

Systematic review of home-based occupational therapy interventions to improve the quality of life of people with moderate and severe dementia and their caregivers

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Abstract

Introduction: The main factors that affect the quality of life (QoL) of people with advanced dementia are related with Neuropsychiatric symptoms (NPS) of dementia, pain and the environment. Many researches demonstrate that occupational therapy interventions may improve the QoL of people with dementia and are cost-effective. Purpose: The purpose of the study is to search and evaluate articles regarding the effectiveness of home-based occupational therapy interventions and the ways that they affect the QoL of people with dementia and their caregivers. Method: Research articles were searched on The Cochrane Library, PubMed and Embase databases. The articles were published in English, during the period 2020 to 2023. The search used the keywords:

(Occupational Therapy AND Dementia), (Dementia AND Quality of Life), (Moderate OR Severe OR Advance AND Dementia AND Home-Based Interventions), (Activities of Daily Living AND Dementia AND Interventions), (Non pharmacological Interventions AND Dementia), (Environmental Modifications OR Home Modifications AND Dementia). Results: Four intervention studies with 671 participants met the inclusion criteria. All were home-based interventions with individuals in the moderate and severe stages. Interventions included training and counseling in modifying environments to prevent falls, tailored activity program and multicomponent intervention established by a psychologist, an occupational therapist, a social worker, a psychiatrist and a volunteer/unpaid family helper. Conclusions: The findings highlight that the provision of NPSs assistance, the education of caregivers and the modification of the environment may have a positive effect on the QoL of the person with dementia and the caregiver. QoL was not measured with a specific test in the studies so as to give reliable results. Occupational therapy is a key part of the intervention team, contributing with the knowledge it has in the specific fields.

Keywords: Occupational Therapy, home-based interventions, moderate and severe dementia, Quality of Life.

Introduction

Over 55 million people worldwide live with dementia. In the UK there are over 885,000, 60% of whom are in the advanced stages of the disease. In the advanced stages of the disease people need a lot of help in carrying out Basic Activities of Daily Living (BADL). Sometimes people with dementia need support in performing the ADL (Backhouse, Killeth, Mioshi, & Khondoker, 2023). Interventions for people with moderate and severe dementia aim to reduce agitation and improve people's wellbeing. It is essential that interventions for people with dementia are organized according to the severity of the disease (Tanaka et al., 2021). Neuropsychiatric symptoms (NPS) of dementia are major problem in dementia care, as almost every patient with moderate to severe dementia develops at least one of them. NPS are not only associated with clinical deterioration in people with dementia but also with a high level of caregiver burden (Rangseekajee et al., 2021).

Dementia is the most common cause of admission to care facilities. QoL deteriorates after admission to care facilities (Howard et al., 2021). QoL in people with dementia is usually defined by a framework that integrates cognitive functions, performance of ADL, social interaction and mental wellbeing (Henskens et al., 2019). In people with dementia, demographic factors do not seem to have a strong effect on QoL, whereas in contrast, NPSs, such as depression, seem to be more responsible and affect QoL (Farina et al., 2020). Studies on the factors affecting QoL in severe dementia have shown that there is an association between dementia NPS, pain and environment. The study by Nagata et al, (2022) suggests that providing NPS and pain relief to people with advanced dementia may improve their QoL. Sleep-wake disorders occur in 60% of people with dementia and are associated with increased comorbidity, mortality and poor QoL (Hodgson et al., 2021). Hearing and vision impairments are more common in people with dementia than in healthy older people. Such impairments negatively affect individuals' QoL, behavior and cognition, as

well as placing a burden on health, social and informal care (Leroi et al., 2020).

The priority for older people, including people with dementia, is to remain independent in their own homes (Jeon et al., 2020). Supporting people with dementia to stay in their own homes is more enjoyable for them and is less costly than staying in care homes (Clemson et al., 2021). Non-pharmacological, complex, individualized interventions can have a positive effect on cognitive functioning, the ADL and on delayed admission of people with dementia to care facilities, as well as improving the wellbeing of caregivers (Burgess et al., 2021). The level of involvement of individuals in activities has a significant impact on patients' behavior and emotions (Tanaka et al., 2021).

Occupational therapy interventions usually focus on daily functioning, the ADL, modification of environment and activities, cognitive training and education of the caregiver (Schmid et al., 2015). Over 75% of occupational therapists recommend retraining people with dementia in the ADL (Nott, Barden, Chapparo & Ranka, 2020). For specific diseases, such as dementia, stroke and Parkinson's disease, studies show that occupational therapy interventions improve people's QoL, performance of daily activities and are cost-effective (Bolt, Ikking, Baaijen & Saenger, 2019). In home-based Occupational Therapy, studies that have been carried out include: The Community Occupational Therapy for people with Dementia (COTiD) study in the Netherlands. People with dementia and caregivers learned to choose and prioritize important and meaningful activities that they wanted to improve. They were trained to make the best use of compensatory and environmental strategies to improve the performance of daily activities. In the Occupational Therapy intervention group, the functioning of people with dementia improved significantly compared to the control group. The results of the study showed that the intervention group had significantly better QoL for people with dementia at 6 weeks compared to the control group. Also, the mood of the individuals and caregivers, as well as their sense of self-control improved significantly (Graff et al., 2006, Graff et al., 2007). Another study is the Care of Persons with Dementia in their Environments (COPE). The project, carried out in the USA, aimed to modify stressful environmental factors to reduce sensory, motor and cognitive demands on the person with dementia. Occupational therapists trained the caregivers to modify the home environment, the ADL, the way of expression and communication. In addition, they trained caregivers to develop problem-solving strategies to find solutions. The results of the study showed statistically significant improvements in the functionality of the experimental group compared to the control group. Caregivers reported "big gains" in terms of several areas of the project, including better care management and keeping people at home (Gitlin et al., 2010). The Tailored Activity Program (TAP). The program seeks to reduce NPSs through tailored activities that match the patients' abilities. Occupational therapists observed the environmental characteristics and assessed the abilities of people with dementia. They identified three activities and developed instructions for each. Caregivers were trained in stress reduction techniques (e.g., deep breathing) and practiced the specific activity. The results of the study showed a significant difference between the groups in the incidence of NPS. Caregivers reported fewer hours of employment with the patient and fewer hours of work than those in the control group. They also reported greater self-control, better self-efficacy and greater use of

simplified techniques (Gitlin, Winter, Burke, Chernett, Dennis & Hauck, 2008).

Method

The design and completion of the present study was carried out through the search of articles in the electronic databases PubMed, Embase and Cochrane Library, having as publication date from 2020 until 2023. The key words were the following: (Occupational Therapy AND Dementia) (Dementia AND Quality of Life) (Moderate OR Severe OR Advance AND Dementia AND Home-Based Interventions) (Activities of Daily Living AND Dementia AND Interventions) (Nonpharmacological Interventions AND Dementia) (Environmental Modifications AND Dementia) (Home Modifications AND Dementia). The search strategy is presented in table 1.

Inclusion and exclusion criteria

We included articles that met the following criteria:

- intervention studies
- Studies published in scientific journals
- Studies in the English language
- Studies published from 2020 to 2023
- participants were in the Moderate and severe stage of dementia
- home based Interventions
- Non-pharmacological interventions

We excluded articles that met the following criteria:

- Systematic reviews and meta-analyses
- Studies that included only mild dementia stage or mild to moderate dementia stage
- Palliative care
- Interventions in rehabilitation centers
- Interventions in elderly care units

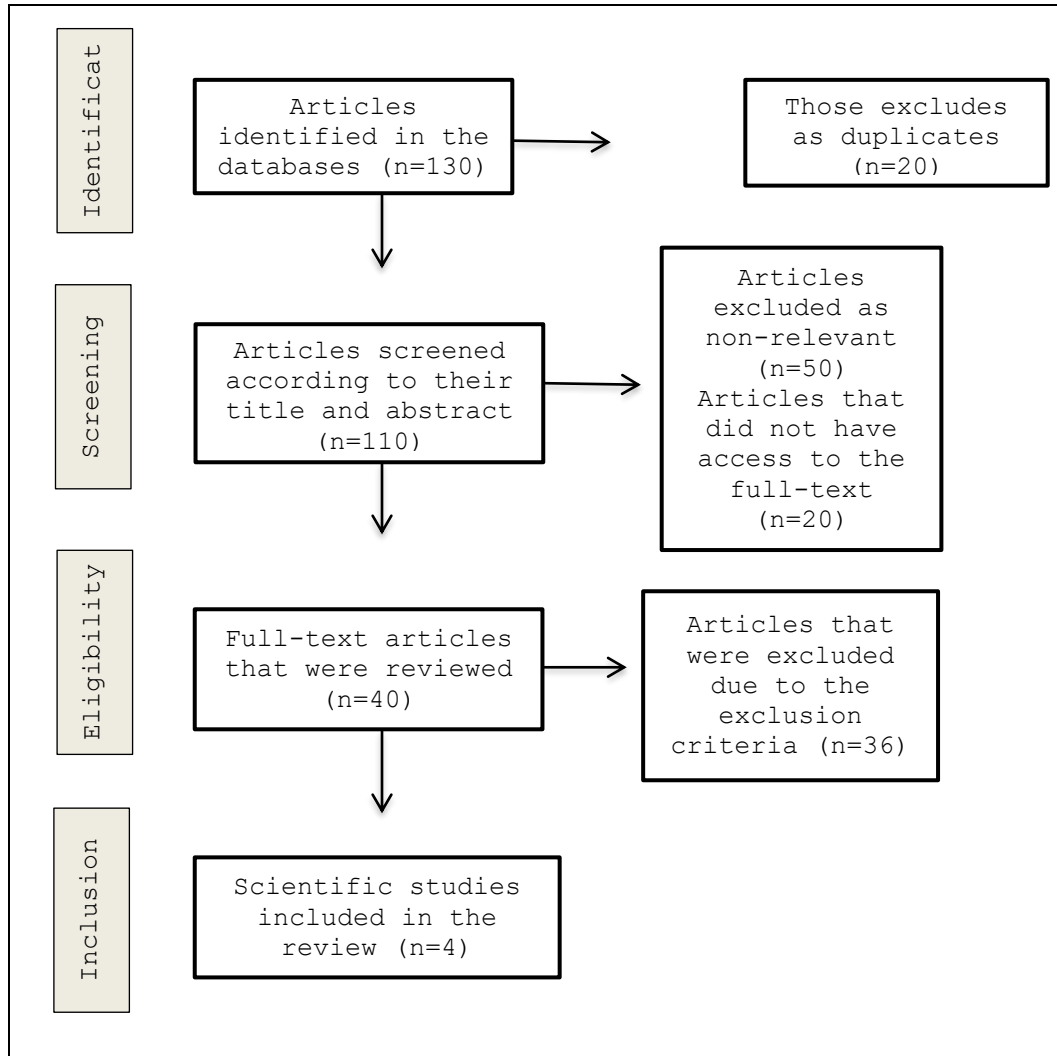
Table 1. Search strategies and databases

Keywords	Databases	Results
Occupational Therapy AND Dementia	PubMed	575
	Embase	769
	Cochrane Library	100
Dementia AND Quality of Life	PubMed	2948
	Embase	7721
	Cochrane Library	759
Moderate OR Severe OR Advance AND Dementia AND Home-Based Interventions	PubMed	283
	Embase	449
	Cochrane Library	216
Activities of Daily Living AND Dementia AND Interventions	PubMed	2121
	Embase	2948
	Cochrane Library	374
Non-pharmacological Interventions AND Dementia	PubMed	603
	Embase	836
	Cochrane Library	74
Environmental Modifications AND Dementia	PubMed	120
	Embase	190
	Cochrane Library	5
Home Modifications AND Dementia	PubMed	37
	Embase	1228
	Cochrane Library	60

Selection of studies

Through searching the databases and matching the search terms, 130 studies were identified. Of these studies, 20 were excluded as duplicates. Records excluded as irrelevant were 50 and studies that did not have full text access were 20. The full-text articles evaluated were 40 and the studies included in the study according to the inclusion and exclusion criteria were 4. The above results are also described in figure 1.

Figure 1. Flow chart of the study selection.



Results

The 4 studies that were included in the systematic review were conducted from 2020 until 2023. The countries in which the studies took place were: Greece (n=1), the USA (n=2) and Turkey (n=1).

The results of the studies were grouped together:

- a) in the participating sample,
- b) in the type and interventions used
- c) the results of the studies.

Table 2 summarizes the characteristics of the studies.

Table 2. Characteristics of the studies included in the systematic review

Reference, country	population	intervention	Results
Yeni & Yilmaz, 2022. Turkey	The study included 42 people with dementia. Mild dementia: 3 people Moderate dementia: 24 people Severe dementia: 15 people	Type: Quasi-experimental study. Intervention: Educating and counseling family members about environmental modifications to avoid hazards that could lead to falls. 3 home visits lasting 1.5-2.5 hours, over a period of 6 months.	The results according to the DENN-Fall Risk Assessment Scale test for the modifications made at home in the first trimester showed that they did not affect the number of falls (p=0.791). In the second trimester, those who had made the modifications at home had a significantly reduced number of falls (p=0.000).
Gitlin et al., 2021. USA	The study included 62 people with dementia in the experimental group with their 62 caregivers (n=124) and 63 people with dementia in the control group with their 63 caregivers (n=126). Mean MMSE=14.34	Type: randomized clinical trial. Intervention: Tailored activity program (TAP). Identification of specific activities. Training the caregiver in communication strategies, to reduce stress. Awareness on NPSs and illness. Environmental adaptations. Up to 8 home visits, lasting 1-1.5 hours, over a period of 3 months.	No statistically significant differences were found regarding the frequency and severity of aggression and agitation after 3 months. Secondary outcomes included people with dementia needing less support in ADL compared to controls. Caregivers reported greater confidence and well-being using the activities.

Reference, country	population	intervention	Results
Mougias et al., 2022. Greece	The study involved 205 pairs of people with dementia and their caregivers. Final results from 144 participants. Mean MMSE= 14.37 ± 6.59.	Type: Prospective single-center study Multicomponent intervention. Psychoeducation and cognitive behavioral therapy in the caregiver. Occupational therapy intervention, social worker intervention, pharmacological intervention and provision of a volunteer/unpaid family helper for the needs of the home and the care of the person. 2 visits per month, lasting 90 minutes each visit, over a period of 6 months.	There were significant differences in NPSs severity (pFDR $\frac{1}{4}$ 0.002), risk for developing NPS (pFDR $\frac{1}{4}$ 0.001) as well as caregivers showing reduced burden ZBI (pFDR $\frac{1}{4}$ 0.004) and reduced depressive symptoms CES-D (pFDR $\frac{1}{4}$ 0.001).
Gitlin et al., 2022. USA	The study involved 250 pairs of people with dementia and their caregivers. Two teams. The first group had white caregivers (white race) (n=145) and the second group had caregivers of color (colored race) (n=90). 15 were eliminated. Mean MMSE=14.2	Type: randomized clinical trial. Intervention: Tailored Activity Program (TAP). Identification of specific activities. Training the caregiver in communication strategies, to reduce stress. Awareness on NPSs and illness. Environmental adaptations. Up to 8 home visits, lasting 1-1.5 hours, over a period of 3 months.	Entering the effective interaction term, there was a significant effect of race (p=0.033). The colored race had greater reductions in frequency of aggression intensity (p=0.006), frequency of aggression (p= 0.03) and rate of aggression (p= 0.035) compared to white race participants from both groups.

Table 2. cont.

Assessment tools

The main assessment tools used in the studies to conduct the main outcomes were:

In the study of Yeni & Yilmaz, (2022), were used the DENN-Fall Risk Assessment Scale (Tekin et al, 2013), developed by the Delmarva Foundation and adapted into Turkish, to assess the falls risk in older adults. The form consists of nine main sections. These sections are: level of consciousness/mental status; history of falling in the previous 3 months; ambulation/toilet status; vision status; gait and balance; orthostatic changes; drugs; diseases; and equipment availability. The evaluation is made over the total score and the falls risk score of the individual is determined. After the assessment is made over the total score, an individual's fall risk score is determined (0-5 points: low risk, 6-9 points: medium risk, 10 and above points: high risk) (Tekin, et al, 2013).

In the studies by Gitlin et al., (2021) and Gitlin et al., (2022), the primary trial outcome was frequency by severity scores of agitation/aggression behaviors at 3 months as measured by two domains of the Neuropsychiatric Inventory-Clinician version (NPI-C) (de Medeiros et al., 2010). For each of the 13 agitation subscale items, caregivers rated frequency (0 = never to 4 = very frequently).

In the study of Mougias et al., (2022) were used for Caregivers:

All caregivers were given the following self-administered scales:

- a) the Center for Epidemiological Studies-Depression (CES-D) Scale (Fountoulakis et al., 2001), for the evaluation of depressive symptoms,
- b) the Zarit Burden Inventory (ZBI) (Zarit, Reever & Bach-Peterson, 1980), for the assessment of the subjective burden experienced by dementia patients' caregivers. Care-recipients: The neuropsychiatric symptoms of care-recipients were evaluated using the Neuropsychiatric Inventory (NPI) (Politis et al., 2004) completed by their caregivers.

Discussion

The purpose of this study was the evaluation of Occupational Therapy interventions in people with moderate and severe dementia to improve their QoL and their caregivers.

In three of the four studies included in the systematic review, Occupational Therapy plays an important role in the intervention, while in the fourth study the intervention is completed from the basic parts of Occupational Therapy. According to the results, the interventions aim to reduce the occurrence of NPSs, to support the caregiver and to modify the environment to avoid falls.

NPSs, pain, and the environment have been shown in studies to influence QOL in advanced stages (Nagata et al., 2022). The multicomponent home intervention by Mougias et al., (2022), showed a significant effect on the neuropsychiatric profile of people with dementia and on the reduction of caregiver burden. The study by Yeni & Yilmaz, (2022) showed that the number of falls decreased after home modifications. In the study by (Gitlin et al., 2021)

there was no statistically significant difference in the main outcomes, but there was an improvement in the performance of ADL, better well-being and self-confidence in the caregivers. In the study by (Gitlin et al., 2022) they found that TAP had significantly more benefits on NPSs for Black participants than White participants when compared as far as attention control is concerned. Black TAP participants compared to White TAP participants and to both Black and White control group participants improved more on the agitation/aggression combined frequency by severity score.

While evidence in the current literature suggests that there are large numbers of people with advanced dementia and non-pharmacological home-based interventions may have a positive effect in many areas, the small number of studies (n=4) indicates the limited scope of interest regarding specific criteria of the review.

The QoL was not tested by a specific test in any of the studies included in the systematic review. Nevertheless, NPSs, ADLs and the environment have a significant impact on the QoL of individuals and for this reason the specific studies were chosen.

Conclusions

NPSs, pain and the environment have a significant effect on the advanced stages of the disease (Nagata et al., 2022). Complex interventions at home show that they may have positive effects in the reduction of NPSs and in reducing the burden on the caregiver. Occupational Therapists have an important role in the intervention team, because the interventions they make focus on daily functionality, ADLs, environment and activity modification, mental training and training of the caregiver. There are several home-based Occupational Therapy studies in the literature, but most of them did not meet the inclusion criteria of this study. Finally, more home-based, well-designed interventions should be conducted to provide more evidence on the QoL of people with moderate and severe dementia.

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