

A home assistance model for dementia: outcome in patients with mild-to-moderate Alzheimer's disease after three months

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Abstract

The treatment of dementias, which are currently incurable pathologies, requires an approach to care that involves both the patients and their families. The effect of alternative interventions, besides the pharmacological approach, therefore warrants evaluation. In this paper, we describe one such intervention, which was provided by our home care team for Alzheimer's Disease.

Patients were granted a three-month period of home care assistance, which included physical and cognitive rehabilitation as well as interventions on the home environment and the family, such as psychological support for the main caregivers. The assistance was provided in thrice-weekly sessions, each lasting six hours. Twenty-two patients (age 78.4±6.5 yrs), all of whom had received a diagnosis of probable AD, were enrolled. There was a statistically significant improvement in the NPI score ($p = 0.004$), Barthel index ($p = 0.01$), Tinetti's scale ($p = 0.013$) and CBI score ($p = 0.016$) at the end of the 3-month treatment period. The patients' caregivers also reported a significant improvement in the physical and social burden at the CBI at the end of the period of home care assistance ($p = 0.026$ and $p = 0.006$). In a further evaluation performed 3 months after the end of the treatment period, the beneficial effect previously observed in both patients and caregivers was no longer present.

Key words

- Alzheimer's disease
- home assistance
- non-pharmacological approach
- outcome research
- rehabilitation

INTRODUCTION

The treatment of demented patients involves various professional figures and disciplines (physician, nurse, psychologist, social welfare, rehabilitation) whose aim is to reduce the burden of disease for both the patients and their families. The effect of currently available drugs on the cognitive and behavioural symptoms in such patients is mainly symptomatic.

Although innumerable non-pharmacological treatments and psycho-educational approaches have been proposed in recent decades, strong evidence of the efficacy of such proposals remains limited.

Moreover, a number of studies have been conducted in the field of home assistance for demented patients, though few have provided scientific evidence of the results yielded by these activities.

A systematic review of a few, high-quality, randomized controlled trials (RCTs) has shown that multicomponent interventions for caregivers may delay the admission of dementia patients to institutions; moreover, it has been reported, though in lower-quality sources, that multicomponent interventions may result in an improvement in cognition, behaviour and activities of daily living in such patients [1]. The need to enhance the level of person-centred and customised care provided by primary care institutions to people with dementia and their families has recently been stressed; moreover, the efficacy of any interventions and alternative models of service delivery with such characteristics needs to be evaluated [2]. The aim of the present study was to assess the effects of a 3-month programme of home care assistance in a group of 22 patients suffering from

dementia of the Alzheimer's type as well as the possible long-lasting effects (after 3 months) of the treatment on the cognitive and behavioural profile of the patients and stress levels of the caregivers.

MATERIALS AND METHODS

Staff and training of the staff

This study was performed in one of the four health districts of Rome (ASL Roma D), with a catchment area of approximately 205 000 people (in 2004), a 19% prevalence of elderly people (over 65 years of age) and an estimated number of 7000 demented patients [3] (3300 of whom Alzheimer's patients). Since June 2006, a home assistance service for demented patients has been available in this area.

The Italian Hospital Group (IHG) was asked to run this service by the Roma D Local Health Unit. The IHG has specific experience in assisting demented people as they had previously set up a network of social assistance services aimed at helping both patients with dementia, particularly those with Alzheimer's disease, and their relatives.

The assistance network set up by the IHG, which is located in Guidonia (just outside Rome) in the Roma G Local Health Unit, is accredited by the Regional Health System and develops projects designed to ensure the continuity of interventions by connecting home, semi-residential and residential care by means of case-specific assistance services selected by the Joint Evaluation Unit. This network is made up of staff members from the state-run Centre for Home Assistance of the Roma G Local Health Unit and of staff members from the IHG. The projects are carried out by the IHG multi-disciplinary team.

The overall dementia network comprises 3 residential units (a total of 60 hospital beds), a daytime care centre, which receives up to 58 patients, and a home service that caters for up to 65 patients living within the Roma G Local Health Unit.

The network staff at the Italian Hospital Group is

composed of a neurologist, a psychologist, a physiotherapist, an occupational therapist, a social assistant, a nurse and a technical operator for assistance.

Specific training courses were held for all the members of the staff who work in the Centre for Dementias at the IHG. The courses were designed to teach those involved in the study how to correctly apply the various assessment scales for dementias and to make them familiar with the multidimensional evaluation instruments. The clinical data and rating scales were computerized by means of the Atl@nte System software, thereby allowing each operator to access information concerning his/her patients' clinical care and progress. During the period of home care assistance, OTA and nurses were continually supervised and supported in their assistance and functional reactivation activities by multi-disciplinary team members.

Characteristics of the patients included in the study

All 22 patients (10 males, 12 females), who were consecutively enrolled from 1 June 2006 to 31 July 2006, had received a diagnosis of probable Alzheimer's disease in the Alzheimer Evaluation Unit of the Grassi Hospital, with a mild-to-moderate degree of cognitive deterioration. Only in one patient was the presence of Alzheimer's disease in another family member reported (one sister). The patients' mean age was 78.4 ± 6.5 years (range 65-89), mean education 7.8 ± 3.7 years. Thirteen patients were living with a spouse, 5 patients (22.7%) with an external caregiver, 4 were widowed and were living with relatives (2 patients with their daughter, 1 with his sister, 1 with her granddaughter). The average number of family members was 3 ± 2 . The main caregiver's mean age was 65 ± 16.1 years, and 86% were female. All the patients had a legal representative and received a retirement pension; 41% received a disability allowance, 45% had applied for such an allowance while the remaining 11% did not receive any allowance.

Table 1

Weekly schedule of the home care programme

Hour	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
8-9	Hygiene-dressing Gastronomic ROT Reminiscence		Hygiene-dressing Gastronomic ROT Reminiscence		Hygiene-dressing Gastronomic ROT Reminiscence	
9-10	ROT		ROT		ROT	
10-11	Outdoor motor activity and socialization		Outdoor motor activity and socialization		Outdoor motor activity and socialization	
11-12	Occupational therapy Validation therapy		Milieu therapy Validation therapy		Film/photo- album Validation therapy	
12-13	Music therapy Gastronomic ROT		Music therapy Gastronomic ROT		Music therapy Gastronomic ROT	
13-14	Setting the table for lunch		Setting the table for lunch		Setting the table for lunch	

ROT: Reality orientation therapy.

Table 2
Assessment of the home care assistance programme

Tests	Mean (SD) at baseline	Mean (SD) at 12 weeks	p	Mean (SD) 3 months after end
Mini-mental state examination (MMSE)	20.9 (4.6)	22.7 (4.7)	0.100	19.39 ± 4.64
Neuropsychiatric inventory (NPI)	41.5(26.6)	26.6 (14.6)	0.004	46.14 ± 21.4
Barthel index	75.5 (24.2)	87.3 (20.3)	0.010	77.32 ± 25.76
Basal activities of daily living (BADL)	4.3 (1.9)	4.3 (1.7)	0.792	n.p.
Instrumental activities of daily living (IADL)	4.9 (3.6)	4.8 (3.5)	0.364	n.p.
Tinetti's scale	19.7 (7.2)	22.9 (6.7)	0.013	20.95 ± 7.4
Caregiver burden inventory (CBI)	42.4 (18.2)	33.3 (15.0)	0.016	42.4 ± 15.14
Caregiver stress index (CSI)	7.0 (2.7)	6.4 (2.2)	0.098	6.95 ± 2.55

n.p.: not performed.

Table 3
NPI items after the treatment

Subitem Neuropsychiatric inventory (NPI)	Mean (SD) at baseline	Mean (SD) at 12 weeks	p	Patients with symptom at baseline (%)	Patients with symptom at 12 weeks (%)	p
Delusions	1.6 (2.4)	2.5 (3.8)	0.253	40.9	40.9	0.960
Hallucinations	1.4 (2.1)	0.9 (2.6)	0.170	31.8	18.2	0.021
Agitation/aggression	3.2 (3.9)	2.7 (3.2)	0.776	59.1	59.1	0.779
Depression/dysphoria	5.1 (4.8)	2.8 (3.7)	0.017	72.7	54.4	0.221
Anxiety	5.1 (4.7)	3.0 (3.8)	0.059	77.3	59.1	0.323
Elation/euphoria	0.8 (2.6)	0,2 (0.8)	0.357	9,1	0.0	0.684
Apathy/indifference	6.6 (4.3)	5.0 (4.7)	0.183	86.4	68.2	0.163
Disinhibition	1.7 (2.9)	0.4 (1.0)	0.090	36.4	22.7	0.595
Irritability/lability	4.9 (4.3)	3.9 (3.4)	0.182	73.3	73.3	0.294
Aberrant motor behaviour	3.9 (5.1)	1.9 (2.9)	0.100	40.9	36.4	0.096
Night-time behaviour	3.9 (4.8)	1.6 (2.6)	0.014	54.4	27.3	0.045
Appetite/eating changes	3.3 (4.2)	2.3 (3.9)	0.230	54.4	36.4	0.027

Clinical procedures

A standardized procedure was used to assist patients: 1) the patient was visited by the physician who collected the clinical history with the caregiver's help; 2) the multi-disciplinary team performed a multi-dimensional assessment, including an evaluation of the patient's cognitive and behavioral conditions, functional-motor profile and environmental and social situation; the caregiver's disease burden and stress levels were also assessed;

3) the assistance and functional reactivation targets, which were approved by the Alzheimer Evaluation Unit of the Grassi Hospital, were chosen and subsequently verified in monthly meetings held by the team.

On the last day of the 3-month period of assistance, the patient was thoroughly re-evaluated to detect any changes resulting from the intervention. At the same time, caregivers received tools and instructions on how to continue caring for the patient.

The multi-dimensional evaluation used in this

standardized procedure included:

the Mini-mental state examination (MMSE) [4], the Neuropsychiatric Inventory (NPI) [5], the Instrumental activities of daily living (IADL) [6], the Basal activities of daily living (BADL) [7], Tinetti's scale [8], the Barthel index [9, 10], the Cumulative illness rating scale (CIRS) for comorbidities [11], the Caregiver burden inventory (CBI) [12] and the Caregiver strain index (CSI) [13].

The 13 items of the CIRS for comorbidities [11] were used to evaluate the effects of each item on the patients' functional activities (mean severity index 1.26 ± 0.2 ; mean comorbidity index 1.78 ± 1.2).

The rehabilitative interventions, which were performed on the 22 patients over a 3-month period, in 6-hour sessions, 3 times per week on alternate days, are summarized in *Table 1*. All the patients and caregivers received psychological support and advice on how to apply for any allowances that are available for families with dementia patients; this type of support was provided by the psychologist and social assistant, who visited the patients' homes on a once/week basis. The occupational therapist offered advice on any prostheses or aids that could be purchased and on how to make the home environment safe.

At the end of the 90-day period, both the patients and caregivers were reassessed. In the present paper, we describe the outcomes of the 22 patients who received 18 hours/week (alternate days) of home assistance for 12 consecutive weeks.

A final evaluation was performed 3 months after the end of the programme.

Interventions performed on the patients during the home assistance programme

The activities performed at home were aimed at stimulating patients to maintain their residual functional resources and, in particular, at keeping up their activities of daily living, at improving the behavioural symptoms of dementia and at enhancing their residual affective and cognitive capabilities.

For these purposes, we used the following techniques:

- a) Memory training [16-23];
- b) Reality orientation therapy (ROT) [24-28];
- c) Occupational therapy [28-30];
- d) Reminiscence therapy [27, 31];
- e) Validation therapy [32-34];
- f) Motor rehabilitation [30];
- g) Milieu therapy [23, 31, 35];
- e) Music therapy [36-40];
- f) Supportive psychotherapy [41, 42].

Interventions on the family

These interventions are [43-46]:

- family counseling: to prevent or treat intra-family problems and any psychological consequences;
- psycho-educational counseling: to inform the caregiver and his family about the patient's conditions; to provide appropriate strategies to help cope with dementia; to offer the caregiver psychological support (self-help groups).

Interventions in the domestic environment

These interventions [30, 47] were designed to make the domestic environment safer to:

- help maintain autonomy by trying to compensate for the disabilities, memory failure and disorientation (notices, calendars, personal photographs on the door of the bedroom, contrasting colors);
- reduce the behavioral symptoms of dementia that may be associated with the domestic environment (reduced or redundant sensorial stimulations).

Data collection

The data from the multi-dimensional evaluation were collected using the Atl@nte System software [14, 15], which monitored changes in the patients and displayed their current conditions in real time, thereby allowing the data to be rapidly updated. The same software was used for the management of the Individual Plans for Assistance (IPA), allowing any changes induced in the patients by the activities of the multi-disciplinary staff to be promptly detected.

Table 4
Barthel index items after treatment

Subitem Barthel index	Mean (SD) at baseline	Mean (SD) at 12 weeks	p
Feeding	8.0 (2.6)	9.1 (1.8)	0.032
Bathing	2.7 (1.9)	3.9 (1.1)	0.006
Grooming	3.5 (1.6)	4.4 (1.0)	0.016
Dressing	6.0 (3.7)	8.7 (2.5)	0.001
Bowels	7.9 (3.3)	9.5 (1.8)	0.011
Bladder	8.0 (2.7)	8.8 (2.3)	0.054
Toilet use	7.6 (3.0)	9.2 (2.4)	0.002
Transfers (bed to chair, and back)	14.3 (2.6)	14.3 (2.9)	0.655
Mobility (on level surfaces)	10.4 (4.5)	11.7 (4.2)	0.088
Stairs	6.7 (3.8)	8.0 (3.2)	0.022

Table 5
Caregivers' burden inventory subitems after treatment

Subitems Caregiver burden inventory (CBI)	Mean (SD) at baseline	Mean (SD) at 12 weeks	p
Objective burden	14.5 (5.7)	14.6 (6.5)	0.836
Psychological burden	12.5 (6.3)	9.5(6.9)	0.077
Physical burden	9.2 (5.9)	6.4 (5.0)	0.026
Social burden	4.4 (4.5)	13 (3.7)	0.006
Emotional burden	2.2 (3.7)	1.4 (3.1)	0.340

Table 6
Frequency of correct responses at the reality orientation therapy

Orientation	1st month	2nd month	3rd month	p
Temporal	60%	67%	69%	0.466
Personal	65%	74%	80%	0.014
Spatial	66%	77%	78%	0.132
Environmental	94%	97%	97%	0.780

Statistical analysis

Data are expressed as means (\pm standard deviation) for continuous variables and as proportions for categorical variables. Differences between groups were assessed using the t test for continuous data and the χ^2 test for categorical data. No statistical correction for multiple comparisons was conducted as this is an exploratory study. All analyses were performed using the SPSS statistical package (Version 17.0).

RESULTS

A statistically significant improvement was observed at the end of the 3-month home care assistance program in the overall NPI score ($p = 0.004$), Barthel index ($p = 0.01$), Tinetti's scale ($p = 0.013$) and CBI score ($p = 0.016$) (Table 2). When the NPI individual scores were considered, significant improvements emerged in depression ($p = 0.017$) and nocturnal behavior ($p = 0.014$), as well as an improvement at the limit of significance in anxiety ($p = 0.059$) and disinhibition ($p = 0.09$) (see Table 3).

As regards the Barthel index, a significant improvement was observed in all the items except transfers and mobility after the home care assistance program (Table 4).

The CBI also revealed a clearly significant improvement in the physical and social burden after the program ($p = 0.026$ and $p = 0.006$), whereas the improvement in the psychological burden was at the limit of significance ($p = 0.077$) (Table 5).

The ROT disclosed a significant improvement in personal orientation alone ($p = 0.014$) (Table 6).

The drug dosages were fairly consistent, though those of Risperidone (average increase = 0.15 mg) and Quetiapine (average increase = 12.5 mg) increased slightly (Table 7).

By the time the third, and last, evaluation was performed 3 months after the end of the program, both

patients and caregivers had lost the benefit previously observed at the end of the treatment period. Indeed, all the values that emerged 3 months after the end of the home care assistance program, particularly those of the NPI (46.14 ± 21.4), Barthel index (77.32 ± 25.76), Tinetti's scale (20.95 ± 7.4), CBI (42.4 ± 15.14) and CSI (6.95 ± 2.55), were no longer significantly different from the corresponding baseline values (Table 2).

In addition, the patients displayed a statistically significant cognitive deterioration over the 6 six-month study period (MMSE 19.39 ± 4.64 vs 20.94 ± 4.64 ; $p = 0.027$).

DISCUSSION

The comparison of the results of the tests administered at the start of the program and after 12 weeks of home care assistance revealed an improvement both in terms of the patients' cognitive and behavioral conditions and in their functional autonomy. The caregivers also displayed a reduction in burden and an improved emotional state. The degree of severity of the patients' systemic comorbidities, as assessed by means of the CIRS, was found to be stable at week 12, as were their drug therapies.

The Barthel scale data revealed an improvement in the functional deficits relative to the activities of daily living; this improvement was not identified by the BADL, most likely owing to the lower sensitivity of this instrument.

A general improvement in behavioural disorders was observed. When the individual items of the NPI were considered, there was a marked improvement in depression and anxiety; a significant improvement was also observed in apathy. Lastly, aberrant motor behaviour was reduced while neurovegetative disorders (sleep and appetite) appeared to improve.

The Tinetti's scale revealed an improvement in motor function; as opposed to be being due to changes in

Table 7
Pharmacological treatment of the patients

Drugs acting on the central nervous system	Total patients Receiving treatment	Range (mg/die)	Mean dosage (mg/die)	
			Baseline	12 ^a
Atypical antipsychotic drugs				
Risperidon	2	0.5-2.25	1.08 ± 0.55	1.23 ± 0.32
Quetiapine	3	50-150	112.5 ± 62.9	125 ± 45.01
Clozapin	1	25	25	25
Typical antipsychotic drugs				
Promazine	2	40	40 ± 0	40 ± 0
Antidepressants				
Trazodon	9	50-150	83.3 ± 30.6	83.3 ± 30.6
Escitalopram	1	10	10	10
Acetylcholinesterase inhibitors				
Donepezil	12	5-10	10 ± 0	10 ± 0
Rivastigmine	6	6-12	9.6 ± 3.29	9.6 ± 3.29
Galantamine	4	8-16	13.33 ± 4.13	13.33 ± 4.13

neuroleptic treatment, which was basically unchanged, this improvement is likely to be a direct consequence of the motor reactivation interventions administered during the period of home assistance.

Lastly, the results yielded by the ROT revealed a progressive improvement in stimulated cognitive activities, which is in keeping with the findings from previous studies [17].

Caregivers also benefited from burden relief (CBI) and an improved emotional state, as shown by the CSI.

The overall opinion of caregivers, who were asked to complete a questionnaire on the quality of the services received, was positive; indeed, they expressed appreciation both for the expertise of the multi-disciplinary team and for the empathic approach of the professional operators.

This type of home care assistance programme, designed to provide personalized functional reactivation treatment for patients suffering from Alzheimer's disease, appears to be an effective means of improving the patients' MMSE score. The patients' behavioural symptoms also appear to respond positively to these interventions, which in turn affects the quality of life of their caregivers, as highlighted by the improvement observed in some of the items of the CBI.

These data point to the usefulness of home care assistance in Alzheimer patients with mild and moderate disease. Indeed, in these stages of the disease, appropriate stimulation of the more preserved cognitive reserves may facilitate the recovery of some activities of daily living, thereby reducing the burden placed on the caregiver.

The caregivers' involvement in the home assistance programme may also help to improve the management of behavioural problems, thereby reducing the stress

associated with such problems.

In a previous study [48], conducted by us on a group of patients with probable moderate-to-severe Alzheimer's disease who received home care assistance for 52 weeks, we had observed that interventions aimed at functional reactivation in patients, even in disease stages in which functional reserves are lower, and the training of family members help to:

- 1) keep the residual abilities stable for a long period of time;
- 2) reduce behavioral disturbances;
- 3) reduce the caregiver's burden;
- 4) reduce the use of institutionalization.

The present work, like the vast majority of studies designed to assess the effects of care interventions on patients and carers, suffers from the absence of a control group.

Indeed, while on the one hand it is quite obvious that a welfare intervention, especially if well planned, can achieve positive results, the lack of a control group, on the other, makes it impossible to say whether this is a specific effect or a placebo effect. Moreover, the evaluations were performed by operators who were responsible for administering the treatment, and were thus not blinded to the treatment the patients received. This may have led to an overestimation of the effects observed.

It should, however, be borne in mind that the use of a control group in an outcome study on multicomponent care interventions in patients with dementia has numerous ethical limitations.

Moreover, the efficacy of individual treatments performed in this study on both the patients and their caregivers has been proven in previously conducted RCTs [1].

The observed benefit following the home care assistance programme may, to a minor extent, be attributed to slightly higher doses of Quetiapine and Risperidone used by 5 patients.

However, only the methodological rigor provided by a RCT would be able to answer the question regarding the efficacy of home treatment in patients with dementia.

The evaluations performed 3 months after the end of the home care assistance programme documented a return to the conditions observed at the start of the study. However, the lack of deterioration in the patients' dementia may itself be considered a positive outcome.

CONCLUSIONS

In this study, we show that a home care assistance program lasting 12 weeks in a group of 22 AD patients yielded an improvement both in terms of the patients' cognitive and behavioral conditions and in their

functional autonomy. The caregivers also displayed a reduction in burden and an improved emotional state. The evaluations performed 3 months after the end of the program documented a return to the conditions observed at the start of the study. We believe that further studies designed to evaluate home care assistance programs are warranted to better understand the effects of such interventions on demented patients.

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Conflict of interest statement

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