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# Hidden patients of Alzheimer's disease: an integrative review of occupational therapy assessment with caregivers

# Pacientes ocultos da demência de Alzheimer: uma revisão integrativa sobre a avaliação da terapia ocupacional com os cuidadores

# Pacientes ocultos de la enfermedad de Alzheimer: una revisión integrativa sobre la evaluación de la terapia ocupacional con los cuidadores

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The purpose of this article was to identify and analyze the scientific literature on the evaluation process of caregivers of elderly people with Alzheimer's dementia promoted by occupational therapists. We carried out an integrative review, considering the period from 2006 to 2016, in English, Portuguese and Spanish with the keywords: “caregivers” combined with “Alzheimer's disease”, “occupational therapy”, and “evaluation”. Information sources considered were: Scopus, Web of Science, MEDLINE/PubMed, CINAHL, PsycINFO ®, LILACS, SciELO, OTseeker and PEDro. 16 were identified. The results show that the articles were intended to identify caregivers’ perceptions about caregiving and about the services the elderly receive, the difficulties faced in daily life, on the quality of life, the strategies adopted and/or the needs to perform the task of care. The findings bring contributions to the development of therapeutic interventions to establish occupational supports for caregivers.

**Descriptors:** Occupational therapy; Alzheimer’s disease; Elderly; Caregivers.

O objetivo deste artigo foi identificar e analisar a produção científica sobre o processo de avaliação dos cuidadores de idosos com demência de Alzheimer promovidos pelos terapeutas ocupacionais. Foi realizada a revisão integrativa, considerando o período de 2006 a 2016, nos idiomas inglês, português e espanhol e, com os descritores: “cuidadores” combinados com “doença de Alzheimer”, “terapia ocupacional” e, "avaliação". As fontes de informação consideradas foram: Scopus, Web of Science, MEDLINE/PubMed, CINAHL, PsycINFO®, LILACS, SciELO, OTseeker e PEDro. Foram identificados 16. Os resultados mostram que os artigos eram voltados para identificar as percepções dos cuidadores sobre o cuidar e sobre os serviços que os idosos recebem, as dificuldades enfrentadas no dia-a-dia, sobre a qualidade de vida, as estratégias adotadas e/ou as necessidades para desempenhar a tarefa do cuidado. Os achados trazem contribuições para a elaboração de intervenções terapêuticas ocupacionais direcionadas ao estabelecimento de suportes para os cuidadores.

**Descritores:** Terapia ocupacional; Doença de Alzheimer; Idoso; Cuidadores.

El objetivo de este artículo fue identificar y analizar la producción científica sobre el proceso de evaluación de los cuidadores de ancianos con demencia de Alzheimer promovidos por los terapeutas ocupacionales. Fue realizada una revisión integrativa, considerando el período de 2006 a 2016, em los idiomas inglés, portugués y español y, con los descriptores: “cuidadores” combinados con “enfermedad de Alzheimer”, “terapia ocupacional” y, "evaluación". Las fuentes de información consideradas fueron: Scopus, Web of Science, MEDLINE/PubMed, CINAHL, PsycINFO®, LILACS, SciELO, OTseeker y PEDro. Fueron identificados 16. Los resultados muestran que los artículos buscaban identificar las percepciones de los cuidadores sobre el cuidar y sobre los servicios que los ancianos reciben, las dificultades enfrentadas en el día a día, sobre la calidad de vida, las estrategias adoptadas y/o las necesidades para desempeñar la tarea de cuidado. Los descubrimientos traen contribuciones para la elaboración de intervenciones terapéuticas ocupacionales dirigidas a establecer soportes para los cuidadores.

**Descriptores:** Terapia ocupacional; Enfermedad de Alzheimer; Anciano; Cuidadores.

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## INTRODUCTION

Alzheimer's dementia (AD)-most prevalent in the elderly is, from 2012, one of the public health priorities[1], for the impact that triggers in the lives of the person affected and their families, in their relations with the society and the health system[2].

Sick elderly people present gradually dependency on activities, from the most complex to the simplest, due to cognitive and behavioral changes specific of this disease[3]. This fact denotes the need for caregiver assistance and/or to perform tasks for the elderly[4].

The process of care can occur between family members, professionals and/or health institutions or social protection[5]. Their care in the family is more adopted by most of the families that have an elderly with dementia[6,7], so this role is assumed, almost exclusively, by feminine relatives[8].

By assuming the role of caregiver, there is a need to reorganize the routine of those who give and who get care and establish, daily, the priorities of each other.

This organization will consider the time when the elderly needs care, the caregiver's own interest activities, the need for changes in the caregiver's family dynamics, the network of support that the caregiver provides, the needs of changes in physical environment, the requirement to give up paid work and the difficulties to perform certain activities for the sick elderly[9-12].

The need to provide uninterrupted care, plan the future, deal with stress and conflict, administer medicines, financial and legal support, and manage behavioral inadequate situations, are situations that will be part of the daily life of the caregiver, which may affect their quality of life[12].

Responsibilities increase with the development of the disease, which increases the caregiver's emotional distress and work[13,14].

Although this care is of great benefit for the elderly with dementia, it can affect their family social interactions, their physical and/or psychic health, their finances and quality of life[14-16].

In front of the needs and challenges of care, several types of feelings -often ambivalent- emerge in this daily relationship[17]. In situations where the presence of negative feelings outweighs the positives, the caregiver needs to look for help or change the way they are offering care.

In the context of health actors that can intervene with AD patients, the occupational therapist is one of the professionals who understand the Alzheimer's type dementia as a family disease, which affects not only the patient but their surroundings, which considers such caregivers as: “hidden patients” of Alzheimer's disease.

Thus, it is important to train the caregiver to manage the stress[18], offer strategies for dealing with the behavioral changes of the elderly with dementia[19], and try to reduce the comorbidities that affect the family[20].

In this panorama, the aim of this article was to identify and analyze the scientific literature on the evaluation process of the caregivers of elderly with Alzheimer's dementia promoted by occupational therapists.

## METHOD

It is an integrative review[21], in which the corpus of the study consists of the national and international scientific production that shed light on the evaluation process with the caregivers.

The guiding question for the research was: which aspects related to the caregiver of the elderly with Alzheimer's does Occupational Therapy (OT) worries about? Do the purposes of this evaluation process favor the development of a network of social support to such families?

The timeframe considered from January 2006 to January 2016, and the searches were conducted in February and March 2016.

The selected information sources were: Scopus, Web of Science, MEDLINE/PubMed (via National Library of Medicine), Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO®, Latin-American and Caribbean

Literature in Health Sciences (LILACS), Scientific Electronic Library on Line (SciELO), Occupational Therapy Systematic Evaluation of Evidence (OTseeker) and Physiotherapy Evidence Database (PEDro).

Regardless the free access to the publications, we considered as inclusion criteria, the papers that addressed: 1) AD in elderly people; 2) the participation of occupational therapist as an author; 3) focus on evaluations with caregivers; and, 4) Portuguese, English and Spanish languages. As exclusion criteria, we discarded: 1) literature review; 2) AD in people younger than 60 years old; and, 3) congress abstracts, annals, editorials and previous notes.

The descriptors considered were: “caregivers” combined with “Alzheimer's disease”, “Occupational Therapy”, “evaluation” and their expressions in English and in Spanish, with the Boolean operators AND and OR.

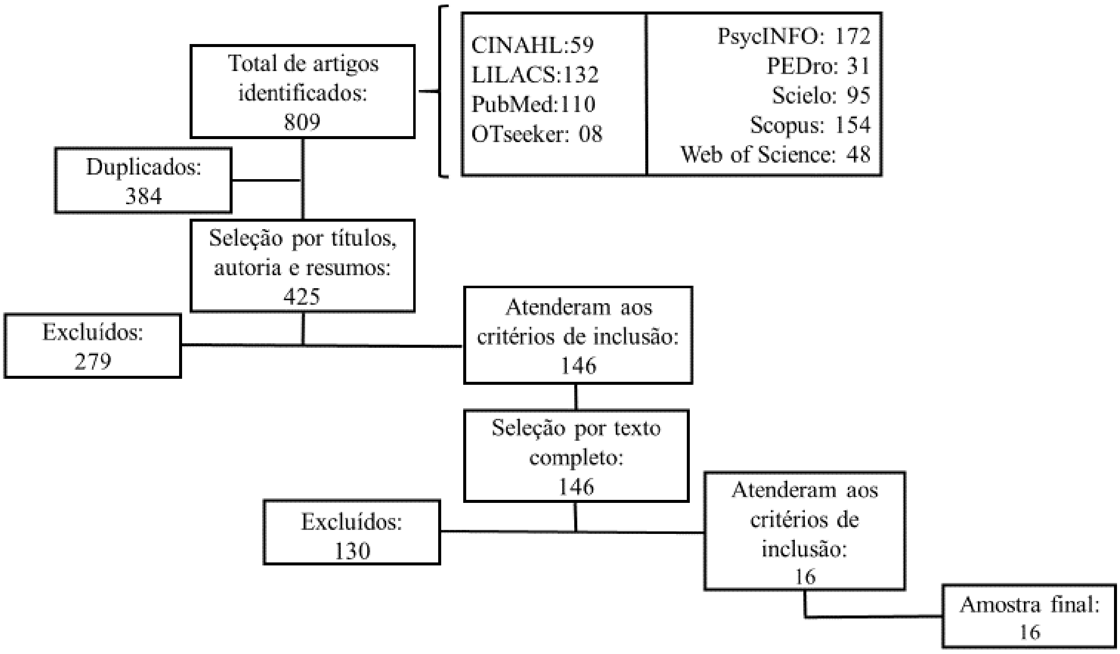
## RESULTS

The details about sources of information, descriptors and results are in Table 1. The documents were exported to online software EndNote ® Web to storage and organize them, for the selection process of the research corpus and they are in Figure 1.

**Table 1.** Sources of information, search expressions and results of the identified documents. March 2016.

| Sources of information | Search expressions | Results |
|---|---|---|
| CINAHL with Full Text (EBSCO) | ("occupational therapy" OR "Occupational therapy/methods") AND ("Alzheimer" OR "Alzheimer disease" OR "Alzheimer's disease")<br>AND (“caregivers”) | 27 |
| | AND (“assessment” OR “evaluation”) | 32 |
| LILACS | "Alzheimer" [Palavras] and "occupational therapy" [Palavras] OR "caregivers" [Palavras] and "Alzheimer disease" [Palavras] | 132 |
| MEDLINE/ PubMed (via National Library of Medicine) | (("occupational therapy"[All Fields] OR "Occupational therapy/methods"[All Fields]) AND ("Alzheimer"[All Fields] OR "Alzheimer disease"[All Fields] OR "Alzheimer's disease"[All Fields]))<br>AND "caregivers"[All Fields] | 47 |
| | AND ("assessment"[All Fields] OR "evaluation"[All Fields]) | 63 |
| OTseeker | ("occupational therapy" OR "Occupational therapy/methods") *AND* ("Alzheimer" OR "Alzheimer disease" OR "Alzheimer's disease")<br>*AND* ("CAREGIVERS") | 04 |
| | AND ("assessment" OR "evaluation") | 04 |
| PsycINFO | Any Field: "occupational therapy" OR "Occupational therapy/methods" *AND* Any Field: "Alzheimer" OR "Alzheimer disease" OR "Alzheimer's disease"<br>*AND* Any Field: "caregivers" | 67 |
| | *AND* Any Field: "assessment" OR "evaluation" | 105 |
| PEDro | “Alzheimer” OR “dementia” | 31 |
| Scielo | Tópico: (occupational therapy) AND Tópico: (Alzheimer disease) OR | 01 |
| | Tópico: (CAREGIVERS) ANDTópico: (Alzheimer disease) | 94 |
| Scopus | TITLE-ABS-KEY ( "Occupational Therapy" OR "Occupational therapy/methods" ) AND TITLE-ABS-KEY ( "Alzheimer" OR "Alzheimer disease" OR "Alzheimer's disease" )<br>AND TITLE-ABS-KEY ("CAREGIVERS" ) | 75 |
| | AND TITLE-ABS-KEY ("assessment" OR "evaluation" ) | 79 |
| Web of Science | Tópico:("occupational therapy" OR "Occupational therapy/methods") *AND* Tópico: ("Alzheimer" OR "Alzheimer disease" OR "Alzheimer's disease")<br>*AND* Tópico: ("CAREGIVERS") | 25 |
| | AND Tópico: ("assessment" OR "evaluation") | 23 |
| | **Total articles searched** | **809** |

**Figura 1** - Selection flow and results of identified documents. March 2016.



The total number of documents identified in the first analysis was 146. After fully reading the selected articles, 16 responded to the entire selection process. Of 130 articles deleted in the second phase, 28 were eliminated because of the methodology used; 63 were publications that did not involve the caregiver or did not present the evaluative part; 30 did not focused in the elderly with the and/or the OT; 05 articles were not in the languages of the selection criteria and 04 did not present the full article.

Subsequently, the articles were submitted to thematic categorization.

The articles are presented in Table 2, according title, authorship, year of publication, location and journals in which they were published.

Most publications were made in the years 2010 to 2015, 04 articles each year. Most of the articles had the Occupational Therapist (OT) as main author (n=14). Four articles are national. Of the 16 journals used in publications, only 06 are specific to the area of Occupational Therapy.

In turn, the analysis of publications is presented in table 3. The articles focus was to identify the perceptions of caregivers about the care and services that the elderly receives, the difficulties faced in day-to-day with the elderly, about the quality of life, the strategies adopted and/or the needs to perform the task of care.

**Table 2**- Corpus of the research according to title, year, authors, periodicals and country. March 2016.

| Nº | Title | Year | Authors | Journals | Country of the Study |
|---|---|---|---|---|---|
| 01 | Living with a person with Alzheimer's disease: Experiences related to everyday occupations | 2006 | PERSSON, M.; ZINGMARK, K.[22] | Scandinavian Journal of Occupational Therapy | Sweden |
| 02 | Relationship between perceived burden of caring for a family member with Alzheimer's disease and decreased participation in meaningful activities | 2009 | HWANG, J.L.E. et al.[23] | Occupational Therapy in Health Care | USA |
| 03 | Perception of the quality of life of the elderly with dementia and their family caregiver: evaluation and correlation. | 2009 | INOUYE, K. et al.[24] | Revista Latino-Americana de Enfermagem | Brazil |
| 04 | Caregivers of elderly with dementia: socio-demographic profile and daily impact | 2010 | NOVELLI, M.M.P.C.; NITRINI, R.; | Revista de Terapia Ocupacional da USP | Brazil |

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| | | | CARAMELLI, P.[11] | | |
| 05 | The influence of neuropsychiatry and functional changes on quality of life in Alzheimer's disease | 2010 | NOVELLI, M.M.P.C.; CARAMELLI, P.[25] | Dementia & Neuropsychologia | Brazil |
| 06 | Quality of life of the elderly with Alzheimer's disease: comparative study of patient and caregivers' report | 2010 | INOUYE, K. et al.[26] | Revista Latino-Americana de Enfermagem | Brazil |
| 07 | The power of the social environment in motivating persons with dementia to engage in occupation: Qualitative findings | 2010 | TEILELMAN, J; RABER, C.; WATTS, J.[27] | Physical & OT in Geriatrics | USA |
| 08 | The design of intelligent in-home assistive technologies: Assessing the needs of older adults with dementia and their caregivers | 2011 | CZARNUCH, S.; MIHAILIDIS, A.[28] | Gerontechnology | Canada |
| 09 | Effects of cognitive function and depressive mood on the quality of life in Chinese Alzheimer's disease patients in Hong Kong | 2011 | CHAN, I.W.P. et al.[29] | Geriatrics & Gerontology International | Hong Kong |
| 10 | Quantitative analysis of formal caregivers use of communication strategies while assisting individuals with moderate and severe Alzheimer's disease during oral care | 2013 | WILSON, R. et al.[30] | Journal of Communication Disorders | Canada |
| 11 | Indicators of perceived useful dementia care assistive technology: caregiver's perspectives | 2014 | MAO, HF. et al.[31] | Geriatrics and Gerontology International | Republic of China: Taiwan |
| 12 | Distance caregivers of people with Alzheimer's disease and related dementia: A phenomenological study | 2014 | EDWARDS, M.[32] | British Journal of Occupational Therapy | USA |
| 13 | Anxiety in family caregivers of hospitalized persons with dementia | 2015 | BOLTZ, M. et al.[33] | Alzheimer Disease Association Disorders | USA |
| 14 | Exploring the need for a new UK occupational therapy intervention for people with dementia and family caregivers: community occupational in Dementia (COTiD) | 2015 | HYNES, S.M. et al.[34] | Aging and Mental Health | United Kingdom |
| 15 | Spousal caregiver perspectives on a person-centered social program for partners with dementia | 2015 | HAN, A.; RADEL, J.[35] | American Journal of Alzheimer's Disease & other dementias | USA |
| 16 | Family caregivers for people with dementia and the role of occupational therapy | 2015 | EDWARDS, M.[36] | Physical & Occupational Therapy in Geriatrics | USA |

**Table 3.** Occupational therapeutic evaluation process aimed at elderly people. March 2016.

| Nº | AUTHORS | OBJECTIVS | METHODOLOGICAL DESIGN | OUTCOMES | LIMITATIONS OF THE STUDY |
|---|---|---|---|---|---|
| 01 | PERSSON; ZINGMARK, 2006[22] | To describe how wives who take care of their partners with AD theirs perceive their lives. | Qualitative Research.<br>Participants: 8 wives<br>Data collection: Individual narrative interviews | 1) Lead to a life of adjustments in planning, organization and performance of the routine<br>2) The support of colleagues, neighbors and relatives is of great value.<br>3) They perceive joy, dignity when they help the demented.<br>4) The importance of doing things without the patient works as a space to breathe and rest, relax and break the routine.<br>5) The changes in the elderly's personality generate feelings of loss, distress, abandonment and loneliness in the caregivers. | Small sample<br>The subjectivity of the researcher is part of the process of the results interpretation |

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| 02 | HWANG et al., 2009[23] | To investigate, between family caregivers of people with DA, the correlation between caring and participation in activities. | Cross-descriptive study.<br>Participants: 54 caregivers.<br>Data collection: The questionnaire with perception of the workload, participation in significant activities, personal/demographic data | 1) The least impacted area: selfcare<br>2) Increased workload reduces caregiver engagement in meaningful activities.<br>3)care load associated with the reduction of opportunities, restriction of personal time and freedom and lack of supports network. | Questionnaire without validity and reliability.<br>Small sample<br>It is not known the stage of the disease |
| 03 | INOUYE et al., 2009[24] | To assess the perception of quality of life of the elderly with dementia and their family caregiver and identify correlations | Study: Descriptive Exploratory, transversal<br>Participants: 53 elderlies and 53 caregivers<br>Data collection: Quality of life evaluation scale in Alzheimer's | 1) Perception of the quality of life: Caregivers find more satisfaction in social relationships.<br>2) All caregivers considered their families as good or excellent, with good marriage and friendship.<br>3) Caregivers show dissatisfaction with their financial situation, health and general life. | Not present |
| 04 | NOVELLI; NITRINI; CARAMELLI, 2010[11] | To know the demographic profile of caregivers of elderly with AD. Identify difficulty in the daily task of care. | Cross-descriptive study.<br>Participants: 50 caregivers/family of 2 outpatient clinics<br>Data collection: Evaluation created based on the objectives | 3) 75,6% dos cuidadores relatam sentimentos negativos, com índice maior na fase inicial da doença (fase da adaptação).<br>1) The network of supporters is formed by family members, women (culture), who are aging. The knowledge of the disease is restricted to medical information (early stage), brochures and Internet<br>2) The number of hours spent with care increases with the progression of the disease and the number spent with leisure is reduced.<br>3) 75.6% of caregivers report negative feelings, greater in the initial phase of the disease (adaptation phase). | Not reported. |
| 05 | NOVELLI; CARAMELLI, 2010[25] | To evaluate the influence of the symptoms of AD in the quality of life (QoL) of patients and caregivers | Type of study: Transversal.<br>Participants: 60 informal caregivers, 60 elderly people with AD.<br>Data Collection: QOL-AD; Physical and Instrumental-Self Maintence Scale; NPI; GDS and CSD | 1) QoL in moderate dementia is lower than initial dementia, both for the elderly and the caregiver.<br>2) There is no correlation between QoL and cognitive damage. Other variables can influence (behavioral change, depression) | The use of transverse drawing (should be longitudinal).<br>Sample size.<br>Only focused on the initial and moderate stage. |
| 06 | INOUYE et al., 2010[26] | To compare the report of the patient and their family caregiver on the general perception and each dimension of QoL of | Type of study: Descriptive exploratory, cross-sectional, with non-probabilistic sampling.<br>Participants: 53 elderly people and 53 primary caregivers. | 1) “memory” and “you in general” show statistical disparities<br>2) did not present significant divergence: housing, leisure, physical health, family, marriage, ability to do chores, friends and life<br>3) family, marriage and housing were overestimated and can be related to the fact that the family member considers themselves good for the elderly.<br>5) physical health, disposition and ability to do tasks are identical. The other items seem to be underestimated by the relative | Not present |

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| | | the elderly with AD | Data collection: Quality of life evaluation scale in Alzheimer's disease | | |
| 07 | TEILELMAN; RABER; WATTS, 2010[27] | To show whether social environment is a potent factor in facilitating the engagement of people with AD. | Qualitative research.<br>Participants: 02 elderly people with the resident of a support house.<br>Evaluations: Mini-Mental and interview with staff and family | 1) The social environment is the indicator for engagement in occupations.<br>2) Caregivers need to be aware that their attitudes and behaviors model the social environment and contribute to motivate the customers to engage in occupations. | Not reported. |
| 08 | CZARNUCH; MIHAILIDIS, 2011[28] | To assess which DA challenge elderly people, which are difficult for the caregiver help, what the role of AT and what characteristics should have | Study: cross-descriptive.<br>Participants: 106 Caregivers<br>Data collection: Online questionnaire. | 1) Caregivers think that elderly people with dementia have partial capacity to complete some basic DA, but not for IDA.<br>2) Caregivers end most of the DA and ID (it's easy), but dressing, bathing, washing hands, brushing teeth are more challenging to help.<br>3) The assistive products could reduce caregiver's burden and increase the independence of the elderly, but the design and interfaces should be easy to use. | Sample should be bigger.<br>Focused on caregiver and did not question elderly people with dementia |
| 09 | CHAN et al., 2011[29] | To investigate the effects of cognitive function and depressive mood on quality of life | Type of study: Transversal.<br>Participants: 111 patients with AD and 65 caregivers.<br>Evaluation: semi structured interview, computed tomography and Cantonese Chinese QOL-AD, GDS, I. | 1) There is no difference in QoL-DA between patients and caregivers.<br>2) Moderate correlation was observed among patients and caregivers, in the fields of physical health, humor, living conditions, family and marital relationship, friendship, me, money and life in general.<br>3) For caregivers, there is also significant association between QoL-DA and Mini-Mental and patient depression scale and number of chronic caregivers' diseases.<br>4) The severity of the cognitive damage affects the QoV in the patient's perspective, but not in the caregiver's perspective. | Only outpatients that lived in the community were recruited. |
| 10 | WILSON et al., 2013[30] | To examine the communication strategies used by formal caregivers while assisting residents with AD (moderate or severe) during tooth brushing. | Study: Observational and transversal.<br>Participants: 13 residents with AD and 15 caregivers.<br>Data collection: ADCS-ADL-SIV.<br>Frequency: About 6 brushing/patient sessions, for 2 weeks. | 1) AD moderate with higher functional capacity than advanced.<br>2) 85% of communication strategies were focused on the task, 10% in social strategies and 5% in mixed strategies.<br>3) in the communication strategies with severe AD: use of a proposition in time (a direction, instruction, an idea of the time), use of the name of the resident, encouraging comments, use of repetition paraphrased, use of closed questions.<br>4) for the moderate AD, the caregivers used: A time proposition, use of closed questions, use of paraphrased repetition and use of 2 propositions and use of verification questions and encouraging comments in that order. | Small Sample.<br>No vision and hearing tests were performed.<br>In addition, reactivity can occur because caregivers can change their typical routine behavior when they are in the presence of a researcher. |
| 11 | MAO et al., 2014[31] | To investigate the perception of caregivers and experts on the usefulness | Study: cross-descriptive.<br>Participants: 75 dyads were evaluated in Phase 1.<br>In phase 02, 7 family caregivers and 14 | 1) From the experts' perspective, the high utility includes allowing accident prevention, intuitive interface, being familiar, easy to use and simplify activities, and the low-utility indicator was suggestions to the customer.<br>2) Caregivers prefer technologies that prevent accidents on those that inform about the occurrence of an accident or just how to handle the consequences. They care about accessibility and cost<br>3) The preservation of privacy and autonomy are also essential for analyzing the assistive products. | Patients' perspective was not representative because the questionnaire was very difficult for them to answer. |

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| | | of assisted products for people with dementia. | professionals (including OT and physio) were composed by the experts | | The caregivers were volunteers, and this may have contributed to better acceptance |
| 12 | EDWARDS, 2014[32] | To explore the experience lived in distance care and examining how health professionals can better help these caregivers. | Qualitative research.<br>Participants: 10 Caregivers (9 women) lived distant. Care was given in person and, most of the time, at a distance. They were caregivers for over six months.<br>Data collection: 2 Interviews | 1) Caregivers spend a lot of time monitoring and looking for services for their sick relative. That demands commitment.<br>2) Caregivers would like health professionals to have more initiative to communicate about the patient<br>3) Cognitive decline affects them. Health professionals are also sources of concern and frustration for not fully trusting.<br>4) The physical health of caregivers is impacted if they do not eat appropriately or do exercises. | Small Sample. Only one man was interviewed |
| 13 | BOLTZ et al., 2015[33] | To examine the factors that contribute to the anxiety of caregivers of hospitalized demented. | Qualitative and quantitative research (descriptive).<br>Participants: 50 caregivers.<br>Data collection of caregiver: Demographic data, mutuality Scale; MSCI, Anxiety Hospital and depression Scale. | 1) Caregiver: 30% with moderate to severe anxiety.<br>2) About the qualitative data related to the experiences lived by the caregivers: increased tension in hospitalization, interferes in the routine, in time, increases the demand for care.<br>3) About the concerns of caregivers: with the loss of cognitive and physical function, with falls, with the non-identification of pain frames, with discharge; keep vigil; need to be listened to; training caregivers diminish the concern | There may be other factors that contribute to anxiety and weren't measured, such as personality, style of confrontation, health of family caregivers. |
| 14 | HYNES et al., 2015[34] | To explore how COTiD intervention from Holland can be useful for the context of British services and how it can be adapted | Qualitative research<br>Participants: 39 people.<br>18 elderly and 21 caregivers.<br>Data collection: 3 focal groups<br>COTiD: Community occupational therapeutic intervention for dementia | 1) Three themes were highlighted in the focal groups: losing and living with dementia, how to help us and consistency and continuity.<br>2) The caregivers support the implantation, but they wanted COTiD to be more flexible, consistent and appropriate to the existing demands. And to include caregiver as a partner for the intervention's offer.<br>3) Most of them suggest improvements: more flexible approaches to time and number of sessions, as well as the intervention objects in the specific needs of the person with AD and their caregiver. | Participants talked about a hypothetical situation because they had no thorough knowledge of what COTiD was. |
| 15 | HAN; RADEL, 2015[35] | To explore the experiences and impact of a social activity program (KUMC PAIRS) for people with dementia and their family caregivers. | Qualitative research.<br>Participants: 5 caregivers.<br>Frequency: 2 attendances per month for 8 months.<br>Data collection: Interviews in depth | 1) They report that the program supports the needs and desires of caregivers and assists in the social participation of dyad, as well as in engaging in meaningful activities.<br>2) The program gives the opportunity to engage, together with the relative with AD or not, in family histories and interests and remembering good memories.<br>3) Caregivers have a strong desire to engage their families in very pleasant social opportunities with other members of the community. | The research was done long after the end of the program KUMC PAIRS and if it has been done earlier could better capture the sustained benefits of the program. |
| 16 | EDWARDS, 2015[36] | To explore the care experiences | Qualitative research.<br>Participants: 10 caregivers. | 1) Care leads to a great personal and challenging change.<br>2) Care leads to feelings of stress, guilt and isolation. There is a decrease in time with friends, family, selfcare and leisure. "Changes alter their biography and identity." | The study was done in a small geographical area of |

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| | (challenges and resources) and how occupational therapy can help caregivers | Only 2 elderly people with dementia lived with the caregivers. Data collection: Interviews | 3) Support groups, education, relaxation techniques, stress management can help caregivers<br>5) Participants experience lack of support from friends and family members. The supports come from a staff of asylums, or from health places where they go, Alzheimer's association, religious groups, co-workers. | North Carolina. All the participants were Caucasian. The data cannot be generalized by the design of the study adopted. |

## DISCUSSION

The caregiver is the most important family support to confront the limitations that arise from the illness and imposed to the elderly[37]. The actions of the caregivers were considered key indicators to motivate older people engage in ocupações27.

Only one study was directed to investigate specifically the formal caregivers, trying to identify communication strategies they adopt when the elderly performs selfcare activities[30].

Most of the studies investigated the experiences of informal/family caregivers, because culturally, care has always been provided at home[6].

Choosing to take care of the elderly within the family life can also be related to the need to reduce costs, because the family would have to spend many expenses to keep the elderly in health care institutions[38]. The society still sees the institutionalization as a form of abandonment and neglection towards the elderly[39]. Thus, the mode of care adopted by the majority is the informal, in which a family member takes on more responsibility to provide care.

In this review, the research that describe the profile of caregivers highlighted: mostly women (wives and daughters), assuming this function, such as other studies confirm[11,40].

This fact is given due to cultural issues, in which the woman was more available to provide care, because they were not inside the labor market[41]. However, although the family conformation has changed, they still play this new role in their lives, and associate the task of taking care with their everyday tasks: work, leisure, self-care, household activities and taking care of their own family.

Another aspect about the profile[23,33], refers to the caregivers' age. Most of them are middle-aged or older. For these issues and the normal process of aging, one more duty can generate for these caregivers a physical and emotional distress[14] that impact on their social life, health and well-being.

Faced with the needs and challenges of care, these experiences can be lived in diverse ways. Some studies[22-25,27,33,34,37] explore the experiences of caregivers during the production of care. The perception of caregivers is related to adjustments in personal life[22], restrictions for work and leisure activities that worsen with the illness advance[1,23,36].

In only one study[23] the caregivers only do not report changes in their self-care, because the time available is enough to accomplish them. The negative experiences lived during care are related to the lack of support for caregivers, feelings of abandonment, reduction of social relations, the number of hours spent with care, degree of overload, number of tasks they need to perform for the elderly, because the elderly's changes in behavior and sleeping reduction[11,22,23,36].

For informal caregivers who do not live close to the sick person, the monitoring at a distance and the organization of services to be provided were associated with fatigue and distress[32].

Negative experiences can lead to caregivers' health and well-being reduction, because they need to deal with stress, provide care, support the sick person and handle conflicts that can appear daily[12].

The symptoms of depression, anxiety, low self-esteem, apathy and emotional irritability, as well as hypertension, digestive disorders and respiratory diseases affect the caregivers' health due to the overload of work[42].

Sleep disorders in caregivers are related to work overload or extended periods of time awaken to take care of the elderely[16].

Although most of the studies were directed to negative feelings assigned by the arduous and uninterrupted task of care, a study[22] pointed out the positive experiences attributed to it.

Family members report joy in being able to take over this function, to be close to their relative with AD and the sense of dignity with the accomplishment. The support of neighbors and relatives appears as a factor that assist in the care plan and organization and contributes positively to the caregivers' well-being[22].

The perception of care is closely related to the assessment of their quality of life[12,37]. In other studies[24,]26, the quality of life was considered by the caregivers as good since they said to have excellent family, good marriage and for friendship, but the negative perception was associated with the overwork, financial situation, health problems and feelings of helplessness.

The more advanced the disease is, the worse the quality of life (QoL) is, but this relationship was not associated with cognitive damage. Non-correlation does not imply that the damage does not affect QoL, but other factors may have more influence. The depressive symptoms, behavioral changes and performance in the IDA were related to the perception of the quality of life[25].

The same relationship between low quality of life and depressive symptoms appears in another research[29].

To mitigate negative feelings and strengthen positive emotions in the relationship between dyad, patient and caregiver, the possible solutions observed were: access to information about the disease, support groups, training to deal with elderly people[11,33,34-36], access to technologies that will empower the elderly to engage more in their occupations[28,31], be recognized for being the greatest connoisseurs of the patient's life and have a differentiated listening for their experiences[27,33], relaxing techniques[36] and participate in occupational therapy programs [23].

These strategies contribute to understand the behavior of the elderly, the choice of management possibilities, the decrease of negative feelings before the patient and the improvement of the quality of care offered[11].

In other studies, the psychoeducational, psychosocial and psychotherapeutic strategies (non-pharmacological interventions) are evaluated as reducing the burden of caregivers, because they provide emotional support and can help the relative for the daily decisions with the sick person[5,43].

International researches in occupational therapy list actions to promote caregivers' health and training, through groups of emotional support, stress management and problem-solving groups. These actions were effective in reducing comorbidities that affect family members, increasing the affective ties and reducing the risk of institucionalization[20].

Understanding the strategies already adopted, together with the caregivers' awareness of the influence of their behavior in the elderly participation, contributes to elaborate an appropriate care plan for the dyad.

This understanding also reinforces the importance of training and other educational strategies, as they can facilitate and engage elderly people with dementia in occupations, as well as mitigating the overwork of the uninterrupted task of care.

In the evaluations focused on caregivers, two studies were found in which occupational therapists investigated the perception of caregivers about the programs offered[34,35]. Family members report that the benefits of the support received result in increased ties between the elderly and caregivers, remembering good memories and new social interaction provided by the progrem[35] and contribute to increase the elderly's skills to engage in occupations.

The investigations of the caregivers' perceptions about the recommendations of assistive products for the patient are also part of the concerns of occupational therapists who work with the elderly with dementia and their respective caregivers,

The caregivers perceive as useful the products that are easy to use, with simple, accessible design and reasonable cost. They prefer technologies that prevent accidents to technologies that report something after an incident[31]. In accordance with the findings, Angels and Regolin[44] inform that the products of low and medium technology -mobile, stopwatch, electronic agenda- have high acceptance, because they are easy to acquire and to use with patients with dementia. Adherence to devices that aid in daily life activities or cognition depends on the caregivers' incentive, support and assistance[8,31].

It is understood, by the reviewed studies, that women suffer more overwork and health commitments because of the function they assume. At the same time, there weren't studies with men caregivers to assess their overwork and analyze what functions are assumed by them. It is important to remember that, by the changes in the profile of the family nuclei, the time available to take care of the diseased is increasingly scarce, either by the reduced number of children or by the jobs they have[45].

For the foreseeable future, it seems that the trend is toward a change in the modality of caring for the elderly with dementia. In this sense, it is reinforced the need to have elderly care institutions appropriate to the needs of the person with dementia, formal caregivers trained for this specific population and/or other support networks to meet the elderly.

Furthermore, it is essential to investigate the organization of the care network for those elderly people who do not have family.

The elderly with dementia who lives alone in their communities attach to the closest neighbors and friends the function of primary caregivers[46]. In this context, the concerns are for the time they remain alone, without assistance, with risks related to home security.

There is a need to think about increasing the number of studies that investigate these caregivers who are not family members, to know about the time available to produce care, the functions they can assume, the strategies they adopt and the perceptions about the functions they assume.

Occupational therapists who work with Alzheimer's dementia have a broad approach to elderly care by inserting the caregiver into their evaluation plan.

A question that remains for reflection is: since caregiver attention is an interdisciplinary area, what are the points of convergence and what are the differences between the performance of the OT and other health professionals? Furthermore, these questions remain: does the attention given to these caregivers brings enough clarity for the type of care they carry out? Under what conditions can blood ties compensate the lack of good training?

Understanding the stressors and rewarding factors that arise from the process of caring, as well as the strategies adopted in the daily relationship and the needs to obtain the caregivers health and welfare, is essential to pressure towards the implementation of public policies that promote the necessary social support for the sick elderly, their families and the society, so that embraces effectively the integral, humanized and universal care for the elderly with Alzheimer's disease.

## CONCLUSION

In evaluations addressed to caregivers, occupational therapists worry about the perception of the family members about caring, with a greater focus on the negative aspects of this continuous and uninterrupted task.

These reactions influenced the care provided, well-being and their health. The strategies adopted by caregivers to reduce the workload were also investigated.

Access to information about the disease, support groups, support network and training to deal with the elderly, appear as elements that protect the health and quality of life of these informal workers.

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