist in the process of providing support to caregivers was validated in the focus groups, although differences were identified regarding interventions for informal vs. formal caregivers.

> *Sometimes I stop to provide some kind of emotional support or qualified listening to the caregiver. Sometimes it's more specific, but I see it as extremely necessary. [...] I try to set aside some time, depending on the time we have for the appointment, to provide support or give some more specific guidance, even guidance on how to handle things. I confess that, because of exhaustion, I can't include the informal caregiver much in the actual appointment. I sometimes even leave it out because they say that's their rest time, but I really try to stop for a moment and talk. (P5)*

Participants also highlighted goals and strategies aimed at self-care (30 mentions) to promote the caregiver's health and wellbeing. In this area, they pointed to interventions for reducing stress and burden, such as relaxation techniques and stress management, guidance for occupational balance, and promotion of involvement in activities, especially leisure and social participation. In the focus groups, participants mentioned using some techniques and promoting meaningful activities.

> *And one of the techniques used is stress management. So, breathing, for example. Creating a space for rest for that caregiver. (P3)*

> *Being able to have this focus on caregiver care. That's something that I, at least once a month, pause everything to have this type of conversation. So, from understanding what meaningful activities are for that caregiver to what support network can help them. [...] I often use multisensory stimulation with caregivers as a means of relaxation, stress reduction, anxiety, and, eventually, depressive symptoms. Another thing I usually use is the practice of mindfulness. (P7)*

Routine organization and care training were mentioned 28 times by participants, highlighting strategies to optimize time management and facilitate daily activities with older adults with dementia. These two aspects were also evident in different statements from participants in the second stage of the research, including in hospitalization processes.

> *I think the first step is giving guidance — how to stimulate, how to organize the routine. (P7)*

> *So I sat with her and said, now I think we need to adjust your routine. We need to work with you. Let's sit down, let's put on paper everything we need to do for you. So, we made several notes. One about household management, one about managing him, about what was still needed, like doctors, appointment days, and then, finally, I opened a third tab. And then it was also a bit of an educational task, linked to what you're going to do for yourself. And then, every time I got there, I would ask, this week, what did you do for yourself? (P4)*

> *Another thing we always do, combining both (patient and caregiver), is that when I think about organizing the routine of this hospitalized patient, I make the caregiver the protagonist of that organization, because the one who knows the patient's routine is not usually me, it's them. (P2)*

> *It's about objects, right? So, what kind of diaper? What kind of grab bar? What kind of bed? Does he need a hospital bed or not? Does the insurance cover it or not? So, that's something that started coming up as a demand, and I also needed to study, right, go deeper into this area, especially in the discharge process, and that meeting, which is relatively quick, lasts, overall, three hours. (P6)*

Still in the field of strategies for caring for older adults, in response to the questionnaire, participants mentioned 15 times the importance of the occupational therapist's role with caregivers, focusing on guidance on effective communication and managing behavioral and psychological symptoms, as also indicated in the focus groups.

> *The tone of voice, the way of being present with that older person, I really believe that this has a big impact. (P7)*

> *They also work on how to minimize the triggers that cause behavioral changes in this older patient. So, we identify, together with the caregiver, what they believe to be the trigger. (P2)*

> *I also see it as a goal, often overlapping with the educational and guidance moment, the issue of training, in the sense of technically explaining, for example, how to manage wandering or perseverative behavior. (P5)*

In this context, four occupational therapists participating in the second phase of the study reported using a structured and systematic occupational therapy intervention program.

> *The other reference I use is my training with TAP, which is the Tailored Activity Program. TAP proposes a sequence of actions, a sequence of sessions. Many times, I can't or don't even want to follow that sequence. But, for example, the activity inventory and activity prescription are tools within TAP that I use. It also has a dementia guide. So, that helps a lot. And I try to use this structure in my treatment process. (P6)*

Additionally, there were 15 mentions about the importance of optimizing the occupational performance of older adults through training in daily activities, use of assistive technology, and promotion of participation in different occupations to maintain independence and autonomy for as long as possible, aspects also evidenced by participants in the second stage of the research.

> *I explain functionality in each stage of Alzheimer's and how it can be stimulated. (P3)*

> *One of the goals I have with caregivers in this case, where we sometimes have one meeting, two meetings, is that I can provide them with guidance regarding assistive technology that they need [...] where to buy it, how to install it, how to use it. (P6)*

> *At the very least, these caregivers need to be well-guided on how to accompany that older person throughout the week, in their basic, instrumental activities, in short, all of them. So, I think the first step is to go through this guidance: how to stimulate, how to organize the construction of that routine, and so on. (P7)*

> *So sometimes they start doing cognitive exercise as part of their routine, they become interested, it becomes a topic between them and the caregiver, so that starts to become a meaningful activity. It wasn't before, but it can become one. (P3)*

In the first stage of the study, participants also mentioned the contribution of occupational therapy in the process of creating and strengthening a support network (15 mentions), highlighting the importance of creating support groups, participating in family meetings, making referrals to different healthcare professionals when necessary, and directing the caregiver to specific courses. This aspect was mentioned more discreetly in the focus groups.

> *We refer them to a psychologist, a psychiatrist, a neurologist. Anyway, we try all possible strategies to surround the family, to provide support. (P4)*

> *I regularly hold meetings with the children. Sometimes it's the couple: my patient and the wife. And then I hold a meeting with the four children online. [...] My idea is that this person (caregiver) can incorporate this course into their routine... teaching the caregiver a bit about taking care of their own health and understanding the importance of their own care. (P3)*

Finally, it is worth highlighting that the promotion of safety for caregivers and people with dementia was mentioned by participants in 10 instances, with emphasis on the prescription of assistive technology and environmental adaptations to prevent falls and other accidents, as well as to minimize the risk of delirium, caregiver burden, and to promote an enriched and functional environment for both. This issue was mentioned in the second stage of the study, especially regarding work within the hospital context.

> *So, for example, if we prescribe a support product to improve mobility, like a lift for transfers. [...] We are not only thinking about preventing the patient's fall, but also about reducing the caregiver's burden during the patient's mobility. [...] We conduct a large screening to enrich the hospital environment, the patient's room. So, I will bring in objects with family significance to enrich that environment. [...] And finally, interventions to prevent delirium. We know that patients with some types of dementia are at higher risk of developing delirium. (P2)*

Main difficulties encountered by occupational therapists in caregiver support

Occupational therapy intervention with caregivers of older adults with AD (Alzheimer Disease) can present some challenges, as mentioned by participants in the second stage of the study. Among the main difficulties identified were family disagreements and conflicts between caregivers.

> *In general, what I see most is when a family, sometimes with four children, for example, one disagrees with the other, and there are many disagreements, even really serious fights. You build a normal relationship, but sometimes the other doesn't even believe in the work. (P5)*

> *I think another situation that has happened to me is when you have a formal caregiver and, in the same environment, you have a very active informal caregiver, and they clash all the time. You give guidance, and they keep arguing,*

> *the informal caregiver wants it done one way, the formal caregiver does it another. You try to intervene, finding a middle ground to make things easier for the older person. (P4)*

Still within the context of conflicts between informal and formal caregivers, in some situations, the occupational therapist needs to expand their knowledge and role to guide and mediate both parties, even about labor rights, for example.

> *I've had a caregiver where I even took on the role of discussing labor rights a bit, because they were those caregivers hired to do everything and more, and being paid a ridiculous amount. And then I said, hold on — is there a contract? What does it say in the contract? Did you read it? Oh no, there's no contract. So, let's sit down with your employer, let's make a contract? (P4)*

Another challenge involved the limited openness of some families to recognize the caregiver as someone who also needs therapeutic attention, as well as to implementing changes in the organization of the care routine.

> *When we understand that the caregiver needs to be the target of occupational therapy intervention, but the family sees that person as not being the protagonist, not the target of care. So, they won't spend their money investing in occupational therapy to intervene with the caregiver. They want that valuable time to be used for the patient. (P2)*
>
> *So, we live with these families over time. These are guidelines that we keep giving, and we receive feedback from the family. Some families are very open. Other families don't want anyone interfering in the household routine. (P1)*

Additionally, high turnover among formal caregivers proved to be a major challenge for intervention:

> *An important barrier is the turnover of caregivers, especially in home care. So, they are very different caregivers. And they don't see the point in engaging in any educational action. So, the first challenge we face is having to deal with this turnover of formal caregivers. So, when I think of an intervention for that patient, the big challenge is how to standardize the guidance in general, knowing that the caregiver in the morning is not the one in the afternoon, not the one at night, and not the one tomorrow. (P2)*
>
> *I've had formal caregivers with whom it was very easy to establish a bond, to have them as partners, because at most there were two people alternating shifts. So, I was always able to stay close in some way. I have more difficulty, for example, when it's a company with huge turnover [...] when you finally manage to build something, the company changes or the person quits. (P5)*

Turnover within the family caregiving itself was also pointed out as an aspect that can negatively affect treatment continuity and the health condition stability of the older person, especially when different family members adopt inconsistent or conflicting care approaches.

> *One specific daughter did everything she wasn't supposed to do, like, the older woman was diabetic, and the daughter gave her the opposite of the recommended diet, alcoholic beverages, it was like the complete opposite. So, when you showed up at the beginning of the week, the older woman was destabilized. It was very difficult work. It was even hard to talk to the daughter; the others were less difficult, so it was a family that had a lot of that going on. (P5)*

Caregivers' insecurity about encouraging the autonomy and independence of the older person, limiting their role to mere companionship out of fear of external judgment regarding the quality of care provided, was also identified as a challenge for the occupational therapist in achieving their goals.

> *Their commitment is to keep them company (...) they don't seek to encourage the autonomy and independence of that patient because they're afraid someone might look at that situation and think they're not fulfilling their duty to care. (P2)*

Specifically regarding informal caregivers, a fragile emotional bond between the caregiver and the older person, financial problems, and a lack of knowledge about the progression of the disease can impact the therapeutic process.

> *So, one of the main limitations is the relationship, and I understand that too. It's not something that professionals can just overcome. There was no affection, no construction of respect, no bond. There's nothing I can do about that. (P3)*

> *One of the most difficult things is the financial situation. Sometimes there's no food, no electricity, no water... and you can't suggest buying anything for the older person. It's very hard. (P1)*

> *A few weeks ago, I had a case where the daughter asked me if he (the older person) was going to get better. What kind of improvement are we talking about? But I understood from her words that she truly had an expectation that there would be an improvement in the sense of returning to what he once was, or at least close to it. [...] I've had to work with families who really didn't have much awareness, who weren't very informed about the prognosis. (P5)*

Finally, a limited understanding of the role of occupational therapy by other professionals was also noted. At times, it is mistakenly reduced to certain functions, requiring a process of clarification and adjustment of expectations during the initial assessment.

> *(...) so, many times for older adults with dementia, the expectation is that occupational therapy will be, I don't know, some kind of entertainer. That usually comes from another professional, and then obviously, during the assessment process, I make it very clear that this is not the idea, so there's a bit of expectation adjustment, and in most cases we're able to have a good conversation. (P6)*

Discussion

The analysis of the results revealed that the main occupational therapy interventions focused on demands such as caregiver burden and stress, followed by fatigue and anxiety. These conditions directly impacted occupational areas such as leisure, social participation, and health management. In response, professionals reported frequent use of strategies such as psychoeducation, emotional support, encouragement of self-care, and routine organization.

Caregiver burden emerged as the main demand, consistent with studies that associate the diagnosis of dementia with significant changes in family dynamics and feelings of disappointment, fear, and isolation (Nascimento & Figueiredo, 2019; Mattos et al., 2020). This condition involves physical, emotional, and occupational impacts (Guerra et al., 2017; Bennett et al., 2019). Stress, cited shortly thereafter, together with fatigue and anxiety, reinforces the need for interventions focused on occupational performance and caregiver wellbeing, with the development of coping strategies and encouragement of participation in meaningful activities (Martínez-Campos et al., 2022; Wenborn et al., 2021).

Findings also indicate that the progression of dementia interferes with caregivers' routines and leads to the abandonment and/or adaptation of activities. As a result of these changes, caregivers often find themselves in an exhausting routine, where the only option is to fully assume the role of caregiver (Prieto-Botella et al., 2024). In this context, the occupational therapist is essential in supporting the reorganization of occupations, time optimization, and the recovery of priority activities. Additionally, the mediation of responsibilities among caregivers and family members contributes to the caregiver's quality of life and sense of autonomy (Mattos et al., 2020; Wenborn et al., 2021).

Regarding occupational therapy interventions, psychoeducation stood out as the most frequent, being valued for promoting knowledge about the disease, its symptoms, and progression. This result may be attributed to the work of healthcare professionals during appointments, which is often marked by the lack of adequate support for the caregiver to effectively perform their role with the older person with dementia in daily activities. This scenario reinforces the uniqueness and relevance of the occupational therapist's role in providing direct support to caregivers (Micklewright & Farquhar, 2023).

Considering that caregivers operate throughout the three phases of the disease – mild, moderate, and severe –, it is essential for the occupational therapist to conduct a comprehensive assessment, considering the abilities of the person with dementia, the physical and social context, as well as the caregiver's availability and readiness (Sarsak, 2018; Gitlin et al., 2021). Based on this assessment, the occupational therapist can develop targeted interventions for caregivers, providing guidance and support to enhance their caregiving competence (Sarsak, 2018).

Emotional support proved to be fundamental in the context of the occupational therapist's intervention, especially considering caregiver burden. The space for active listening promotes trust, reduces stress, and strengthens caregiver self-confidence (Micklewright & Farquhar, 2023; Wenborn et al., 2021). In parallel, actions focused on self-care were reported, such as relaxation techniques, occupational balance, and encouragement of leisure and social life. These strategies promote caregiver health and wellbeing and reinforce the importance of restoring desired activities that contribute to quality of life (Martínez-Campos et al., 2022; Micklewright & Farquhar, 2023).

Routine organization and care instrumentalization were also mentioned by participants, highlighting strategies to optimize time management and facilitate the execution of daily activities with older people with dementia (Bernardo, 2018a; Mattos et al., 2020). In addition, the occupational therapist holds a crucial role in improving communication with the older person and managing behavioral changes and in reducing behavioral and psychological symptoms in dementia that affect the performance of daily activities and care, offering effective management strategies such as the Tailored Activity Program (TAP) (Novelli et al., 2018; Gitlin et al., 2021). This role becomes essential, especially because caregivers who face the challenge of dealing with behavioral and psychological symptoms without sufficient knowledge are at greater risk of developing physical and mental health problems (Duarte & Jacinto, 2023).

Participants also emphasized that the role of occupational therapy in promoting autonomy and independence of the older person with dementia through activity training, use of assistive technology, environmental adaptations, and encouragement of participation in meaningful occupations can contribute to reducing caregiver strain and stress, which aligns with both national and international literature (Graff et al., 2007; Bernardo, 2018b; Bernardo & Raymundo, 2018; Micklewright & Farquhar, 2023). Assistive technology and environmental adaptations also emerged as central strategies for promoting safety, with an emphasis on fall prevention, delirium reduction, and caregiver burden relief, creating a functional and welcoming space for both the older person and the caregiver. However, it is necessary to consider critical factors such as accessibility to technologies, the learning process, the cultural context of the older person and caregiver, as well as continuous monitoring, in order to avoid abrupt changes that may cause confusion or agitation (Bernardo & Raymundo, 2018; Davidoff et al., 2024).

Actions aimed at creating and strengthening the support network were also mentioned, such as support groups, family meetings, referrals to other professionals, and offering specific courses for caregivers. These findings align with well-established evidence in the literature, which reinforces the need for multidimensional approaches to dementia care by occupational therapists (Bernardo & Raymundo, 2018; Bernardo, 2018b; Wenborn et al., 2021; Martínez-Campos et al., 2022; Micklewright & Farquhar, 2023).

Occupational therapy actions aimed at caregivers encompassed both formal and informal caregivers, with strategies adapted to the specificities of each group but also with common elements. In both contexts, the interventions involved support in managing care demands, psychoeducation, promotion of self-care, encouragement of engagement in meaningful activities, and adaptation of the home environment (Bernardo, 2018a; Bernardo & Raymundo, 2018; Martínez-Campos et al., 2022; Tekeste & Lawson, 2025).

In the case of formal caregivers, actions aimed at organizing the routine and promoting occupational justice stood out, such as the clear definition of tasks, shifts, and responsibilities, in addition to raising family awareness regarding the technical and professional role of these caregivers (Martínez-Campos et al., 2022). As for informal caregivers, the interventions included family meetings and instrumentalization strategies, focusing on practical guidance for the safe and effective performance of care activities (Bernardo, 2018a; Bernardo & Raymundo, 2018; Tekeste & Lawson, 2025). A balanced division among those involved in care contributes to maintaining routines, reducing burnout, and improving caregiver quality of life (Faria et al., 2017; Martínez-Campos et al., 2022).

Among the challenges faced, participants mentioned disagreements among family members and between caregivers, as well as low adherence to occupational therapy interventions. Factors such as caregiver burden, lack of time and motivation were identified as barriers to effective participation (Donkers et al., 2018). Although occupational therapy has interventions described in the literature for the care of older adults with dementia and their caregivers (Bernardo, 2018b; Micklewright & Farquhar, 2023; Tekeste & Lawson, 2025; Duarte & Jacinto, 2023), this research showed that mistaken conceptions about the role of this professional still persist, which reinforces the need for occupational therapists to remain attentive to this issue. By clarifying the scope of their work, occupational therapists strengthen information exchange, promote appropriate referrals, and align expectations, contributing to a care plan centered on the needs of the older adult, their family, and caregivers (Martínez-Campos et al., 2022).

The findings revealed that misconceptions about the role of this professional still persist, which underscores the need for occupational therapists to remain attentive to this issue.

The results revealed that interventions predominantly focused on the direct care of the older adult with dementia, which supports the findings of the systematic review by Micklewright & Farquhar (2023). Despite the recognition of caregivers' fundamental needs, the proposed interventions often prioritize improving assistance to the older person, relegating caregiver support to a secondary role (Faria et al., 2017; Martínez-Campos et al., 2022). Therefore, the study emphasizes the urgency of developing and implementing strategies that encompass not only the enhancement of care for older adults with dementia but also the promotion of caregiver wellbeing, including the recovery and maintenance of their meaningful occupational roles and activities (Martínez-Campos et al., 2022).

It is important to highlight that, although occupational therapists are initially hired to work with the older person, their work directed at the caregiver as the main client proves to be essential for care sustainability. Thus, it is crucial that occupational therapists themselves recognize the caregiver as a primary client, value this dimension of their practice, and promote this approach to facilitate referral flows and consolidate the caregiver's role in the therapeutic process (Martínez-Campos et al., 2022).

Finally, the study presents limitations regarding representativeness, since the second stage included only professionals from the South-east region, and the online recruitment may have limited the reach to certain groups. For future research, it is suggested to expand the channels and period of dissemination, as well as include participants from different regions and professional contexts. It is also recommended to conduct quantitative or mixed-method studies focusing on work in Long-Term Institutions for Older People and analyzing variables such as years of experience and institutional characteristics. Despite these limitations, the adoption of a multimethod approach (questionnaire and focus group) allowed for an in-depth and consistent analysis of the studied phenomenon.

Conclusion

This study achieved its objective, which was to analyze occupational therapists' perceptions of interventions carried out with caregivers of community-dwelling older adults with dementia, as well as the main difficulties encountered in this process. According to the findings, caregivers presented various physical, psycho-emotional, and social demands that impacted different occupational areas, especially leisure, social participation, and health management.

Regarding the interventions, it was identified that professionals develop comprehensive practice with caregivers, integrating different objectives and intervention strategies. Psychoeducation, emotional support, routine organization, care instrumentalization, management of behavioral and psychological symptoms, improvement of communication, promotion of self-care, and strengthening of the support network were highlighted as central elements of the practice. The main difficulties cited for the implementation and effectiveness of these interventions involved family and caregiver conflicts, high turnover of caregivers, limited knowledge about the disease, financial difficulties, and mistaken conceptions about the role of occupational therapy.

Occupational therapy intervention has proven to be relevant for promoting caregiver wellbeing and, consequently, the quality of care provided to older adults with dementia. Thus, this research can contribute to the fields of occupational therapy and gerontology by highlighting the need to expand the recognition of the importance of specific care for caregivers and to develop strategies to broaden interventions and overcome implementation barriers. Furthermore, it has the potential to enhance reflections on the development of broader policies for dementia care.

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Author's Contributions

Ingrid Gregory Silveira Almeida was responsible for the study's development, data collection, formatting, data analysis, and review. Janaína Santos Nascimento was responsible for the study's supervision, data collection, data analysis, and review. Júlia Cortines Menengoi da Conceição was responsible for data analysis and review. Carolina Rebellato was responsible for co-supervision, data collection, data analysis, and review. All authors approved the final version of the text.

Data Availability

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

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