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Original Article

# Occupational therapy in the care of an older adult with Alzheimer's disease and their caregiver in a *favela*: a case study

## *Terapia ocupacional no cuidado de pessoa idosa com Doença de Alzheimer e de sua cuidadora em uma favela: estudo de caso*

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## Abstract

**Introduction***:* Older adults with Alzheimer's disease and their caregivers may develop limitations that affect participation in their occupations, especially in contexts of social vulnerability. **Objective:** To describe the main occupational therapy assessments and interventions carried out with an older adult with Alzheimer's disease and their caregiver in a Compassionate Favela. **Method***:* This is a single case study conducted in a Compassionate Favela located in Rocinha, Rio de Janeiro. Ten sessions were carried out with the older adult and their caregiver between December/2024 and April/2025. Data collection was conducted through the development of an interview guide, application of validated instruments, and systematic recording of interventions in a field diary. Data were analyzed qualitatively using reflexive thematic analysis. **Results***:* The older adult presented total dependence in most Activities of Daily Living. The caregiver presented difficulties in self-care and in managing behavioral changes of the older adult's father, as well as routine disorganization and severe physical and emotional burden. Occupational therapy interventions included optimization of the older adult's occupational performance through caregiver training, promotion of caregiver self-care, and participation in meaningful activities. **Conclusion***:* The study reinforces the contribution of occupational therapy in compassionate communities and the need for contextually grounded strategies for older adults with Alzheimer's disease and their caregivers.

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**Keywords:** Occupational Therapy, Alzheimer Disease, Caregivers, Poverty Areas.

***Resumo***

**Introdução:** Pessoas idosas com Doença de Alzheimer e seus cuidadores podem desenvolver limitações que afetam a participação em suas ocupações, especialmente em contextos de vulnerabilidade social. **Objetivo:** Descrever as principais avaliações e intervenções terapêutico-ocupacionais realizadas com uma pessoa idosa com Doença de Alzheimer e sua cuidadora em uma Favela Compassiva. **Método:** Trata-se de estudo de caso único, realizado em uma Favela Compassiva localizada na Rocinha, Rio de Janeiro. Foram desenvolvidos dez encontros junto a pessoa idosa e a sua cuidadora, entre dezembro/2024 a abril/2025. A coleta de dados ocorreu por meio da elaboração de um roteiro de entrevista, aplicação de instrumentos validados e registro sistemático das intervenções em diário de campo. Os dados foram analisados qualitativamente por meio de análise temática reflexiva. **Resultados:** A pessoa idosa apresentava dependência total na maioria das Atividades de Vida Diária. A cuidadora apresentava dificuldades no autocuidado e no manejo das alterações comportamentais do pai idoso, além de desorganização da rotina e sobrecarga física e emocional grave. As intervenções terapêutico-ocupacionais incluíram otimização do desempenho ocupacional da pessoa idosa por meio da instrumentalização da cuidadora, favorecimento do seu autocuidado e da participação em atividades com atribuição de significado. **Conclusão:** A pesquisa reforça a contribuição da terapia ocupacional em comunidades compassivas e a necessidade de estratégias contextualizadas para a pessoa idosa com Alzheimer e sua cuidadora.

**Palavras-chave:** Terapia Ocupacional, Doença de Alzheimer, Cuidadores, Áreas de Pobreza.

## Introduction

In Brazil, approximately 8.5% of the population aged 60 years or older live with some form of dementia, corresponding to about 2.71 million cases. Projections indicate that, by 2050, this number may reach 5.6 million people diagnosed with some form of the disease (Brasil, 2024a).

Dementia is a term that encompasses a group of diseases, mostly progressive, that affect memory, other cognitive functions, and behavior, significantly interfering with the person's ability to perform activities of daily living. Alzheimer's disease (AD) is the most common form of dementia and may account for 60 to 70% of cases, constituting the focus of this study (World Health Organization, 2017).

The challenges in the care of older adults with AD and their caregivers are numerous, especially in contexts of social vulnerability, influenced by socioeconomic, historical, and cultural factors (Martins, 2023). Restrictions in access to basic rights, such as health care, tend to intensify in these settings, compounded by discrimination and structural economic inequalities (Mesquita et al., 2023).

The 2022 census revealed an increase in the population living in favelas, totaling 16 million people across 11,403 favelas, representing 8.1% of the Brazilian population. Rocinha favela, where this study was conducted, is the most populous, with a total of 72,021 inhabitants (Instituto Brasileiro de Geografia e Estatística, 2022), which reinforces the relevance of studies that address the specificities of this population.

In this scenario, where structural inequalities and limitations in access to health services become even more evident, the adoption of care models that value community participation and the strengthening of local support networks becomes increasingly relevant. It is within this context that the concept of Compassionate Communities is situated, grounded in the collective construction of social support to promote dignity, comfort, and well-being for people facing the end of life, involving both health professionals and local residents and leaders (Kellehear, 2013). The Compassionate Favela represents an example of this model, adopting a broadened approach to care that seeks to support individuals, families, and caregivers living in vulnerable contexts in coping with life-threatening illnesses (Mesquita et al., 2023).

From this perspective, an experience developed in Rocinha will be described below, involving local volunteers and health professionals – including occupational therapists – in the implementation of this care approach. This report is considered relevant and original, as the literature remains scarce regarding the role of occupational therapy within Compassionate Communities. Only one study addressing this topic was identified, in which Smith et al. (2024) explore the role of occupational therapists in palliative care in supporting the development of Compassionate Communities, highlighting contributions such as strengthening support networks, community articulation, and promoting meaningful participation of people at the end of life and their caregivers.

However, to date, no studies have been identified describing occupational therapy practice within Compassionate Communities with older adults with dementia and their family caregivers, especially in contexts of social vulnerability, such as favela territories. Occupational therapy interventions aimed at older adults with AD in other contexts have been more frequently described, such as in Long-Term Care Facilities for Older Adults (Bernardo, 2018), at home (Ham et al., 2021; Schuartz et al., 2023), through telehealth services (Delgado & Martín Mediavilla, 2021), and in hospital settings (Ballarin et al., 2018; Ham et al., 2021).

Such interventions generally involve maintaining the person's performance skills and residual capacities, as well as adopting compensatory strategies in response to difficulties emerging in occupational performance and participation, considering cognitive decline, functional limitations, and behavioral and psychological symptoms of AD (Bernardo & Raymundo, 2018; Ham et al., 2021; Smallfield et al., 2024).

The importance of occupational therapy interventions that also address caregivers or family members of older adults with AD is also emphasized, as disease progression increasingly requires care from family members and/or caregivers, often on a full-time basis, which may lead to physical and emotional burden and affect their quality of life and self-care (Cruz et al., 2018; Mattos & Kovács, 2020).

Given this, the purpose of this study was to describe the main occupational therapy assessments and interventions carried out with an older adult with AD and their caregiver in a Compassionate Favela.

## Method

This is a qualitative exploratory-descriptive study with a single-case study design. The case study method, used across various fields of knowledge, enables an in-depth exploration of complex real-life phenomena (Yin, 2014). In occupational therapy

research, this method is useful for an accurate understanding of subjectivities and particularities of the person and their occupational engagement (Carey, 2021).

The case study was developed according to the *CARE Statement and Checklist* guidelines (Riley et al., 2017) and conducted by a final-year occupational therapy student under the supervision of a faculty advisor with more than 10 years of experience in palliative care and gerontology. The study was developed within the scope of an extension project carried out in the first Compassionate Favela in Brazil, located in Rocinha, and involved an older adult with AD and their family caregiver.

Case selection considered its uniqueness in dementia care within a community context, as well as its originality and potential contribution to occupational therapy practice, in addition to meeting eligibility criteria such as clinical diagnosis of AD and participation in project activities.

Assessments and interventions were defined after awareness of the case previously shared by the technical team and local volunteers. An interview guide was developed for initial data collection, aiming to understand family dynamics and characterize the occupational profile of each participant. The occupational profile encompasses occupational history and experiences, patterns of daily living, as well as interests, values, and needs relevant to clients (Gomes et al., 2021).

Initially, questions about the older adult were addressed to the caregiver, such as biographical and occupational profile, degree of kinship, duration of caregiving, organization of the older adult's routine, main difficulties faced in the caregiving process, activities performed by the older adult and required level of support, and presence of behavioral changes. Subsequently, the caregiver answered aspects about herself: biographical and occupational profile, routine and changes after becoming her father's caregiver, main barriers and facilitators in providing care, reduced or discontinued activities, and strategies for managing the father's behavioral changes.

A sociodemographic questionnaire was administered, followed by an assessment of the occupational needs of the older adult and their caregiver, based on the Occupational Therapy Practice Framework (Gomes et al., 2021). All questions were answered by the caregiver.

For functional analysis of the older adult, the Functional Independence Measure (FIM) was used, with scores ranging from 18 to 126 points (Riberto et al., 2004), and the Palliative Performance Scale (PPS), which classifies global functionality on a scale from 0 to 100% (Sereno et al., 2022). Functional disability related to Alzheimer's disease was assessed using the Functional Assessment Staging Tool (FAST), composed of seven stages of progression (Brucki et al., 2022). Caregiver burden was measured using the reduced Zarit Burden Interview, which classifies burden levels with scores ranging from 7 to 35, with higher scores indicating greater burden (Brasil, 2013).

The total assessment time was approximately 1 hour and 30 minutes, distributed across two separate in-person days with a one-week interval, conducted before the proposal of interventions. Information from the aforementioned instruments relied on the caregiver as the informant.

To complement data collection, a field diary was used, in which written accounts, researchers' observations, and photographic records were documented. The field diary consisted of a document that compiled reflections, observable facts, and perceptions produced through mediation of language and experience in the studied context

(Teixeira et al., 2023). In addition, occupational therapy interventions were fully recorded and transcribed to preserve information accuracy and support qualitative analysis.

Ten sessions were conducted between December 2024 and April 2025, five of which were in-person, simultaneously with the older adult and caregiver at the family home located in Rocinha favela, and the remaining sessions remotely via *Google Meet*, only with the caregiver. Sessions, regardless of modality, lasted approximately two hours. All interventions were grounded in the principles of Palliative Care, prioritizing the understanding of the impacts of a life-threatening illness and the different types of suffering experienced by the older adult and their family, as well as coordination with the volunteer team and professionals involved in care.

In the first stage of the study, related to assessments, results were descriptive and exploratory, based on instrument scores according to their validated scoring systems. Interviews were conducted using reasoning grounded in the Occupational Therapy Practice Framework (Gomes et al., 2021), aiming to support the development of a care plan aligned with identified needs.

In a subsequent stage, narratives produced during interventions were qualitatively analyzed using reflexive thematic analysis proposed by Braun and Clarke (2020), aiming to systematically identify, organize, explore, and interpret meanings within the dataset. Theme searching, reviewing, and defining were also performed, resulting in the categories presented in the results, constructed from the caregiver's narratives throughout the interventions, reflecting recurring patterns of meaning related to her caregiving experience (Braun & Clarke, 2020).

This study was approved by the Research Ethics Committee of the Clementino Fraga Filho University Hospital (HUCFF), under CAAE no. 83607924.0.0000.5257. To ensure participant anonymity, names were changed to Carlos and Ana and identifying personal data were omitted. The Informed Consent Form was signed by the legal guardian, authorizing both her participation in the study as a caregiver and that of her father.

## Results

### Compassionate Favela: how care is organized?

The Compassionate Favela is a project that provides palliative care to people living in the communities of Rocinha and Vidigal, in Rio de Janeiro. As part of its activities, monthly outreach actions are carried out on Saturdays, with the participation of local volunteers who are trained in the care of patients with serious illnesses and play a central role by working in an integrated manner with professional volunteers from different fields, such as nursing, medicine, occupational therapy, speech-language therapy, dentistry, social work, psychology, physiotherapy, nutrition, physical education, and chaplaincy.

Activities begin with a meeting at the project headquarters, during which general announcements are shared and, briefly, the cases of the patients to be visited that day are discussed. Participants are then organized into groups that go to the patients' homes. Currently, eight groups operate in the Rocinha community, each responsible for following, on average, three patients.

Home visits have two main objectives: the admission of new users and the continuous follow-up of those already enrolled, including support for their families and caregivers. At the end of each outreach action, the groups return to the project headquarters for a moment of collective listening and interdisciplinary discussion, aiming to evaluate each case and define care strategies. Possible follow-up actions include family conferences, individual care provided by professionals – such as occupational therapists –, and coordination with the Rede de Atenção à Saúde (RAS), Brazil's Health Care Network model.

It is important to highlight that the Compassionate Favela project does not aim to replace the actions of the RAS, but rather to expand access, welcoming, and support for people in situations of social vulnerability, contributing to the strengthening of the existing care network.

Patient referrals to the project occur predominantly through three pathways: Family Health Clinics in the region, the work of local volunteers themselves, or direct requests made by family members and/or friends who are aware of the initiative. Eligibility criteria include people experiencing intense suffering and social vulnerability, with a predominant or exclusive need for palliative care.

**Occupational history**

Carlos was a 76-year-old man, with education up to the 9th grade of elementary school, retired, with a monthly income of approximately two minimum wages. Originally from Ceará, Catholic, he lived in the Rocinha favela, in the home of his daughter and son-in-law. Widowed for about one year, he had only one daughter, Ana, with whom he maintained a close bond. He left Ceará at a young age, at 20 years old, in search of new opportunities in Rio de Janeiro. He was married for 46 years and, within the family context, was responsible for organizing all documentation and family records.

He worked for many years at a newspaper stand. Although he had no formal academic education, he cultivated the habit of reading, especially works on theology, building a large collection of books. He served as a deacon in the church he attended and enjoyed walking his dogs, Chico and Dudu, along the beachfront of São Conrado.

Ana was 49 years old, married, Christian, and her father's primary family caregiver. She previously worked as a shop clerk but had to interrupt her career to dedicate herself to Carlos's care. She lived with her husband and her father, and the family's main source of income came from Carlos's pension.

Ana supplemented the family income through occasional sales of sweets, an activity she enjoyed due to her interest in cooking. In addition, she valued moments of self-care and leisure, such as caring for plants and animals, sunbathing, watching films, visiting the Rocinha street market, and actively participating in her church – experiences that reinforced her well-being and spirituality.

Due to her father's clinical condition, Ana's routine was almost entirely restricted to caregiving activities. She was only able to leave home on specific occasions, when her husband – who had a low level of readiness – temporarily assumed caregiving responsibilities. During these outings, Ana sought to perform essential tasks, such as paying bills, grocery shopping, and participating in religious activities. Her faith was highlighted by her as a strategy to mitigate caregiving challenges.

In this context, Ana reported feelings of burden, sadness, and anxiety, as well as difficulties in accepting her father's new condition and recognizing him as the paternal

figure she once knew. She presented difficulties both in managing behavioral and psychological symptoms and in balancing her father's care with her own needs.

Her father's loss of ability to participate in necessary and desired activities, transitioning from an independent individual to a dependent one, represented a constant emotional challenge for Ana. This situation led her to reflect on the fragility of life and on how the caregiving relationship had changed over time.

The impossibility of hiring a formal caregiver on a daily basis, due to financial constraints, combined with Ana's difficulty in accepting the presence of third parties in her father's care, contributed to increased caregiver burden. Additionally, difficulties related to the location of the residence, such as drug trafficking activity and lack of accessibility, further aggravated the conditions of daily care.

## Occupational therapy assessment

Carlos was diagnosed with AD in 2023 by the local Family Health Clinic, where he remains under follow-up. Regarding comorbidities, he presents hypercholesterolemia, pre-diabetes, and hypertriglyceridemia. His food intake has been irregular due to episodes of agitation, disorientation, drowsiness, and dysphagia.

At the time of the assessment, the patient weighed 45 kg and measured 1.50 meters in height, with visible signs of weight loss, although the family was unable to report the exact amount of weight lost. Diet was administered orally, with semi-liquid to pasty consistency, due to complete tooth loss.

The daughter, primary caregiver, appeared visibly distressed and with depressed mood, demonstrating difficulties in managing her father's care as well as his behavioral and psychological changes. Signs of intense emotional suffering were identified, including feelings of fear and guilt, as well as difficulties in accepting her father's illness, alongside a suggestive caregiver burden profile.

In the functional assessment using the FIM, Carlos scored 36 points out of a possible 126, indicating significant dependence and the need for total assistance in most Activities of Daily Living (ADLs), as well as cognitive decline (Figure 1).

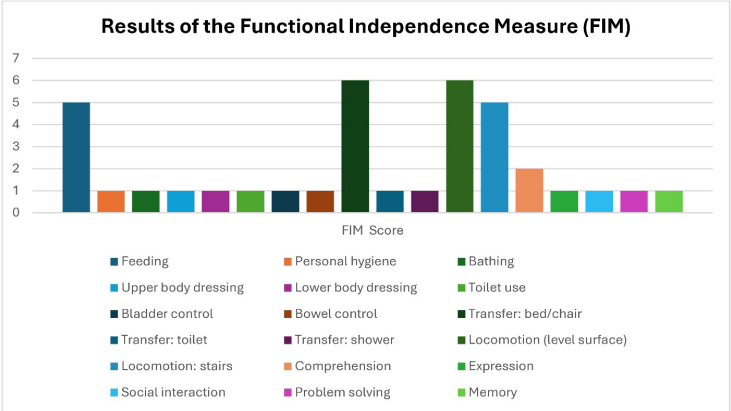


**Figure 1.** Results from the application of the FIM.
**Source:** Author's own elaboration.

Carlos presented urinary and fecal incontinence, performing elimination in his own clothing or on the bedroom floor. The patient did not accept the use

of diapers, nor did he notify when he was soiled. Resistance to initiating and maintaining bathing activities was also observed, with episodes of aggression directed toward his daughter, which made it impossible to perform this activity on a daily basis. When bathing was successfully carried out, the patient required maximum assistance.

Regarding feeding, due to complete tooth loss, Carlos required, as previously reported, modified consistency food (semi-liquid) and constant supervision from his daughter. In terms of comprehension, he demonstrated partial understanding of everyday conversations and texts, requiring assistance in more than 50% of situations.

Regarding functionality assessed through the PPS, Carlos presented a score of 30%, being unable to perform any work activity, with extensive disease, total assistance for self-care, reduced intake, and a level of consciousness marked by periods of confusion. In relation to dementia staging, Carlos was at stage 7A, corresponding to severe dementia, with limited speech ability, using approximately half a dozen different intelligible words or fewer during a typical day or over the course of an intensive interview.

Carlos presented behavioral and psychological changes, including anxiety, frequent sputum production (expectoration), aggression, and restlessness. According to his daughter's reports, such manifestations tended to intensify on hotter days or during moments requiring closer physical contact, such as bathing, oral hygiene, and other personal care activities. Ana's accounts highlighted the difficulties she faced in attempting to carry out these care activities.

> *Unfortunately, I ended up adopting a strategy that made me feel very bad, but if it weren't for that, I wouldn't have been able to bathe him because he had been all dirty since yesterday. I tied him up, told him to check his blood pressure, then I put his little hand on the shower chair and tied both hands, but even so, he got very agitated and tried to kick me, but that was the way I managed to bathe him because he hadn't had a bath in three days. (Ana).*

Ana also had difficulty accepting her father's illness, demonstrating through her words the complexity of the feelings of someone dealing with this reality.

> *I'm still in the process of accepting this illness, you know. So, every new thing that comes along is different, and I end up feeling destabilized. I understand that it's a degenerative disease, that there's no cure, that's what we have for now, and the tendency is for it to get worse. I understand all of that, but my biggest problem is accepting that this is happening. (Ana).*

Within the framework of occupational therapy practice, it becomes necessary to evaluate and analyze other components relevant to patients' occupational performance, such as performance skills, performance patterns, and environmental factors, described below.

**Performance skills**

Carlos presented loss of balance during functional mobility, which required supervision to perform this activity safely. Process skills, which involve initiation, planning, organization, and sequencing, were also impaired. In addition, Carlos demonstrated difficulty in communication management, resulting from deficits in process skills and social interaction, caused by AD. This communication difficulty generated frustration, especially for his daughter. Therefore, it was observed that Carlos presented impairments in performance skills, directly impacting his occupations.

**Performance standards**

Carlos presented an impoverished routine, with few activities imbued with meaning and restricted social participation, as he remained confined to his bedroom for most of the day.

Regarding his daily routine, Carlos would usually wake up, have breakfast in the living room, and then return to his bedroom, where he remained for most of the day. In this environment, he presented perseverative behaviors, such as wandering, manipulating personal objects, tearing pages from books, and pushing the armchair. He also engaged in risky behaviors, such as attempting to tear off the window protection screen, damaging the sofa, opening his daughter's closet to throw materials into the trash or toilet, and even attempting to remove the toilet fixture itself. In response to these episodes, his daughter chose to restrict his movement to the bedroom, allowing him to leave only during mealtimes and always under supervision. For this purpose, she installed a door in the bedroom.

At the onset of the disease, Ana used to take Carlos for outdoor walks. However, due to episodes of agitation in which he would run toward other places, she decided to keep him at home to ensure his safety. In order to avoid him remaining only in the bedroom, she tried to include moments in the routine on the terrace – located on the upper floor, where Carlos could sunbathe and interact with his pets, Chico and Dudu. However, he began to show difficulty in going up and down the stairs, especially due to the excessive height of the steps, above recommended standards, and the absence of handrails.

**Environmental factors**

When analyzing the location of Ana's residence, a lack of accessibility in the streets was observed, with the presence of narrow alleys and pathways, hills with steep uneven terrain, non-standardized stairways, and intense movement of people, motorcycles, and other means of transportation in a reduced space, interfering with Carlos's mobility within the community. Additional recurrent aspects of daily life in the favela were also noted, such as large amounts of exposed garbage in the streets, open sewage, stalls with the open sale of drugs, and individuals carrying weapons and communication radios.

Furthermore, Carlos and Ana's residence was located far from the entrance of the favela, where markets, transport points, banks, and the Family Clinic are usually concentrated. This distance, associated with structural and environmental barriers in the territory, restricted mobility within the community, especially for Carlos, who presented balance impairments and required more time to carry out displacements (Figure 2).


**Figure 2.** (A) Image taken from Google Maps showing the street leading to Carlos's residence, with non-standardized steps and no contrast. (B) Simulation of the approximate distance between Carlos and Ana's house and the beginning of the Rocinha favela.
**Source:** *Google Maps.*

Another situation frequently experienced in the favela concerns the impact of police operations on the management of residents' care. When these occur, home visits by the Family Clinic are suspended. In addition to external difficulties, access to and the internal structure of Carlos and Ana's home also presented barriers: it was necessary to pass through a gate and climb two flights of narrow stairs, without handrails, signage, or adequate lighting. Inside the house, there was an additional flight of stairs leading to the terrace, as well as small and overly furnished rooms and the presence of cats.

The house had six main rooms: a living room, two bedrooms, a bathroom, a kitchen, and a terrace. In Carlos's bedroom, there was a single bed, a plastic chair, and a glass cabinet containing materials for Ana's preparation of sweets.

## Specific assessment conducted with caregiver Ana

Regarding Carlos's daughter, Ana scored 29 on the Zarit Scale, indicating severe burden, as shown in Figure 3.

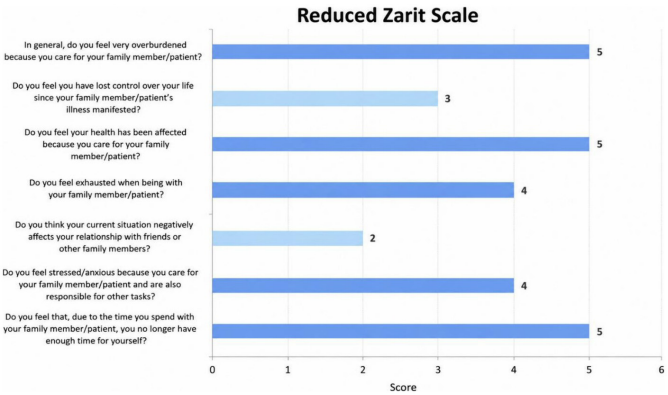


**Figure 3.** Results of the caregiver burden assessment – Reduced Zarit Scale.
**Source:** Author's own elaboration.

Regarding Ana's occupational demands, in addition to the presence of overload, an occupational imbalance was observed, with a lack of self-care and desired activities. In one of the telehealth sessions with Ana, she reported:

> *It's because I actually get overwhelmed. I don't know how to explain a word that sometimes comes to mind: burnout. Because I've always worked outside the home. I've always had my independence. And today my routine drives me a little crazy. Because I wake up in the morning thinking: Oh my God, here it all starts again. Changing the pee, cleaning up the cats' poop because they can't use the litter box. Making his coffee. Planning his breakfast so he doesn't get constipated. I understand that. He's not to blame for anything. I'm trying to do the best I can. But there are days when I'm exhausted. (Ana).*

**Occupational therapy diagnosis**

Carlos presented with a life-threatening condition, with difficulties performing ADLs (Activities of Daily Living) and IADLs (Instrumental Activities of Daily Living). Impairments were also observed in other occupations, such as social participation and leisure activities, as well as loss of occupational roles. Deficits in procedural skills, difficulties in communication and social interaction, and occupational deprivation were also identified. Ana presented with physical and psychosocial complaints related to her caregiving routine, as well as occupational overload and imbalance.

**Occupational therapy interventions**

During the interventions, it was possible to extract three main categories from the narratives of the caregiver and the researchers, namely: 1) doubts about the disease and strategies that may support care; 2) caring for the person who cares; and 3) not all suffering can be alleviated. It is important to highlight that care sessions are dynamic and new demands may emerge over time, requiring continuous professional assessment.

**Doubts about the disease and strategies that may support care**

Ana presented many doubts about AD and fears, as well as difficulties in providing care for her father. In this context, in a first moment, Ana was supported and received guidance about the disease, mainly regarding the most frequent behavioral and psychological changes presented by Carlos, as well as strategies to manage distressing situations. These strategies included coordination with the medical team for medication adjustment and guidance on the management of these changes, especially during bathing and personal hygiene activities.

Initially, the caregiver used physical restraint during bathing. However, with the guidance provided, it was possible to restructure this activity, eliminating the need for restraints. The interventions included establishing strategic schedules, considering the limits and needs of both, as well as identifying triggers that could lead to behavioral changes. The timing of medication administration was also adjusted, being given one hour before bathing.

> *While I was washing his hair, he was rubbing his own body, rubbing everything. And I shook him... while washing his hair, he sat there super calm, didn't need to be restrained, he even helped me. Thank God. He's been very calm, very calm, since the day she changed the dose and the way he was given it. (Ana).*

Ana's account described how she gradually adjusted the rhythm of Carlos's care and adopted more effective communication, which resulted in greater participation and cooperation from him. Instead of using restraint, as she initially did, the caregiver began to involve Carlos in the activity, encouraging him to perform steps compatible with his abilities, such as washing his own body while she helped him wash his hair.

Throughout the interventions, Ana expressed feelings of guilt regarding her decision to install a door in Carlos's bedroom and keep him mostly confined. In response, the occupational therapist adopted a supportive stance, validating Ana's feelings and promoting a space for listening and reflection.

The therapist suggested that Ana consider, on days when she felt better able to manage the situation, leaving the door open, allowing Carlos to move through other rooms. This proposal provided Ana with greater autonomy in decision-making related to the care environment, without imposing a rigid solution. In understanding the implications for Carlos, the occupational therapist also focused on ensuring that the bedroom environment was structured in a way that allowed his participation in meaningful activities whenever possible.

In this sense, the occupational therapist advised Ana to provide objects that Carlos could manipulate, such as books to browse, game pieces, old banknotes, watches, and items of clothing – objects that were part of Carlos's life history and occupational identity.

**Caring for the person who cares**

Ana's level of burden appeared to impact her occupational performance and daily routine. She reported that her routine was highly disorganized and unstable, with difficulty initiating and completing activities. Her routine was centered on Carlos's care, which led her to neglect her own self-care, resulting in symptoms such as stress, anxiety, and discouragement. Furthermore, there was a narrowing of daily life and interruption of other occupational roles.

In this context, occupational therapy emphasized the importance of Ana prioritizing her own well-being in order to provide adequate care for her father, as well as the possibility of financial reorganization to hire a caregiver to share responsibilities, if feasible. Together with her, strategies were developed to support self-care and enable her return to participation in meaningful and prioritized activities in her life.

Among the established strategies were: the installation of a camera in Carlos's bedroom; guidance to share caregiving responsibilities with another person (hiring a formal caregiver once a week); organization of the daily routine in a planner to facilitate the distribution of weekly tasks and activities, including those that were meaningful and prioritized; and health education focused on self-care.

With the installation of the cameras, Ana reported greater calm and safety to engage in other home activities, such as receiving sweet orders in the kitchen, watching a film

in her bedroom, or even carrying out short outings such as going to the market, bank, and shops.

Regarding the hiring of a formal caregiver, this remained a sensitive issue for Ana, as she had always felt apprehensive about someone else assuming this role. After a period of dialogue and reflection, she was able to hire a trusted professional to accompany her father once a week. Initially, Ana showed hesitation in delegating caregiving responsibilities.

However, trust in the caregiver developed gradually. Currently, Ana feels more secure and is able to dedicate herself to other activities while the professional supports Carlos. These activities include going to the beach, shopping, going to the mall, and having lunch with her husband. This process has contributed to the expansion of her occupational repertoire, strengthening of social participation, increased mobility within the community, and appreciation of shared moments with her husband.

From Ana's reports, it was observed that the presence of a professional supporting Carlos's care, even once a week, contributed to her participation in meaningful activities and self-care, reducing symptoms associated with caregiver burden. In addition, the organization of weekly tasks and activities enabled her to achieve greater occupational balance, conciliating her father's care, household responsibilities, and time dedicated to herself.

> *I managed to improve a little bit (...). There are days when our lives turn upside down, and we can't get anything done, but there's the day to put the laundry in, which I no longer do outside of that day, that was already a step forward. (Ana).*

Despite these changes, Ana was experiencing a grieving process related to the losses caused by her father's AD. She reported difficulty in understanding the changes resulting from the disease and, at many moments, when looking at Carlos, she was unable to recognize him as her paternal figure.

In light of the emotional difficulties faced by Ana, supportive and attentive listening was provided at several moments to allow her to express her feelings. The occupational therapist encouraged her to openly share her distress and to seek psychological support to cope with the intense emotions that emerged throughout the caregiving process. In addition, the occupational therapist emphasized that there is no perfect care, but rather the possible care, adapted to the needs and challenges of each situation.

Furthermore, one possible intervention involved the retrieval of Carlos's life history, as well as the recollection of meaningful moments, with the aim of re-signifying and strengthening the relationship between father and daughter. In this regard, Ana, together with the occupational therapist, created a box containing Carlos's personal belongings and photographs, so that when she looked at them, she could positively remember who her father was, his virtues, his qualities, and his essence.

This activity had two stages, one remote and one in-person. In the online session, the proposal was discussed with Ana and the process of selecting objects that reminded her of her father was initiated. Ana chose: a green cap, a Fortaleza football team cap, a blue swimsuit, and a brooch from the time Carlos served as a deacon in the church (Figure 4).


**Figure 4.** (A) Carlos's brooch. (B) Ana writing about memorable moments with her father. (C) Assembling the memory box.
**Source:** Authors' record

Each object found made Carlos's daughter remember and tell a story or a moment about her father, and she stated that she did not feel sadness, but rather tranquility and joy in having these memories. Regarding the photos, Ana said that she was not yet feeling ready, but that she would choose at an opportune moment. Ana expressed her feelings in this activity and shared an experience that occurred at a moment close to the day of this appointment, when her church brother referred to Carlos as his example of wisdom and intelligence.

In the face-to-face appointment, the occupational therapist, together with Ana, began the process of making the box. Ana decorated the lid with her father's name and, during the construction, showed herself to be involved in the activity, in addition to reporting that she liked it and felt good.

> *When I started moving these things around, and remembering everything I experienced with my father, I thought: this isn't going to work, because I'm going to start remembering him, it's going to be anguish, there's going to be a lot of crying. But it didn't. I picked up one thing at a time and recalled the moments, which made me feel good and want to look for more things, I enjoyed doing this activity. (Ana).*

**Not all suffering can be alleviated.**

Ana reported that, at times, she felt powerless in the face of her father's suffering, especially when he experienced episodes of intense agitation or no longer recognized his

daughter. Ana expressed guilt for distancing herself from him at many points during the day to avoid seeing him and suffering even more.

> *Sometimes I put him in his room, close the door just to avoid contact with him, just to avoid being near him, as if being near him, seeing the way he acts, clueless, doing things he doesn't know he's doing, that would punish me, and seeing my father like that, I suffer, and this false illusion I have of distancing myself from him is as if I were avoiding my suffering. (Ana).*

Ana also demonstrated distress related to her family's current socioeconomic situation. She said she felt bad about not having a better financial situation to care for her father, and carried with her a feeling of guilt.

> *Because I came to think that a lot of my father's illness progressed because of me, you know? Because I always think that if I had done things differently, studied, had a better-paying job, I think he might be a little more lucid today, he might have more resources to take care of himself. Because I think there were many things that contributed to its progression. I don't know if I can blame myself, being unfair to myself too. (Ana).*

Ana felt repulsed by one of Carlos's behavioral changes – namely, his frequent spitting – and was unable to sit and eat with him at the table. This also made her feel guilty about her father's dementia progressing.

The occupational therapist, using active and empathetic listening, validated Ana's feelings and guided her on the importance of recognizing the limits of therapeutic intervention and care.

> *One thing I'd like to tell you. You do everything possible for your father, and you also can't forget to recognize your own limitations so that you can continue caring for him. There's no such thing as ideal care; there's only the care that's possible for each family, and within what's possible for you, you offer the best care for your father. (terapeuta ocupacional ).*

Additionally, in the occupational therapy sessions, the fact that not all suffering can be alleviated was addressed, making it necessary to consider strategies to cope with its presence. Ana expressed gratitude for the support received and for the opportunity to share her distress and challenges.

## Discussion

The detailed assessment and intervention related to the occupations of the older adult and their caregiver constitute one of the main distinctions of occupational therapy in relation to other health professions. The specificity of occupational therapy is grounded in the promotion of health and well-being through support for participation in meaningful occupations that people want, need, or are required to perform (World Federation of Occupational Therapists, 2025).

Regarding the specificities of favela territories, there are factors that may impact both occupational performance and care. Ries & Thomson (2020) highlight that, in addition to social inequalities faced by vulnerable populations, there are barriers to access to basic human rights such as safety, health, and preservation of autonomy.

The scarcity or absence of essential services may contribute to *misthanasia*, defined as a process that anticipates death or prolongs pain and suffering, generally associated with the lack of access to health treatments and services (Castellani, 2025). According to the Brazilian Institute of Geography and Statistics (IBGE), in 2022, individuals born in favelas had a life expectancy reduced by 13 years solely due to living in such environments, being exposed to inherent vulnerabilities of the territory.

Continuing the analysis of the data, the results of this study evidenced the impact of environmental factors, both within the household and in the community, on the care and occupational performance of Carlos and Ana. Holmes & Joseph (2011) highlighted that physical barriers and the presence of violence negatively influence the functionality and social life of older adults, including restricting their mobility outside the home.

Issues related to personal factors, such as lack of financial resources, also interfere in the caregiving process. Studies conducted by Noronha et al. (2021) and Lima-Costa et al. (2016) assessed the relationship between socioeconomic factors and housing arrangements with limitations in Activities of Daily Living (ADLs) among non-institutionalized older adults. The results indicated that older adults in more vulnerable socioeconomic contexts and with lower levels of education present greater functional limitation but, paradoxically, receive less support for performing ADLs and Instrumental Activities of Daily Living (IADLs). This scenario reveals a structural inequality in access to care, often worsened by a lack of resources or, in some cases, the absence of a caregiver (Noronha et al., 2021; Lima-Costa et al. (2016)).

Occupational therapy practice in this study was guided by principles such as the promotion of autonomy, person-centered care – not focused solely on disease – and shared responsibility among professionals, caregivers, and the community. This intervention model aligns with contemporary guidelines in occupational therapy practice in Gerontology, which emphasize approaches that go beyond the biomedical paradigm, incorporating subjective, social, and cultural dimensions in the care of older adults with dementia and their family systems (Mohr et al., 2021; World Health Organization, 2017). Furthermore, the interventions were grounded in the principles of Palliative Care, which recognize the complexity of human suffering in its physical, emotional, social, spiritual, and occupational dimensions, valuing care centered on the person–family dyad (World Health Organization, 2023).

Based on the results, it was observed that the lack of adequate guidance contributed to the adoption of inappropriate strategies, such as physical restraint, highlighting the importance of technical and emotional support from the beginning of the caregiving process. Bathing has frequently been identified as one of the most challenging activities in the care of people with Alzheimer's disease (AD) (Kucmanski et al., 2016; Maresova et al., 2020; Konno et al., 2024). Difficulty in understanding the purpose of the activity may lead the older adult to perceive it as a threat or invasion of privacy, triggering resistance behaviors and emotional changes (Gitlin & Piersol, 2015).

Recent evidence indicates that specific caregiver training contributes to safer, more respectful, and person-centered care practices (Konno et al., 2024). In this context, occupational therapy intervention may involve both caregiver training and the

adaptation and modification of bathing activity steps, facilitating the older adult's participation (Bennett et al., 2019; Curnow et al., 2024; Smallfield et al., 2024).

This study showed the importance of occupational therapists recognizing that unequal social structures can influence possibilities for occupational performance and participation, restricting access to certain activities and contexts. Thus, occupational justice is a central element of occupational therapy practice in these settings (Townsend, 2022). According to the Gomes et al. (2021), occupational justice refers to the recognition of all people's rights to inclusive participation in daily occupations.

Smith et al. (2024), who investigated the role of occupational therapists in palliative care, particularly end-of-life care, within Compassionate Communities in Australia, highlighted the need to reorient professional practice considering territorial specificities, as well as to strengthen a practice more centered on occupational therapy identity and competencies in order to expand its contributions in this context.

The study findings revealed that the disease and its consequences may cause occupational impacts on caregivers, including routine changes, abandonment of meaningful occupations, and the need to modify how activities are performed. Based on caregivers' demands, there is a need to develop occupational therapy interventions focused on coping strategies, well-being, and encouragement of engagement in meaningful activities by caregivers themselves (Martínez-Campos et al., 2022; Micklewright & Farquhar, 2023). Other possible contributions of occupational therapy to caregivers are related to routine organization, occupational management, and the development of time-management strategies (Mattos & Kovács, 2020).

Given the difficulty in carrying out all sessions in person, remote interventions with the caregiver facilitated the care process. Telehealth practice for caregivers of people with dementia may help reduce emotional burden and stress, as well as improve the quality of care provided (Santana et al., 2018; Dadalto & Cavalcante, 2021).

The instrumentalization and guidance provided to caregivers may enhance the occupational participation of older adults with AD, as well as contribute to the management of behavioral and psychological symptoms of dementia. The Tailored Activity Program (TAP) is an intervention that highlights the importance of occupational therapists in guiding caregivers in the use of meaningful activities as a care strategy (Gitlin et al., 2021). The study by Kim (2020) evaluated artistic, musical, and sensory activities based on life memories in older adults with dementia, observing improvements in quality of life, reduction of depressive symptoms, and enhancement of cognitive functions.

It is emphasized that, in the context of irreversible diseases such as AD, care must be progressively adjusted, requiring technical preparation and continuous support for caregivers so that they can follow the transformations and respond to the increasing demands imposed by disease progression (Mataqi & Aslanpour, 2020). The irreversibility of the disease and of the associated functional and occupational losses may impose cumulative challenges on daily care, requiring not only practical reorganization but also emotional processing and continuous re-signification of strategies and established bonds.

Care-related challenges reinforce the reflection proposed by Garcia (2025), who questions the notion, widely disseminated in Palliative Care, that suffering becomes intolerable only in the absence of care. The author highlights that dimensions of suffering, especially those of an existential nature – such as loss of roles, anticipatory

grief, and transformation of family relationships –, go beyond the reach of technical or empathic interventions, however ethical and sensitive they may be.

It is also emphasized that there is a mismatch between the need for prevention and long-term care pathways, from AD diagnosis to end of life, which are often fragmented or even nonexistent (World Health Organization, 2017). This gap highlights the urgency of strengthening social and community support networks, such as Compassionate Communities, as well as intersectoral public policies capable of including vulnerable populations, especially in territories marked by structural inequalities and reduced state presence.

In this scenario, two recent normative frameworks stand out: Law No. 14.878/2024 (Brasil, 2024b), which establishes the National Policy for Comprehensive Care for People with Alzheimer's Disease and Other Dementias, and Law No. 14.843/2024, known as the "Care Law," which recognizes care as a right, work, and state policy, in addition to strengthening intersectoral actions and support for family caregivers (Brasil, 2024c). Thus, the findings of this study contribute to understanding care as an ethical practice that acknowledges the limits of what is possible, without relying on unattainable interventions. This stance avoids the pursuit of absolute solutions – which often intensify suffering – and aligns with contemporary approaches in Palliative and Compassionate Care, centered on the patient–family dyad.

## Conclusion

The study achieved its objective by describing the main occupational therapy assessments and interventions carried out in the care of an older adult and their caregiver, within the context of a life-threatening condition such as AD, and embedded in a favela territory marked by social vulnerability. The main occupational therapy approaches included empowering the primary caregiver through adaptation and organization of care occupations and routines for the older adult with AD, supporting caregiver self-care, encouraging participation in meaningful prioritized activities, and re-signifying and strengthening the emotional bond between both.

It is emphasized that the approaches used were shaped by socioeconomic, territorial, and political nuances of the environment, requiring the articulation of goals and therapeutic plans consistent with the lived reality.

This study may contribute to the advancement of occupational therapy research and practice in the field of Gerontology and related areas, especially in contexts involving vulnerable populations.

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**Authors' Contributions**

Julia Maria dos Santos was responsible for conceptualization, data curation, formal analysis, methodology, project administration, supervision, visualization, validation, writing – original draft, writing –, revision, and editing. Matheus

Rodrigues Martins was responsible for conceptualization, data curation, formal analysis, methodology, project administration, visualization, validation, and writing – original draft. Carolina Rebellato was responsible for writing – revision, and editing. Janaína Santos Nascimento was responsible for data curation, formal analysis, project administration, supervision, validation, writing – original draft, writing –, revision, and editing. All authors approved the final version of the text.

**Data Availability**
The data supporting the results of this study are available from the corresponding author upon request.

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