Dement Neurocogn Disord. 2025 Oct;24(4):233-245
https://doi.org/10.12779/dnd.2025.24.4.233
pISSN 1738-1495·eISSN 2384-0757

DND Dementia and Neurocognitive Disorder

Original Article

Home-Based Occupational Therapy Intervention for the Improvement of Quality of Life in Individuals With Moderate to Severe Dementia and Their Caregivers

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Received: May 28, 2025
Revised: Sep 6, 2025
Accepted: Sep 29, 2025
Published online: Oct 21, 2025

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Conflict of Interest
The authors have no financial conflicts of interest.

Author Contributions
Conceptualization: Georgiadis T; Data curation: Georgiadis T; Formal analysis: Georgiadis T; Investigation: Georgiadis T; Methodology: Georgiadis T; Project

ABSTRACT

Background and Purpose: The quality of life (QoL) of individuals with dementia is influenced by their ability to perform activities of daily living (ADLs), social engagement, and emotional well-being. Instrumental ADLs (IADLs) decline even in early stages, while basic ADLs (BADLs) are significantly affected in advanced stages. This study examined whether a home-based occupational therapy intervention improves QoL in people with dementia, reduces caregiver burden, depression, and anxiety, and enhances BADL performance.
Methods: Forty-nine participants with moderate to severe dementia were assigned to an intervention group (n=26, mean age 83.5±5.0 years, t=2.63, p=0.011) or a control group (n=23, mean age 80.0±4.2 years). QoL was assessed using the QoL in Alzheimer's disease (QoL-AD) and QoL in late-stage dementia (QUALID) scales. The intervention group received a 3-month standardized home-based occupational therapy program (12 individualized sessions) focused on BADL training, in addition to ongoing support from the Greek Alzheimer's Disease Association. The control group received only standard support. Caregivers in both groups participated in counseling or standard support sessions, respectively.
Results: Significant improvements were observed in patients' QoL (QoL-AD, p=0.008; QUALID, p=0.009) and in caregivers' anxiety and depression (p<0.001). No significant effects were found for BADL performance (p=0.857) or caregiver burden (p=0.773).
Conclusions: Home-based standardized occupational therapy interventions enhance the quality of life and emotional well-being of individuals with moderate to severe dementia and improve caregiver mental health, highlighting their crucial role in community dementia care.

Keywords: Dementia; Activities of Daily Living; Occupational Therapy; Home Care Services; Quality of Life

administration: Georgiadis T; Software: Georgiadis T; Supervision: Katsouri IG, Tsormpatzoudis C, Tsolaki M; Visualization: Georgiadis T; Writing - original draft: Georgiadis T; Writing - review & editing: Katsouri IG, Tsormpatzoudis C, Tsolaki M.

INTRODUCTION

The global population suffering from dementia exceeds 55 million, and it increases by 10 million each year. The ratio of individuals with dementia in the elderly population over 65 years old is 5%–8%. According to the World Health Organization, more than 55 million people globally suffered from dementia.[1] The rapid increase in dementia cases is likely to have significant consequences for healthcare providers, caregivers, and the economy.[2]

Quality of life (QoL) is a multidimensional concept, and for this reason, many definitions have been proposed. Studies investigating the factors associated with QoL in individuals with dementia living at home have found that depressive symptoms, behavioral disturbances, cognitive deficits, and reduced functionality may be linked to low QoL.[3] In people with dementia, neuropsychiatric symptoms such as depression and agitation seem to be the primary contributors to poor QoL.[4] People with dementia who experience cognitive impairments face greater difficulties in performing activities of daily living (ADLs), affecting both their QoL and that of their caregivers.[5]

Basic ADL BADLs include fundamental activities essential for managing basic physical needs, basic autonomy, and independence. BADLs are learned in the early years of life and are preserved in most individuals with cognitive deficits.[6] In line with this, the American Occupational Therapy Association[7] defines BADLs as including bathing or showering, toileting and toilet hygiene, dressing, eating and swallowing, functional mobility, personal hygiene and grooming, and sexual activity.

In the U.S. among the 4.3 million adults over 55 years old with cognitive impairments living alone in the community, it is estimated that 46% report difficulties in performing ADLs,[8] and over 250 million people experience moderate to significant disabilities worldwide.[9] These difficulties are influenced by multiple factors, including cognitive abilities (e.g., attention and in general executive functions), motor (e.g., balance and dexterity), and psychological abilities (e.g., motivation and depression), as well as other environmental and mediating factors such as age, gender, education.[10]

Research studies highlights deficits in executive functions (e.g., cognitive flexibility, organization, integration, and maintenance of actions or plans), information processing speed, and delayed memory recall. These factors have been associated with reduced performance in ADLs, particularly in IADLs.[5]

Several intervention studies have examined the impact of occupational therapy on daily functioning and QoL. Pimouguet et al.,[11] found that people with dementia living in their own familiar environment may have the ability to maintain their social network and enjoy better QoL. Other studies show that occupational therapy interventions improve QoL, the performance of daily activities for both individuals and caregivers, and are cost-effective.[12] Additionally, a study conducted in the Netherlands implemented a community-based occupational therapy program. The intervention consisted of 10 home sessions lasting one hour over 5 weeks, focusing on both individuals with dementia and their caregivers. The aim of the study was to investigate the effects of occupational therapy on the performance of daily activities. The results showed significant differences between the two groups. In the intervention group, the functionality of individuals with dementia improved significantly compared to the control group.[13] Furthermore, it was

found that the QoL of individuals with dementia in the intervention group was significantly better compared to the control group.[14] The same intervention program was also applied in Germany,[15] and the United Kingdom.[16] However, the results from both studies did not show statistically significant differences in the performance of ADLs or the QoL of individuals with dementia. In a study conducted in the United States, "Care of Persons with Dementia in their Environments,"[17] aimed at supporting functionality and QoL in individuals with dementia and the well-being of their caregivers, the results showed statistically significant improvements in the functionality of the experimental group compared to the control group. Improvements were primarily observed in IADLs. Caregivers reported "great benefit" in several behaviors, including better management of caregiving and the ability of individuals to remain at home. In another study by Gitlin et al.,[18] examined the effectiveness of the Tailored Activity Program. This structured program aimed at reducing neuropsychiatric symptoms through personalized activities that were adjusted to the patients' abilities. The results showed a significant statistical difference between the groups in the frequency of neuropsychiatric symptoms. Researchers concluded that, regardless of the stage of dementia, guidelines and frameworks for performing activities could be created. Furthermore, as the disease progressed, individuals required more simplified activities and the use of auditory and visual stimuli to support and guide the steps of the activity.

An evaluation of the above studies shows that the combined effect of an intervention to improve both BADLs and QoL in individuals with moderate to severe dementia and their caregivers has not been thoroughly studied. This study aims to investigate the impact of a home-based occupational therapy intervention on BADL performance and QoL in individuals with dementia, as well as its effects on caregiver burden, depression, and anxiety.

METHODS

The study involved 26 individuals in the intervention group and 23 individuals with moderate to severe dementia in the control group. In the intervention group, 69.2% (n=18) were women and 30.8% (n=8) were men. In the control group, 47.8% (n=11) were women and 52.2% (n=12) were men. Additionally, in the intervention group, 80.8% (n=21) of the caregivers were women, while in the control group, 78.3% (n=18) of the caregivers were women. There was no significant difference in sex of patients in caregivers between the two groups (**Supplementary Table 1**).

There was a significant difference in age of patients and caregivers and in years of education of caregivers between the 2 groups (**Table 1**).

Table 1. Age and years of education of patients and their caregivers in the two groups

Variable	Intervention group	Control group	*t*	*p*-value
Age of patients	83.5±5.0	80.0±4.2	2.634	0.011
Years of education of patients	8.5±4.2	10.2±5.0	−1.241	0.221
Age of caregivers	63.8±13.4	57.1±5.1	2.273	0.028
Years of education of caregivers	11.7±3.6	13.7±2.6	−2.113	0.040

Values are presented as mean ± standard deviation.

https://doi.org/10.12779/dnd.2025.24.4.233

Intervention

The intervention included 12 sessions over a total duration of approximately 3 months, during which the patients with dementia were trained in BADL (feeding, dressing, personal hygiene, toilet use, bathing, functional mobility). Additionally, caregivers received structured counseling and guidance on supporting patients in improving their performance in the BADLs, ensuring proper adaptation strategies during daily activities. Each session lasted 45 minutes. In the first session, the tests and the consent form were provided to the caregivers. In the second session, both the caregivers and the patients were informed about the importance of performing BADLs. In the following sessions, the patients were trained in each activity separately. A total of twelve sessions were conducted with each individual. The program did not include any intervention related to sexual activity. The training was done through realistic images that depicted the breakdown of each activity into steps. After viewing the images, the patients tried to perform the activity (**Supplementary Figs. 1-4**). Additionally, when necessary, verbal guidance or physical assistance was provided. In each session, there was counseling for the caregivers, and they received a handout regarding ergonomic adjustments and better management of performing BADLs. In the final session, the same tests that were administered in the first session were repeated (**Fig. 1**).

The sessions were delivered through individual home visits to each participant by an occupational therapist who held national licensure to practice occupational therapy. The therapist had received training during his initial professional education in occupational therapy, and the present study was implemented within the framework of a master's thesis at the Aristotle University of Thessaloniki, in the MSc program "neurosciences and neurodegenerative disorders."

In the control group, as in the experimental group, the participants were supported by the services provided by the home care team of Alzheimer Hellas, which includes a neurologist, dentist, psychologist, social worker, and physiotherapist. The main focus of the entire team is the continuous education of the caregiver, both by clarifying questions regarding dementia and teaching simple skills that can effectively improve the daily care of the person living with dementia and the caregiver's QoL. These visits take place every 2 to 3 months, depending on the needs of the patient. These services are provided free of charge to the patients and their caregivers, however, the healthcare professionals are funded by the state for the services they provide.

Tools

The QoL in late-stage dementia (QUALID) scale

The QUALID scale was initially developed by Weiner et al.[19] This scale provides information about the patient's QoL through assessments conducted by caregivers. The scale consists of 11 items, which include both positive and negative aspects of mood and behavior, considered

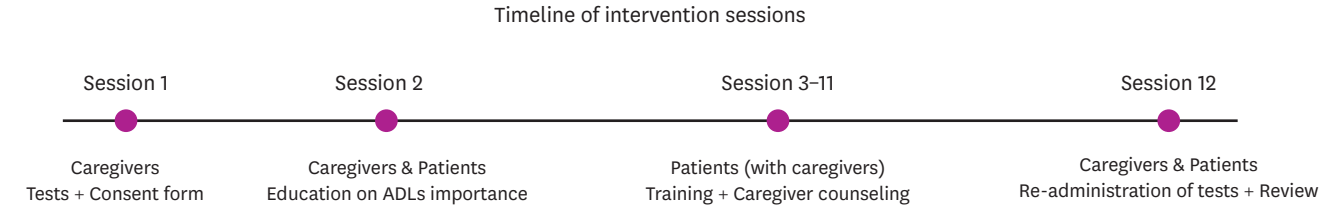

Fig. 1. Timeline of the 12-session home-based occupational therapy intervention for patients with dementia and their caregivers.
ADLs: activities in daily living.

https://doi.org/10.12779/dnd.2025.24.4.233

indicative of QoL in late-stage dementia. These items are evaluated based on their frequency on a scale ranging from 1 to 5. The total score ranges from 11 (indicating better QoL) to 55 (indicating worse QoL).[20]

QoL in Alzheimer's disease (QoL-AD) scale

The QoL-AD scale was developed by Logsdon et al.[21] The QoL-AD consists of 13 items (physical health, energy, mood, living conditions, memory, family, marriage, friends, self-care, ability to do household chores, ability to engage in leisure activities, finances, and overall life satisfaction). Response options range from 1 (poor), 2 (fair), 3 (good), and 4 (excellent), with scores ranging from 13 to 52, where higher scores indicate better QoL.[22]

The Zarit Burden Interview (ZBI)

The ZBI,[23] was translated and adapted for the Greek population by Papastavrou et al.,[24] following appropriate permissions. This test consists of 22 questions reflecting the feelings of individuals caring for people with dementia. For each question, participants are asked to indicate how often they have experienced certain emotions on a scale from 0 = never to 4 = almost always. The composite index (total score) is the sum of the scores across all items. Higher scores indicate greater caregiver burden, with a maximum possible score of 88. The burden is categorized into four dimensions: role strain, personal strain, deprivation of relationships, and management of care.[25]

Beck Depression Inventory-II (BDI-II)

The BDI-II,[26] is a self-report questionnaire comprising 21 items. Each question is rated on a Likert scale, with higher scores indicating higher levels of depression. Participants provide responses to 21 questions. According to the BDI-II manual, scores of 0–13 indicate low levels of depression, 14–19 indicate mild depression, 20–28 indicate moderate depression, and 29–63 indicate severe depression.[27]

Beck Anxiety Inventory (BAI)

The BAI,[28] is a 21-item self-report questionnaire that quantifies symptoms of anxiety. Participants rate how much each symptom has bothered them over the past week. Symptoms are scored on a four-point scale from "not at all" (0) to "severely" (3). The test demonstrates excellent internal consistency (α=0.92) and high test-retest reliability (r=0.75).[29]

Katz Index of independence in ADL (Katz ADL)

Among the tests used to assess basic daily living activities, the Katz ADL is the most recognized in clinical practice and the most widely used in clinical studies. The Katz ADL was developed by Katz et al.[30,31] in the 1960s. The test assesses self-care activities such as bathing, dressing, using the toilet, transferring in and out of a chair, maintaining continence, and feeding. The six-item test is brief and can be administered during an interview.[32] Patients are assessed on their ability to independently perform each of the 6 activities, with responses recorded as either 'yes' (independent) or 'no' (dependent). A total score of 6 indicates full functionality, while lower scores correspond to varying degrees of impairment. A score of 6 indicates full functionality, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment.

Assesment of dementia stage

The dementia stage of each patient was assessed using the Global Deterioration Scale.[33] This test includes descriptions of the clinically distinct stages of dementia, ranging from stage 1 (healthy) to stage 7 (severe dementia).

https://doi.org/10.12779/dnd.2025.24.4.233

Participants resided in the Thessaloniki region, and recruitment was conducted via telephone communication through the Greek Alzheimer Society. Participants were informed about the research protocol and objectives, and ethical approval was obtained from the Alzheimer Hellas Ethics and Deontology Committee (82/19-10-2022).

Statistical analysis

The data analysis was conducted using SPSS software (version 27; SPSS Inc., Chicago, IL, USA). Descriptive and inferential statistical indices were employed for the description and analysis of the data. Additionally, a mixed-design repeated measures analysis of variance (ANOVA) was used to examine whether the intervention had a significant effect on patients' QoL, anxiety, depressive symptoms, caregiver burden, and, finally, the level of performance in patients' BADL. In the model, the intervention and control groups served as the between-subject factor, while time served as the within-subject factor. The significance level was set at 5%.

RESULTS

The *t*-test comparisons revealed that the two groups of patients with dementia did not differ in all the tools before the intervention (**Table 2**).

Effect of the intervention on QoL

To investigate the effect of the intervention on the parameters studied, a repeated measures ANOVA was applied. The findings showed that the QoL scores significantly improved from the 1st to the 2nd measurement in the intervention group (from 24.2 to 19.2), while they slightly worsened from the 1st to the 2nd measurement in the control group (from 24.8 to 25.7). Furthermore, a significant interaction was found between the group and time in the patients' QoL as assessed by the QUALID scale ($F=45.193$, $p<0.008$, $\eta^2=0.496$) (**Supplementary Table 2**, **Fig. 2**).

Fig. 2 shows that the quality QoL was improved significantly in the intervention group compared to the control group.

The findings showed that QoL significantly improved from the first to the second measurement in the intervention group (from 23.3 to 25.5), while it decreased from the first to the second measurement in the control group (from 24.0 to 23). The results of the analysis indicated a significant interaction between group and time on the patients' QoL as assessed by the QoL-AD scale ($F=30.502$, $p<0.009$, $\eta^2=0.399$) (**Table 3**, **Supplementary Fig. 5**).

Table 2. Results from pre-intervention measurements in the two groups

Measurement tool	Intervention group	Control group	*t*	*p*-value
GDS	6.0±0.5	6.0±0.6	−0.030	0.976
QUALID	24.2±7.7	24.8±8.0	−0.264	0.793
QoL-AD	23.3±3.7	24.0±3.3	−0.678	0.501
BAI	8.4±7.0	6.6±5.2	1.040	0.304
BDI-II	12.3±7.2	13.6±9.1	−0.523	0.604
ZBI	37.7±14.0	31.0±16.2	1.551	0.128
Katz	0.9±1.2	1.0±1.7	−0.275	0.784

Values are presented as mean ± standard deviation.
GDS: Global Deterioration Scale, QUALID: quality of life in late-stage dementia, QoL-AD: quality of life in Alzheimer's disease, BAI: Beck Anxiety Inventory, BDI-II: Beck Depression Inventory-II, ZBI: Zarit Burden Interview.

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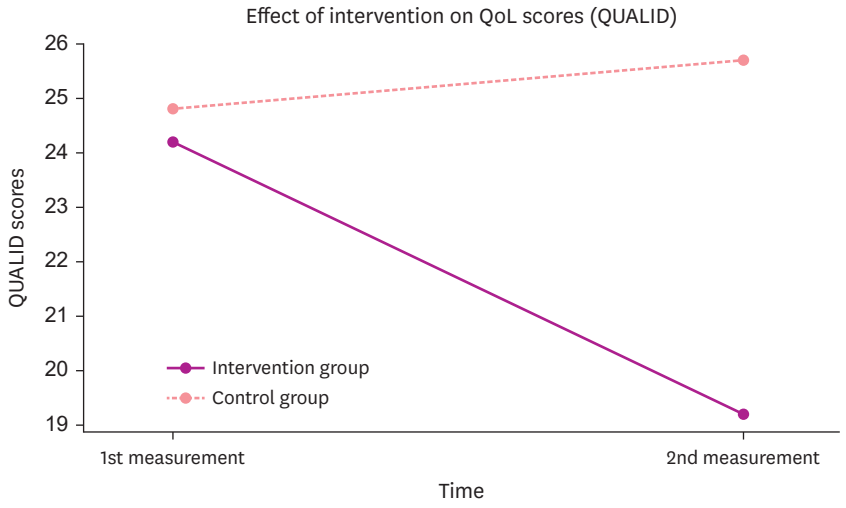

Fig. 2. Changes in QUALID scale scores in the two groups after the intervention.
QoL: quality of life, QUALID: quality of life in late-stage dementia.

Table 3. Results for the effect of the intervention on patients' QoL based on the QoL-AD scale*

Measurement time	Group	Values
Before the intervention	Intervention	23.3±3.7
	Control	24.0±3.3
	p-value	*p*=0.501
After the intervention	Intervention	25.5±3.9
	Control	23.0±2.2
	p-value	*p*=0.009

Values are presented as mean ± standard deviation.
QoL: quality of life, QoL-AD: quality of life in Alzheimer's disease.
*For the QoL-AD scale, higher scores indicate better QoL.

Supplementary Fig. 5 shows that QoL significantly improved in the intervention group, while it worsened in the control group.

Effect of the intervention on anxiety

The findings showed that anxiety symptoms significantly decreased from the first to the second measurement in the intervention group (from 8.4 to 4.7), while they remained stable from the first to the second measurement in the control group (from 6.6 to 6.7). The results of the analysis indicated a significant interaction between group and time on caregivers' anxiety symptoms, as assessed by the BAI scale ($F=24.834$, $p<0.001$, $\eta^2=0.351$) (**Supplementary Table 3**, **Fig. 3**).

Fig. 3 shows that anxiety symptoms were significantly decreased in the intervention group, while they remained stable in the control group.

Effect of the intervention on depression symptoms

The findings showed that depression symptoms significantly decreased from the first to the second measurement in the intervention group (from 12.3 to 9.0), while they increased from the first to the second measurement in the control group (from 13.6 to 14.9). The results of the analysis indicated a significant interaction between group and time on caregivers' depression symptoms, as assessed by the BDI-II scale ($F=30.849$, $p<0.001$, $\eta^2=0.401$) (**Supplementary Table 4**, **Fig. 4**).

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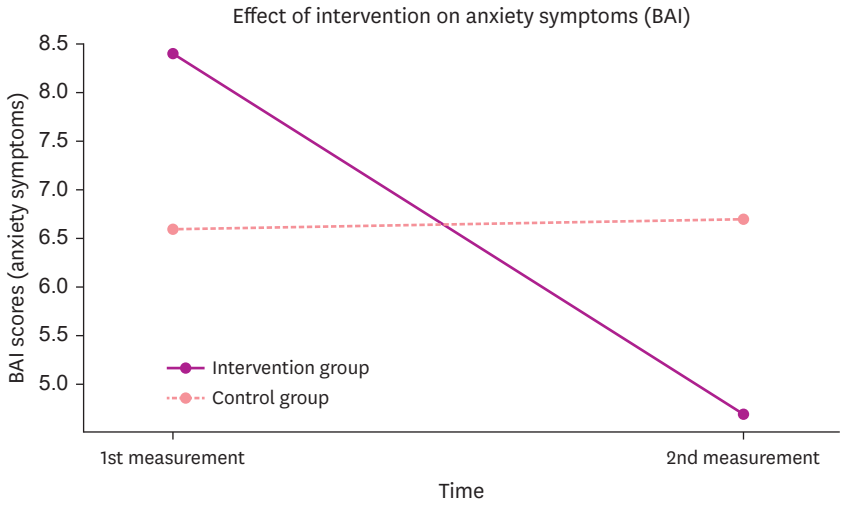

Fig. 3. Change in anxiety scale scores in the two groups before and after the intervention.
BAI: Beck Anxiety Inventory.

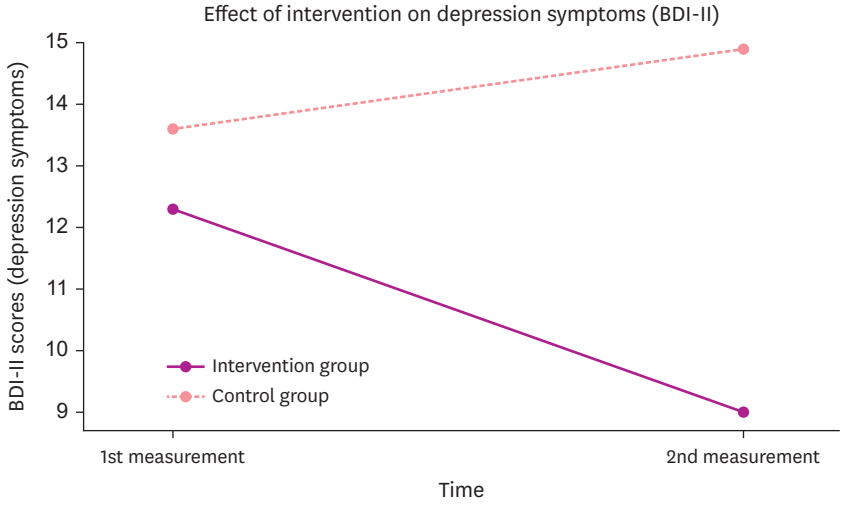

Fig. 4. Changes in depression scale scores in the two groups after the intervention.
BDI-II: Beck Depression Inventory-II.

Fig. 4 shows that depression symptoms were significantly decreased in the intervention group, while they were increased marginally in the control group.

Effect of the intervention on caregiver burden

The findings show that caregiver burden levels marginally improved from the first to the second measurement in the intervention group (from 37.7 to 32.4), while they increased from the first to the second measurement in the control group (from 31.0 to 33.5), though these differences were not statistically significant. The results of the analysis indicated no significant interaction between group and time on caregivers' burden levels, as assessed by the ZBI scale ($F=42.146$, $p=0.773$, $\eta^2=0.478$) (**Supplementary Table 5**, **Supplementary Fig. 6**).

https://doi.org/10.12779/dnd.2025.24.4.233

Effect of the intervention on BADL

The findings showed that patients' independence levels marginally improved from the first to the second measurement in the intervention group (from 0.88 to 0.92), while they remained stable from the first to the second measurement in the control group (from 0.99 to 1.01). The results of the analysis indicated no significant interaction between group and time on patients' independence levels, as assessed by the Katz scale (F=0.399, p=0.857, η^2=0.049) (**Supplementary Table 6**, **Supplementary Fig. 7**).

DISCUSSION

The aim of this study was to investigate the impact of an occupational therapy program on the QoL of people with moderate to severe dementia and the burden experienced by their caregivers.

The findings revealed that after the intervention, the QoL of individuals significantly improved according to the two assessment tools used (QUALID and QoL-AD). This improvement could be attributed to the active participation of individuals in tasks, which are more meaningful than passive involvement for both the individuals and their caregivers, regardless of the outcome. Additionally, regular social interaction may have contributed to this improvement, as individuals with moderate to severe dementia appear to have a strong need for social contact. These results align with those of a study conducted in the Netherlands by Graff et al.,[14] which showed significant QoL improvement in the intervention group compared to the control group after 12 weeks. Similarly, the findings by Gitlin et al.,[18] indicated a trend toward QoL improvement in individuals with dementia in the experimental group following the intervention.

Furthermore, anxiety and depression levels in caregivers were improved following the intervention, as evidenced by the results of the BAI and BDI-II assessments. Caregivers often experience significant challenges due to the energy and time required to care for their relatives. It is assumed that the improvement was due to a better understanding of their relatives' needs, the value of engaging them in BADL, and learning ways to manage these activities more effectively. Caregivers often need to share their concerns and seek guidance from professionals. The systematic and frequent contact (once a week) with a health professional (in this intervention, an Occupational Therapist) provided caregivers with the motivation to improve their caregiving.

Regarding caregiver burden, as assessed by the ZBI, there was no statistically significant difference between the two groups after the intervention. This may be due to the already high burden experienced by caregivers, given the advanced stage of dementia and the increased demands of care. In practice, it was observed that involving individuals with moderate to severe dementia in BADL requires significant emotional resilience, time, and physical fitness from caregivers. Statistical analysis revealed that 80.8% of the caregivers in the intervention group were women, with a mean age of 63.8 years. This indicates that the majority of caregivers were over 60 years old, often dealing with their own health issues or functional difficulties. It is often easier and less time-consuming for caregivers to feed the patient rather than prepare the activity to enable the patient to participate actively. This tendency applies to nearly all BADL. These finding partially align with those by Gitlin et al.,[18] where caregivers significantly reduced their objective burden, although subjective burden evaluations were unaffected.

https://doi.org/10.12779/dnd.2025.24.4.233

In the present intervention, it was noted that patients of this age and disease stage had significantly reduced visual acuity, making it difficult for most to distinguish images depicting the steps of each activity. Verbal instructions and guidance were essential for these individuals. Additionally, since each activity has its own flow, it was challenging to pause at every step to show the corresponding images. Practically, all images for a specific activity were presented before execution, followed by verbal instructions and physical support during the activity.

In the field of BADL, the results of the Katz assessment showed no statistically significant difference between the two groups after the intervention. One explanation for these findings is that people with moderate to severe dementia have significantly impaired functionality, requiring at least supervision for the completion of their daily activities. The level of assistance needed before and after the intervention may not have been affected due to the scale's limited scoring range. For example, when a patient is entirely fed by the caregiver and post-intervention requires only slight physical support or verbal guidance, the scoring on this scale remains unchanged. This assessment tool may be more appropriate for individuals in the earlier stages of the disease. Nevertheless, in order to maximize its clinical utility, the scale should include additional gradations that more precisely reflect the level of assistance required by each patient. Such refinement would enable a more accurate identification of patients' functional needs and limitations. Once these needs are clearly delineated, the type and intensity of therapeutic interventions can be determined with greater precision. Furthermore, this process allows for a better estimation of caregiver burden and highlights the specific domains in which caregivers require targeted education and training to provide effective support. Caregivers, out of a protective feeling, tend to assist their relatives even when supervision alone suffices. This behavior fosters passivity in patients, leading to a faster decline in their abilities.

Overall, the intervention proved effective in achieving targeted changes in daily functioning and QoL for patients in advanced stages of dementia, as well as in addressing several psychological variables in their caregivers.

This study has certain limitations. For example, the sample size was small due to difficulties in recruiting patients, and the program was quite demanding, as the occupational therapist had to conduct home visits, often over long distances. A larger team of occupational therapists might have been better equipped to handle the demands of a study with a larger sample size.

Age differences among participants, particularly among caregivers, could have influenced the results. The mean age of caregivers in the intervention group was 63.8 years (SD=13.4), while in the control group it was 57.1 years (SD=5.1). This difference may have affected their response to the intervention and their ability to implement BADLs effectively. Future studies should examine whether age-related differences impact the effectiveness of home-based occupational therapy interventions.

Furthermore, the lack of a follow-up period prevents the assessment of the long-term effects of the intervention. It remains unclear whether the observed improvements in QoL and psychological well-being are sustained over time. Future studies should include longitudinal assessments to evaluate the persistence of these benefits.

In summary, this study highlighted the significant role of home-based occupational therapy interventions for people with moderate to severe dementia. The results demonstrated

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statistically significant improvements in the QoL of patients and in the levels of anxiety and depression among caregivers. However, no statistically significant improvements were found in the execution of BADL or in the burden experienced by caregivers.

An issue that warrants further investigation is that, during the literature review, it was noted that most occupational therapy studies have focused on individuals with mild or moderate dementia. Thus, comparisons of the findings of this study with those of others should be made cautiously. Future studies should be designed to be more comprehensive and innovative to draw more definitive conclusions regarding the management of individuals with moderate to severe dementia at home.

SUPPLEMENTARY MATERIALS

Supplementary Table 1
Sex of the patients and their caregivers in the two groups

Supplementary Table 2
Results of the effect of the intervention on patients' QoL, as assessed by the QUALID scale*

Supplementary Table 3
Results of the effect of the intervention on caregivers' anxiety

Supplementary Table 4
Results of the effect of the intervention on caregivers' depression symptoms

Supplementary Table 5
Results of the effect of the intervention on caregiver burden

Supplementary Table 6
Results of the effect of the intervention on patients' independence in basic activities of daily living

Supplementary Fig. 1
Feeding.

Supplementary Fig. 2
Personal hygiene-grooming.

Supplementary Fig. 3
Using the toilet.

Supplementary Fig. 4
Dressing-undressing.

Supplementary Fig. 5
Change in QoL-AD scale scores in the two groups before and after the intervention.

Supplementary Fig. 6
Changes in caregiver burden scale scores in the two groups after the intervention.

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Supplementary Fig. 7

Changes in independence scale scores in the two groups after the intervention.

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