

ORIGINAL REPORT

EFFECTS OF REHABILITATION PROGRAM FOCUSED ON IMPROVING REAL-LIFE DAILY ACTIVITIES OF PATIENTS WITH MILD COGNITIVE IMPAIRMENTS OR DEMENTIA AND THEIR CAREGIVERS

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Objective: To evaluate the effectiveness of a dyadic outpatient rehabilitation program focused on improving the real-life daily activities of patients with mild cognitive impairments or dementia and their caregivers.

Design: Retrospective study.

Subjects: Eight patients with mild cognitive impairments or dementia and their caregivers.

Methods: The rehabilitation program comprised eight 1-hour sessions by occupational therapists with patients and his/her caregivers. Patients were assessed for motor function, cognitive function, and quality of life, and their caregivers were assessed for depression and caregiver burden. Participants were assessed at pre-program and post-program, and 3-month follow-up.

Results: The scores of caregiver-assessed Quality of life in Alzheimer's disease scale in patients significantly improved at post-program (median [interquartile range], 30.0 [7.0]) compared with pre-program (27.0 [2.8], effect size = 0.77, p = 0.029). In caregivers, the Zarit Caregiver Burden Interview scores decreased significantly at post-program (16.5 [13.0]) compared with pre-program (22.0 [17.5], effect size = 0.72, p = 0.042). There were no significant differences in other assessments.

Conclusions: The rehabilitation program focused on real daily activities and demonstrated to improve patients' quality of life and caregivers' depression and caring burden through patient-caregiver interaction. Future enhanced follow-up systems are warranted.

Key words: Alzheimer's disease; behavior therapy; caregivers; dementia; rehabilitation.

LAY ABSTRACT

Although various non-pharmacological interventions have been reported for patients with dementia, few studies have reported interventions focussing on improving activities in the real daily lives of patients and their caregivers. This study evaluated the effectiveness of a dyadic outpatient rehabilitation program focused on the reallife daily activities of patients with mild cognitive impairment or dementia and their caregivers. It consisted of 8 individual 1-hour sessions by occupational therapists to 8 patient-caregiver pairs. Patients were assessed for motor function, cognitive function, and quality of life, and caregivers were assessed for depression and caregiver burden. Participants were assessed before and after the program and at a 3-month follow-up. After the program, patients' motor and cognitive functions did not change; however, their quality of life improved significantly and caregivers' sense of caregiver burden decreased significantly. The rehabilitation program demonstrated positive effects on both patients and their caregivers.

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The prevalence of dementia is increasing rapidly worldwide, with physical, psychological, social, and economic impacts on both patients and their caregivers,

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p. 2 of 7 Activity-focused dementia program

family members, and society (1). Japan has the highest aging population globally (2), and the number of patients with dementia is expected to increase remarkably. Dementia has been the leading cause of the need for care in Japan since 2016 (3). Approximately 54.4% of caregivers for patients with dementia living at home were family members residing with patients, whereas 13.6% were family members living separately in Japan in 2019, with family members taking on most caregiving responsibilities (4). Caring for patients with dementia causes psychological, physical, and financial burdens (5–7). Support for both patients with dementia and their caregivers is crucial in Japan, where dementia-related issues are likely to deteriorate.

There are 2 types of treatments for patients with dementia: pharmacological and non-pharmacological. The nonpharmacological interventions have been reported to be as effective as or more effective than pharmacological interventions in affecting the behavior of patients with dementia, without any side effects (8). Various non-pharmacological interventions have been conducted (9-14). These include exercise, for improving functional independence and reducing caregiver burden (10); cognitive stimulation, for delaying or preventing the progression of dementia (14); music therapy, which improves the emotional, psychological, and behavioral symptoms of dementia (13); and psychological treatments, which reduce depression and anxiety (11). Moreover, there are several approaches using activities that are individualized for patients with dementia. In previous studies, interventions as a treatment using individualized occupational activities and pleasant events based on a person's history, needs, preferences, personality, functioning, and abilities have been reported to improve behavioral and psychological symptoms and quality of life (QOL) in patients with dementia (15-19). However, there are few reports on the effectiveness and development of rehabilitation programs that focus on improving patients' real-life daily activities. A previous study that intervened in patients' real-life daily activities demonstrated that these interventions directly improved the activities of patients with dementia (20). Moreover, direct interventions for activities in the patient's daily life that focus on both caregivers and patients with dementia have also been reported to improve the caregivers' QOL and reduce their burden of caregiving (21, 22). Since the number of studies on this aspect is small to adequately determine the effectiveness of interventions that focused on real daily activities of patients with dementia and their caregivers, developments of rehabilitation programs and further evaluations of effectiveness are warranted.

Furthermore, such programs are yet to be established in Japan, which has the highest number of social issues associated with dementia worldwide. The implementation of intervention methods in different countries is not always effective, owing to cultural differences (23). Therefore, it is necessary to develop and verify the effectiveness of interventions tailored to the Japanese social system and



culture. This study aimed to conduct a retrospective analysis of the effectiveness of a dementia rehabilitation program that focused on real-life daily activities. The rehabilitation program was implemented in a Japanese hospital for patients with dementia and their caregivers to gain preliminary insight into the establishment of interventions for community-dwelling patients with dementia and their caregivers.

METHODS

Study design

This retrospective study analyzed the results of a dementia rehabilitation program developed and conducted at Fujita Health University Hospital for patients with mild cognitive impairments (MCI) or dementia and their caregivers between December 2018 and January 2021. The study protocol was approved by the Ethics Review Committee of Fujita Health University (approval number: HM20-233). Although this was a retrospective study, all patients and caregivers were informed of the study, and their consent was obtained.

Participants

Patients were recruited using invitations on the posters placed in the hospital. Moreover, the physicians also introduced the program to outpatients in the Department of Geriatrics and Cognitive Disorders. The inclusion criteria were as follows: (i) older community-dwelling patients attending the Department of Geriatrics and Cognitive Disorders of Fujita Health University Hospital, (ii) patients presenting with mild cognitive impairment or mild-to-moderate dementia, (iii) patients physically or psychologically burdened by dementia, either by themselves or by caregivers, and (iv) patients willing to participate in the dementia rehabilitation program. Pairs of patients and caregivers who did not complete all 8 sessions of the program were excluded from the analyses in this study. During the study period, 9 pairs of patients and caregivers participated in the program; one of the 9 pairs ceased the program because they did not feel that it was effective, while the remaining 8 pairs completed the entire program. Eight pairs of patients and caregivers who completed the program were included (3 Alzheimer's disease [AD], 1 AD with cerebrovascular disease, 3 MCI due to AD, and 1 semantic dementia). A clinical diagnosis of MCI due to AD or AD was made using the National Institute on Aging-Alzheimer's Association diagnostic criteria (24, 25). In principle, MCI was defined as a Mini-Mental State Examination (MMSE) score of 24-30 points and a Clinical Dementia Rating (CDR) of 0.5, and AD as an MMSE score of 26 points or less and a CDR of 1.0 or above. In addition to the MMSE and CDR, Wechsler Memory Scale-Revised logical memory test (immediate and delayed), executive function tests, visuospatial

p. 3 of 7 Activity-focused dementia program

Table I. Participant	characteristics
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Case	Diagnosis	Age, years Sex	, Disease duration	MoCA	Complication
1	${\rm AD}^{\dagger}$ and ${\rm CVD}^{\ddagger}$	77, M	9 months	18	Benign prostatic hyperplasia
2	MCI§	82, F	2 years	17	None
3	SD [¶]	74, F	8 months	21	None
4	AD	71,F	2 years	20	Liver cyst
5	AD	76, M	8 months	21	None
6	MCI	76, M	2 years	22	Post-gastric cancer
7	AD	72, M	2 years	16	None
8	MCI	74, M	6 months	25	None

 $^{\dagger}\text{Alzheimer's}$ disease; $^{\ddagger}\text{cerebrovascular}$ disease; $^{\$}\text{mild}$ cognitive impairment; and $^{\$}\text{semantic}$ dementia.

MCI: mild cognitive impairments; AD: Alzheimer's disease; MoCA: Montreal Cognitive Assessment.

cognitive tests, and questions about instrumental activities of daily living were also administered. Diagnoses of semantic dementia were made according to the criteria by Neary et al. (26). Participant characteristics are shown in Table I. Five patients were males aged 71–82 (mean, 75.2) years. All caregivers were the spouses of patients aged 69–85 (mean age 73.4).

Dementia rehabilitation program

The dementia rehabilitation program was developed by a research group comprising physicians, physical therapists, and occupational therapists from the Department of Rehabilitation and Department of Geriatrics and Cognitive Disorders. It comprised eight 1-hour sessions, with either 1 or 2 weeks interval between sessions, depending on the participant's schedule. The program was a dyadic intervention, in which the patients and caregivers both participated in the program. Patients and caregivers received physician consultations together before, after, and 3 months after completion of the program. At the preprogram consultation, participants received an explanation of the overall content of the program and their willingness to participate was confirmed. In the subsequent consultation, participants received feedback on the results of the assessments conducted within the program. One therapist was assigned to the patient and the other therapist was assigned to the caregiver. The patient and caregiver each participated in one-on-one rehabilitation with the same occupational therapist throughout the program.



The program aimed to prompt a change in patient behavior and improve the caregivers' coping skills by focusing on activities, setting goals, and solving problems for each participant pair, rather than improving cognitive function. The contents of the rehabilitation program are shown in Table II. In the initial session, the therapists conducted functional and psychological assessments and interviews with the pair. During the interview, the patient and caregiver were asked about their actual daily life problems, their work interests, the quality of the patient-caregiver relationship, and their expectations of the program. Based on this information, the therapist and patient or therapist and caregiver discussed and set goals for the program. At the end of each session, the therapists shared the results of the evaluation and what they had undergone in the session, modifying the program goals and content as needed.

Patients were encouraged to implement compensatory strategies, resume hobbies, try to start new activities, and establish an exercise routine to achieve the patients' or caregivers' goals depending on the needs, situations, and conditions. The therapist assessed which activities were difficult for the patient and determined which hobbies to resume based on the needs of the patient and caregiver. The therapist then instructed the patient and caregiver on the target activities and the use of assistive devices to accomplish them, if required. The therapist also informed the caregivers about how to support the patient in the activity and how the difficulty with the activity was related to dementia symptoms. The therapists recommended walking and other exercises that can be performed at home for patients with no exercise habits, according to the patients' functions. Moreover, they encouraged the patients to manage their exercises by using a diary to check the degree of implementation and devices such as pedometers so that they can continue after the program ends. Therapists also informed caregivers how to help patients continue their exercises.

Caregivers were trained to support patients and use compensatory strategies to achieve caregiver and patient goals and were informed about dementia symptoms and how to cope with them. Between each session, the caregivers practiced supporting the patient's activities and interacting with the patient based on the therapist's instructions and recorded their ability to implement them and the degree

Table II.	Dementia	rehabilitation	program
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	Patient	Caregiver			
Consultation	Explanation of the overall program (e.g. objectives of the program and what they will do)				
	Confirmation of willingness to participate in the program				
Session 1 (pre-program evaluation)	Assessment of problems in ADL and IADL	Assessment of patient's problems in ADL and IADL			
	Assessment of cognitive and motor impairments	Assessment of care burden			
Session 2-7	Practice of ADL using compensatory means	Tips on how to cope with troublesome behavior			
	Daily physical exercise	Information on symptoms for the patient's family			
	Activity-oriented rehabilitation	Tips on how to cope with daily frustrations			
		Possibility to use social resources			
		Connecting to a peer support network			
Session 8 (post-program evaluation	Assessment of problems in ADL and IADL	Assessment of the patient's problems in ADL and IADL			
	Assessment of cognitive and motor impairments	Assessment of care burden			
Consultation	Feedback on assessment results conducted within the program				

ADL: activities of daily living; IADL: instrumental activities of daily living.

p. 4 of 7 Activity-focused dementia program

of anxiety and burden they experienced. The records were shared with the therapists and caregivers at each session and were referred to in the program when reflecting on the caregivers' daily difficulties and the coping strategies they practiced. The therapist provided feedback on the caregivers' efforts, including positive points and suggestions. As the program progressed, as new issues or targets in daily life were raised by the caregivers, the therapists and caregivers worked on them. The therapists observed the patients working on the program, with the caregivers as required, providing an opportunity for the caregivers to objectively evaluate what the patient can or cannot do and learn how the caregiver helps the patients perform activities. For participants requiring case management, occupational therapists worked with medical social workers to provide knowledge and coordinate service use. To provide comprehensive intervention to participants, case conferences were held at monthly intervals by a multidisciplinary team (physicians, physical therapists, and occupational therapists) to share program implementation and results, and to discuss subsequent plans.

Outcome measures

The patients and caregivers were assessed at the first (preprogram) and 8th sessions (post-program) of the program and 3 months after completion of the program (followup). Patients were assessed using the Timed Up and Go (TUG) test, Montreal Cognitive Assessment (MoCA), and QOL in Alzheimer's disease (QOL-AD) scale. The TUG test is an assessment of standing balance and gait, measuring the time taken by a person to get up from a chair, move around a landmark 3 m away, and sit down in the chair again (27). This test has been verified for reliability and validity (27, 28). The MoCA is used to assess cognitive function by interview, with a score ranging from 0 to 30 with higher scores indicating better cognitive function; mild cognitive impairment is suspected in patients with a score of ≤ 25 (29). Its reliability and validity have been confirmed (29, 30). The QOL-AD scale is a QOL scale developed for patients with mild-to-moderate dementia, with total scores from 13 to 52, with higher scores indicating better QOL (31). Assessment can be performed by the patient themselves or by their caregivers as a proxy (32). In the present study, patients and their caregivers separately assessed patients' QOL-AD scale. Its reliability and validity have been confirmed (32, 33).

Caregivers were assessed using the Center for Epidemiologic Studies Depression Scale (CES-D) and Zarit Caregiver Burden Interview (ZBI). The CES-D is a self-administered depression questionnaire used as a screening tool for the early detection of depression (34). The total score ranges from 0 to 60 points, with ≥ 16 points indicating depression and higher scores indicating more marked depression. Its reliability and validity have been confirmed (35). The ZBI is a questionnaire that assesses the caregiver's perception of care burden, including psychological, physical, social, and economic burdens, with



scores ranging from 0 to 88 and higher scores indicating greater caregiving burden (36). Its reliability and validity have been confirmed (37).

Analysis

Differences in each outcome between the pre- and postprogram periods and between the pre-program and follow-up periods were examined. The Wilcoxon rank-sum test was used for statistical analysis, and r was used to calculate the effect size (ES). Effect sizes were interpreted according to Cohen's classifications as follows: 0.10, small; 0.30, medium; and 0.50, large (38). All statistical analyses were performed using SPSS version 28 (IBM Corp., Armonk, NY, USA). A p < 0.05 was considered statistically significant.

RESULTS

The results of patient assessments are shown in Fig. 1. The QOL-AD scale score given by caregivers significantly improved from the pre-program to post-program with a large ES (Z=2.18, ES=0.77, p=0.029). There were no significant differences in other assessments from the pre-to post-program (p=0.397–0.863). Furthermore, there were no significant differences in any assessment between the pre-program and follow-up periods (p=0.526–0.999).

The results of the caregiver assessment are shown in Fig. 2. There was a significant decrease in ZBI scores with a large ES between the pre- and post-program (Z=2.04, ES=0.72, p=0.042) and a marginally significant decrease with a large ES in CES-D scores (Z=1.94, ES=0.69, p=0.051). Neither assessment showed a statistically significant difference between the pre-program and follow-up periods; however, both scores tended to decrease with large ES (CES-D: Z=1.47, ES=0.52, p=0.141; ZBI: Z=1.42, ES=0.50, p=0.156).

DISCUSSION

This study examined the effects of a dementia rehabilitation program on patients with dementia and caregivers by analyzing the changes in related indicators before and after it. Post-program, the patients' QOL improved, and the caregivers' depression and care burden decreased.

In this study, interventions to improve real-life daily activities for patients with mild to moderate dementia did not change patients' function but improved their QOL assessed by their caregivers. Improving activities of daily living in patients with mild to moderate dementia directly improves patients' performance and satisfaction with activities, not their functions or symptoms (20). The patients in the present study may also have increased their performance and satisfaction with activities by working on their real-life daily activities, resulting in an improved QOL. A systematic review examining the effects of person-centered care on patients with dementia showed

p. 5 of 7 Activity-focused dementia program



Fig. 1. Patient assessments. TUG: timed up-and-go test; MoCA: Montreal Cognitive Assessment; and QOL-AD: Quality of Life in Alzheimer's Disease. QOL-AD* indicates the patient's assessment of their own quality of life, and QOL-AD** indicates the caregiver's assessment of the patient's quality of life. Assessments were conducted during the first (pre-program) and last (post-program) sessions of the dementia rehabilitation program and 3 months after completion (follow-up). The horizontal lines inside the boxplots and the values beside the boxplot represent the median values; the edges of the boxplots represent the maximum and minimum values. Line graphs show the results for individual patients.

that improvements in QOL were more likely to occur in patients with less severe dementia (15). This study and previous findings indicate that individualized interventions are effective in improving QOL for patients with mild to moderate dementia.

The intervention in this study also focused on the caregivers, which reduced caregivers' depression and burden of care. "Focus on the person with dementia as well as the caregiver" is an essential element for successfully supporting caregivers (39). Consistent with the current study, educational programs for caregivers of patients with dementia have been shown to reduce depression and the burden of care (40–42). In contrast, a recent systematic review reported that providing caregivers with knowledge related to the disease and lectures on how to self-manage JRM-CC

symptoms had no significant effect on depression and a significant effect on the burden of care with a small ES (43). The greater effectiveness of the current program could be attributed to the fact that the interventions for caregivers were combined with those for patients with dementia. Based on the therapist's assessment of the patient's symptoms and performance of activities, the caregiver could understand and learn appropriate coping skills. Furthermore, the caregiver sometimes participates in the patient's program activities; the caregiver might have been able to understand the patient's symptoms and learn coping strategies better, leading to improved actual coping skills and a reduced psychological burden.

The improvement in the OOL of the patients and caregivers' depression and burden may have been enhanced due to interactions between patients and caregivers. The improved QOL of patients assessed by caregivers may have been influenced by the reduction of the psychological burden on caregivers, which may have improved their ability to cope with problems and interact appropriately with patients. In addition, the reduction of psychological burden on caregivers may have made their evaluation of patients positive. A qualitative study has shown that the quality of the relationship between the person with dementia and their caregiver was affected not only by the caregiver's depression and anxiety but also by the behavioral symptoms and QOL of the person with dementia (44). Therefore, interventions targeting the dyadic may be more effective than interventions targeting only the patient or caregiver. In support of this, previous studies of comprehensive interventions for dyadic have shown their effectiveness (20, 22, 45-48). The outpatient rehabilitation program for both dementia patients and caregivers in this study may have resulted in positive effects for both



Fig. 2. Caregiver assessments. CES-D: Center for Epidemiologic Studies Depression Scale; and ZBI: Zarit Caregiver Burden Interview. Assessments were conducted during the first (pre-program) and last (post-program) sessions of the dementia rehabilitation program and 3 months after completion (follow-up). The horizontal lines inside the boxplots and the values beside the boxplot represent the median values; the edges of the boxplots represent the upper and lower quartiles, and the whiskers represent the maximum and minimum values. Line graphs show the results for individual patients.

p. 6 of 7 Activity-focused dementia program

due to the interactions that occurred between them. Some of the assessments in this study with improved outcomes after the program had large ES between the pre-program and follow-up periods, but none of them were significantly different. However, in previous studies, the effects remained at follow-up; for example, Graff et al. reported that 10 client-centered occupational therapy sessions over 5 weeks improved patient and caregiver QOL and that these effects persisted 6 weeks later (21). Although differences in the frequency of interventions, outcomes, and the duration between program completion and follow-up make general comparisons impossible, the lack of sustained effects at follow-up indicates that the interventions in this study may not have produced sufficient behavioral modifications in patients or caregivers. Teri et al. reported that a total of 12 home-based interventions over 3 months that combined an exercise program for patients with coping skills training for caregivers and 3 followup sessions over 3 months resulted in functional maintenance for 2 years (45). Since it has been shown that the effects of the program can be maintained depending on the approach, we need to improve the program to maintain the effects in the future.

This was only a preliminary study that did not fully verify the effectiveness of the dementia program. After modifying the program, future comparative studies to evaluate its effectiveness should be conducted with a sample size calculated based on the results obtained in this study.

CONCLUSIONS

The patients' QOL significantly improved, and their care burden was significantly reduced after our activityoriented dementia rehabilitation program for people with dementia and their caregivers in outpatient settings. Further studies with a control to confirm the effectiveness of this program are warranted.

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The study protocol was approved by the Committee of Ethics Review of Fujita Health University (approval number: HM20-233). This study was conducted in accordance with the Declaration of Helsinki of 1964, revised in 2013.

The authors have no conflicts of interest to declare.

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p. 7 of 7 Activity-focused dementia program

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