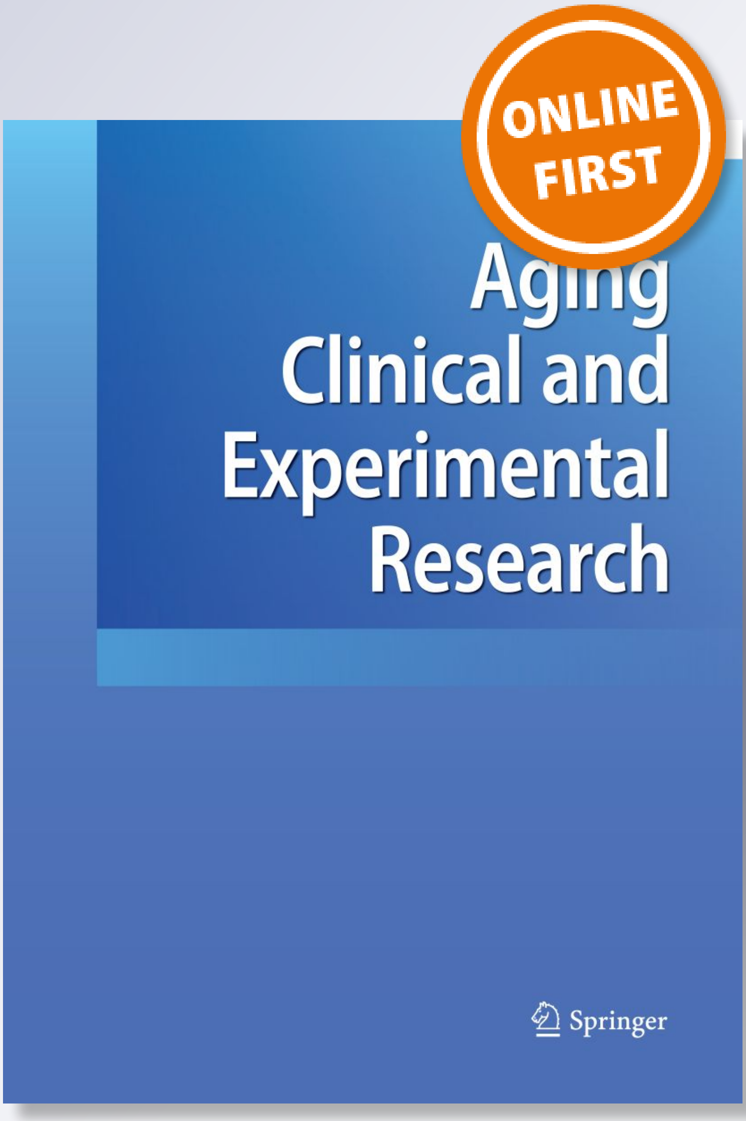
Alzheimer Café: an approach focused on Alzheimer's patients but with remarkable values on the quality of life of their caregivers

Paola Merlo, Maria Devita, Alessandra Mandelli, Maria Luisa Rusconi, Raquel Taddeucci, Alice Terzi, Gianpiero Arosio, et al.

Aging Clinical and Experimental Research

e-ISSN 1720-8319

Aging Clin Exp Res
DOI 10.1007/s40520-017-0844-2



Aging Clin Exp Res
DOI 10.1007/s40520-017-0844-2

ORIGINAL ARTICLE

Alzheimer Café: an approach focused on Alzheimer's patients but with remarkable values on the quality of life of their caregivers

Paola Merlo[1] · Maria Devita[2] · Alessandra Mandelli[1] · Maria Luisa Rusconi[2] · Raquel Taddeucci[3] · Alice Terzi[1] · Gianpiero Arosio[1] · Maria Bellati[3] · Maura Gavazzeni[3] · Sara Mondini[4,5]

Received: 15 June 2017 / Accepted: 3 October 2017

Abstract
Background Alzheimer's disease (AD) affects the global quality of life of persons who suffer from it and their caregivers, because of the behavioral and psychological consequences associated with the pathology and its caring. The Alzheimer Café (AC) is one example of approach aimed to help persons and caregivers deal with their disease.
Aim This is a pilot study focusing on the efficacy of AC in relieving caregivers' and persons' burdens due to dementia.
Methods The quality of life of both caregivers and persons who attended the AC was compared with the quality of life of those who did not. Basic and instrumental daily activities and neuropsychiatric functioning were assessed. Caregivers also answered to general well-being and caregiving burden questionnaires. The evaluation took place at the beginning of the intervention and after 1, 3, 6, 9 and 12 months.
Results Caregivers who joined the AC with their persons with dementia showed to have significantly benefited in the daily care of persons with dementia, in terms of total well-being, vitality, and emotional burden.
Discussion Although improvements were not observed in persons with dementia who attended the AC, significant benefits were reported by their caregivers, suggesting that the intervention may produce better management of social and economic problems and lead to better emotional support.
Conclusions The AC seems to help families of AD persons to better manage the disease, and also delay the institutionalization of these persons, which is certainly an ambitious goal for an incurable disorder such as Alzheimer's disease.

Keywords Alzheimer Café · Alzheimer's disease · Caregivers · Quality of life · Burden

Introduction

In recent years, significant improvement in quality of life has caused the inevitable rapid aging of the global population. As a result, the survival median has increased [1, 2], as have also the number and variety of neurodegenerative diseases [3]. Dementia is a progressive, public health, medical and social problem, and it is recognized as a cause of disability and death [4]. Alzheimer's disease (AD) is one of the most common dementias, characterized by neuropsychological (i.e., memory loss, apraxia, aphasia and agnosia) and neuropsychiatric (i.e., depression, behavioral disturbances and psychotic features) disorders [5]. This symptomatology requires constant assistance and care often provided by family members. Caregivers usually refer to this experience as "enduring stress and frustration" [6]. Eighty percent of AD caregivers usually show high levels of stress and almost half of them suffer from depression [7]. For example, caring for a person with AD may require the caregiver to diminish his/her working hours or to leave work altogether, thus producing depression and social isolation and even aggressiveness towards the patient with the consequence of feeling guilty. Indeed, although in the earliest stages of the disease, persons

✉ Maria Devita
maria.devita@unibg.it

[1] Neurological Unit, U.V.A. Centre, Humanitas Gavazzeni, Via Mauro Gavazzeni, 21, 24125 Bergamo, Italy

[2] Department of Human and Social Sciences, University of Bergamo, P.le S. Agostino 2, 24129 Bergamo, Italy

[3] Humanitas Foundation, Elios Project, Bergamo, Italy

[4] Department of General Psychology, University of Padua, Via Venezia 8, 35131 Padua, Italy

[5] Human Inspired Technology Research Centre, University of Padua, Padua, Italy

need only assistance with the most difficult tasks, in the later stages, the demands on caregivers in terms of physical and psychological resources are enormous and it becomes necessary to help the patient also in the most basic daily activities such as feeding and bathing. Furthermore, caregivers frequently have to cope with behavioral disorders such as anxiety, psychomotor agitation, depression, wandering and hostility. All psychological and relational consequences of dementia [8] have a serious impact on families, and any suitable supports for both persons with dementia and families are helpful.

As it is widely recognized, caregivers of persons with AD commonly show high levels of psychological distress. Emotional involvement, comprehension and acceptance of a disease that currently does not have a specific cure, are all factors to be considered for their emotional impact on the caregiver's life [9]. Because of these aspects, researchers and clinicians have been encouraged to find interventions that could deal with the manifold consequences of caregiving. Caregivers of persons with dementia can certainly be considered as "the invisible second patients" [10], so that their care becomes fundamental to guaranteeing better quality of life for themselves and for their relatives. Soresen et al. [11] distinguished caregivers' oriented interventions in those aiming to reduce the amount of care directed to persons with dementia, and those whose goal is to improve caregivers' well-being, helping them adequately cope with the disease and its consequences [11]. Several meta-analysis and review papers have given overviews of the most effective interventions aiming to reduce caregivers' burden. The majority of studies generally propose psycho-educational interventions as the most effective [11–14]. However, it has also been suggested that psycho-educational interventions alone can lose their own efficacy if not appropriately integrated with other supports [13]. For example, a relevant role was attributed to psychotherapy [11] and to short personalized interventions [15]. More conflicting data exist on whether interventions should be carried out in individual or in group sessions. In this regard, Knight et al. [14] found that individual psycho-educational interventions have the strongest effects on benefiting caregivers. However, these conclusions seem to be denied by more recent findings [11, 13, 15], which highlighted the better efficacy of group interventions. What all these studies justifiably suggest is that a single isolated intervention is not enough to deal with the many difficulties linked to caregiving. A combination of different kinds of interventions and treatments would therefore help better cope with the burdens and struggles of the disease. In addition, as Brodaty et al. [13] proposed, the involvement of persons with dementia in structured programs specifically designed for caregivers would be extremely useful if they included everyone concerned, patients too. In this regard, the Alzheimer Café (AC) could be considered as one of the most representative examples of multi-composed interventions. This approach was originally developed in order to reduce the social isolation that the disease creates around persons with dementia and caregivers, improving quality of life for both of them. The AC is conceived as a space and time for persons with dementia, caregivers and family members who can find a place where to exchange ideas, information and experiences. The aim of the AC is to provide support to patients and their caregivers helping them deal with the disease. This intervention has three main purposes: (1) to inform about medical and psychosocial aspects of dementia; (2) to discuss persons' with dementia problems openly and directly, and (3) to prevent the isolation of patients and their families. In the AC, families have the opportunity to meet people with similar experiences, to develop new ways for interpersonal exchanges, and to stay with other people and other persons with the same disease. Participating in pleasant activities promotes positive communication and well-being in these persons. In the AC, caregivers and patients can share old memories, which are generally easily recalled by people with dementia, thus highlighting the person's well-maintained abilities, rather than their impairments [16]. Results from previous studies showed that the AC allowed all participants (i.e., both persons with dementia and their caregivers) to improve their communication skills [17], to exchange experiences with others in similar conditions, and to regulate the emotions that the disease and its care can trigger [18]. Self-reports of persons with dementia have been also published reflecting participants' satisfaction after attending the AC [19].

To conduct this study, we created an Alzheimer Café in the garden of our clinic to welcome AD persons, caregivers and their families, in order to recreate the environment just described. We compared quality of life and impact of psychological, emotional and social burdens of caregivers coming to the AC with a control group of caregivers whose persons with dementia did not attend the AC. Furthermore, we followed the change over time of the functional impairment and psycho-behavioral disorders of AD persons who attended the AC, and then we compared it with a group of persons with dementia who did not attend the AC. Since our AC was conceived to involve the interventions that were deemed as the most efficient in reducing caregivers' distress, we hypothesized that benefits would occur in those who attended the AC and not in those who did not. As a matter of fact, our AC combined the activities—for details, see "Materials and Methods"—that were previously reported to be effective for these purposes [18, 19]. However, we did not expect the efficacy of the AC in reducing patients' functional and psycho-behavioral impairments to last over time. Because of the well-recognized degenerative nature of AD, we thought that stabilization of symptoms would be more credible and predictable than real amelioration.

Materials and methods

All participants were recruited in a Unit for Alzheimer's evaluation in Bergamo (northern Italy) and the diagnosis was made after extensive neurological assessment and neuropsychological evaluation. The participation of persons with dementia/caregivers in the AC project was decided on a voluntary basis. Those who agreed to our project received information about the study, its objectives and procedures. The study was approved by the local Ethics Committee and all participants signed an informed consent form. Participants usually met in groups in the garden of the hospital 1 day a week, and each meeting lasted 2 h. A psychologist was present at all times during the meetings. Some volunteers, purposely trained for adequate interaction with AD persons, were also involved. Their number guaranteed a 1:1 ratio with patients. All caregivers attended self-help groups coordinated by the psychologist, who was also able to arrange individual interviews for people who needed more focused and personalized support. In this way, caregivers could share their experiences and exchange opinions and feelings with the other caregivers and with the psychologist. At the same time, persons with dementia were entertained with simple and recreational occupations such as playing cards, talking to each other, and recalling memories from the past on topics chosen each time by the volunteers. During the meetings, some convivial moments were planned, such as drinking coffee together, which gave the feeling and rhythm of a family gathering. Persons with dementia were helped to arrange a snack time and all participants were invited to join in. Each activity aimed to recreate specific moments of interaction among participants, making sure that social exchanges occurred not just "within" groups (patients with patients and caregivers with caregivers) but also between groups. Persons with dementia were also taken for short walks in the hospital garden by the volunteers. Caregivers were encouraged to join in, entertaining their own patients with conversations about the surrounding natural elements (e.g., flowers and plants) which were also used to stimulate their senses and elicit memories [20]. A team composed of one psychologist, two neurologists and two physicians met weekly in order to supervise the participants' progress.

Participants

Twenty persons with a diagnosis of dementia and 20 caregivers participated in the study.

Persons with dementia and caregivers were divided in four groups:

1. Ten persons with dementia who attended the AC-experimental group.
2. Ten persons with dementia who did not attend the AC-control group.
3. Ten caregivers of persons with dementia who attended the AC.
4. Ten caregivers of persons with dementia who did not attend the AC.

No more than ten persons with dementia and ten caregivers were included in order to facilitate communication and encourage an efficient relational exchange. A bigger group of participants would have created a barrier for intimate and confidential relationships among participants. Table 1 shows the characteristics of persons with dementia and their caregivers.

The four groups were followed up for 1 year: they were evaluated at the beginning of the AC (T0) and after 1 (T1), 3 (T3), 6 (T6), 9 (T9) and 12 months (T12).

Patient inclusion criteria

- Males and females, aged 55–90, diagnosed with probable Alzheimer's disease according to the international diagnostic criteria [21];
- MMSE (Mini-Mental State Examination) score between 10–24/30 [22].

Caregiver inclusion criteria

Males and females, aged 18–80, who cared for the persons with dementia daily (spouses and daughters).

Patient exclusion criteria

- Psychiatric comorbidities.
- General or neoplastic pathologies.
- Advanced dementia (MMSE < 10).

Caregiver exclusion criteria

- Psychiatric disorders.
- General or neoplastic pathologies.

Caregivers' eligibility to the study was evaluated with a qualitative clinical interview carried out by an expert psychologist who attested their normal psychiatric and cognitive functioning.

Table 1 Characteristics of participants

Characteristics of persons with dementia	AC (*n* = 10)	No AC (*n* = 10)
Mean age ± SD	75.8 ± 9.96	77.6 ± 4.03
Gender, F/M	4/6	7/3
Therapy		
Acetylcholinesterase inhibitor (AchE-I)	5	5
Memantine	3	2
Combination therapy (AchE-I + Memantine)	1	2
Neuroleptics	4	2
Antidepressant	4	7
Cardiovascular risk factors	4	6
Caregivers' characteristics		
Mean age ± SD	65.4 ± 9.96	61.4 ± 13.06
Gender, F/M	8/2	6/4
Caregivers' relationship to person with dementia		
Spouse, *n*	6	3
Daughter, *n*	4	7

AC participants who attended the Alzheimer Café, *No AC* participants who did not attend the Alzheimer Café, *SD* standard deviation

Tools

Persons with dementia were evaluated by means of:

- The Basic Activities of Daily Living (BADL) to assess functional mobility and personal care [23].
- The Instrumental Activities of Daily Living (IADL) to assess instrumental activities of daily living functions [24–26].
- The Neuropsychiatry Inventory (NPI) for the assessment of psychological and behavioral disorders [27]. We considered only the scores for severity and caregiver distress.

Caregivers were evaluated by means of:

- The Psychological General Well-Being Inventory (PGWBI) for the multidimensional assessment of psychological well-being. It analyses the psychological-emotional burden through six domains: anxiety, depression, positive and well-being, self-control, general health, and vitality [28]. A global score is provided.
- The Caregiver Burden Inventory (CBI) for the multidimensional evaluation of caregiver burdens [29]. The CBI consists of 24 questions grouped into five different domains: "The time-dependence burden", which includes items (1–5) estimating the time needed by the caregiver to care for the patient; "The developmental burden", which includes items (6–10) evaluating the regret for missed opportunities and feelings for life expectations as a result of care commitments; "The physical burden", which includes items (11–14) describing feelings of chronic fatigue and possible health problems of psychosomatic nature; "The social burden", which includes items (15–19) evoking the caregiver's feelings on relationships with other members of the family and the possible presence of family conflicts; "The emotional burden", which includes items (20–24) concerning the negative feelings of the relative providing the care towards his/her family.

Descriptive baseline statistics are reported in Table 2.

Statistical analysis

A Mann–Whitney test was conducted in order to compare baseline performances of all groups. Linear regression models analyzed the effect of GROUP on the dependent variables. AGE, SEX, CBI SOCIAL BURDEN, PGWBI GENERAL HEALTH, MMSE and NPI scores were used in all caregivers' analyses as covariates because of their potential confounding effects on the dependent variables. Only AGE and SEX were used as covariates for the AD persons' groups. Covariates were selected not only as a result of the difference that emerged between groups at the baseline (statistical approach), but also in line with theoretical and clinical criteria [30], according to which covariates can be chosen based on background knowledge [31]. Because of the small samples, relative difference scores were used to evaluate the extent of change of the dependent variables over time and were implemented in the linear regression models.

Table 2 Characteristics of persons with dementia and caregivers who attended the Alzheimer Café (AC) compared with those who did not (no AC), before (PRE AC) and after (POST AC) the intervention

	PRE AC					POST AC				
	Persons with dementia (mean ± DS)		Caregivers (mean ± DS)		*p* value*	Persons with dementia (mean ± DS)		Caregivers (mean ± DS)		*p* value*
	AC	No AC	AC	No AC		AC	No AC	AC	No AC	
MMSE	15.3 ± 5.9	14.4 ± 4			0.91	10.1 ± 7.7	10.4 ± 3.5			0.95
BADL	4.8 ± 1.4	3.6 ± 1.7			0.07	3.1 ± 1.7	2.5 ± 1.4			0.60
IADL	2 ± 2.4	1.5 ± 1.4			0.68	0.71 ± 1.1	0.4 ± 1.2			0.36
NPI	3.1 ± 4.5	10.8 ± 9.1			0.03	7.8 ± 5.4	11.1 ± 8			0.53
PGWBI total score			81.1 ± 3.9	77.8 ± 4.9	0.15			77.5 ± 3.6	77.8 ± 4.2	0.88
PGWBI positive well-being			14.4 ± 1.9	13.8 ± 1.5	0.28			13.8 ± 1.2	13.5 ± 1.5	0.53
PGWBI general health			13 ± 1	11.1 ± 1.8	0.03			12.4 ± 1.1	10.8 ± 1.4	0.03
PGWBI depressed mood			18 ± 1.4	17.7 ± 1.9	0.95			17.4 ± 1.1	17.3 ± 2.6	0.47
PGWBI self-control			8 ± 1	7.4 ± 1.7	0.30			7.1 ± 0.6	7.5 ± 2	0.88
PGWBI anxiety			16.1 ± 2.5	16.2 ± 1.3	0.58			16 ± 1.1	15.4 ± 1.6	0.47
PGWBI vitality			11.5 ± 7	11.6 ± 1.7	0.33			10.7 ± 0.48	13.3 ± 2.1	0.05
CBI total score			30.1 ± 12.6	35.5 ± 6.4	0.49			30.4 ± 8.7	45.8 ± 19.2	0.07
CBI time dependence			11.5 ± 2.6	10.9 ± 5.1	0.73			16.2 ± 2.4	15.5 ± 4.3	1.0
CBI developmental			7.5 ± 5.2	8.3 ± 6.1	0.96			7.2 ± 7	10.5 ± 6.7	0.23
CBI physical burden			4.1 ± 2.5	6.4 ± 5.2	0.49			2.4 ± 1.7	7.8 ± 5.5	0.04
CBI social burden			0.4 ± 0.5	2.7 ± 3	0.05			1.8 ± 2.5	5.9 ± 5.7	0.16
CBI emotional burden			4.4 ± 3.8	4.2 ± 5.5	0.53			2.5 ± 2.9	6.1 ± 6.4	0.27

P value* *U* Mann–Whitney test

MMSE Mini-Mental State Examination, *BADL*, Basic Activities of Daily Living, *IADL* Instrumental Activities of Daily Living, *NPI* Neuropsychiatric Inventory, *PGWBI* Psychological General Well-Being Inventory, *CBI* Caregiver Burden Inventory

Results

Persons' with dementia results

At the baseline, the groups did not differ for AGE, MMSE ($\beta = 0.10$, $t = 0.37$, $p = .71$), BADL ($\beta = 0.39$, $t = 1.64$, $p = .12$) and IADL ($\beta = 0.04$, $t = 0.18$, $p = .85$) scores, while differences emerged for the NPI variable ($\beta = -.46$, $t = -2.07$, $p = .05$). No significant effects of GROUP were found on the extent of CHANGE over time.

Caregivers' results

At the baseline, the groups only differed in the CBI SOCIAL BURDEN and PGWBI GENERAL HEALTH scores, which were then used as covariates in our statistical model. A significant confounding effect of these variables on the SELF-CONTROL PGWBI subscale was found. Significant effects of GROUP emerged on the extent of CHANGE over time on the PGWBI TOTAL ($\beta = -0.63$, $t = -2.29$, $p = .04$) and on the VITALITY ($\beta = -0.46$, $t = -2.23$, $p = .04$) scores. As for the CBI measure, significant GROUP effects were found only at the EMOTIONAL ($\beta = -0.68$, $t = -3.04$, $p = .01$) scale.

Table 3 shows a summary of all results.

Discussion

From the Introduction it is clear that the aim of the AC is to educate about the AD symptoms, to overtly discuss the problem, but also to make the disease more acceptable to both persons with dementia and caregivers. AC members share their own experiences, problems and/or information about dementia and all possible ways to deal with them. The purpose of the present study was to describe the effect of the AC on the well-being of AD persons and their families. Furthermore, we evaluated the subjective burden of caregivers [4–12] to better understand the level of their stressful situation. Baseline findings showed that the performance on MMSE, BADL and IADL tests of the AD persons who had decided to attend the AC was similar to that of the persons with dementia who had not attended the AC. It could be that the difference showed at the baseline NPI scores may have influenced the decision to join the intervention. Higher neuropsychiatric scores suggest the existence of behavioral disorders that could have prejudged the wish to share the illness experience with other persons with dementia. Significant differences in the social burden and general health variables also emerged between caregivers who attended the AC and those who declined to attend it. Social isolation might influence the decision to join interventions and

Table 3 Percentage of change in persons with dementia and caregivers who attended the Alzheimer Café (AC) and those who did not (no AC)

	AC		No AC		*d*′ Cohen	*β**	*p**
	Mean difference	SD	Mean difference	SD			
Persons with dementia							
MMSE	7.50	31.59	9.10	13.94	− 0.57	0.44	0.10
BADL	7.50	24.84	10.05	24.56	− 0.51	0.21	0.47
IADL	11.57	39.33	7.20	48.30	1.10	−0.34	0.25
NPI	10.86	225.79	7.70	349.23	0.10	0.08	0.77
Caregivers							
PGWBI total score	7.29	7.17	10.20	2.4	− 0.79	0.62	**0.04**
PGWBI positive well-being	9.57	8.59	8.60	6.08	− 0.15	0.29	0.31
PGWBI general health	8.29	5.79	9.50	7.67	− 0.33	0.28	0.22
PGWBI depressed mood	9.14	11.80	8.90	9.24	0.01	0.33	0.29
PGWBI self-control	6.43	10.30	10.80	9.53	− 1.11	0.30	0.42
PGWBI anxiety	9.79	25.64	8.45	7.17	0.39	−0.13	−0.41
PGWBI vitality	4.64	7.26	12.05	15.70	− 1.82	0.59	**0.05**
CBI total score	7.57	40.74	10.00	846.27	− 0.04	0.33	1.22
CBI time dependence	9.64	52.93	8.55	560.57	− 0.39	0.29	0.30
CBI developmental	6.79	77.90	10.55	45.01	− 0.41	0.27	0.39
CBI physical burden	8.21	90.61	9.55	24.79	− 0.46	0.02	0.93
CBI social burden	7.64	223.60	9.95	149.78	− 0.09	0.08	0.78
CBI emotional burden	4.71	31.06	12.00	42.89	− 1.83	0.67	**0.01**

The scores of persons with dementia were adjusted for AGE and SEX, while those of Caregivers were adjusted for AGE, MMSE, NPI scores

MMSE Mini-Mental State Examination, *BADL* Basic Activities of Daily Living, *IADL* Instrumental Activities of Daily Living, *NPI* Neuropsychiatric Inventory, *PGWBI* Psychological General Well-Being Inventory, *CBI* Caregiver Burden Inventory activities in which interpersonal exchanges are encouraged. Similarly, general medical impairments could represent a real impediment in daily activities, which, in turn, could increase the just mentioned social isolation. As for the evaluation of symptoms over time, the general progression of the disease, in terms of neurocognitive and neurobehavioral symptoms, was similar in persons with dementia attending the AC and in those who did not. Furthermore, data obtained from the MMSE, the BADL, the IADL and the NPI scales showed no significant differences between the two groups of persons with dementia. These findings are clearly and not surprisingly congruent with our expectations and with the normal evolution of the disease, in which cognitive and behavioral disorders become increasingly severe, although tentative stimulation approach such as the AC. However, different and more promising results were observed among the caregivers. As mentioned above, the caregivers' subjective burden is particularly significant. Emotional and physical disorders, reduced time for oneself, sense of abandonment and inability in family management are all factors that contribute to a reduction of the caregiver's quality of life. However, after attending the AC with their persons with dementia, the caregivers showed increased "PGWBI Total" and "Vitality", whereas other items did not reveal any statistical difference (i.e., health, anxiety and depression). Although a series of problems still remain, our results seem to suggest that global well-being and vitality perception can improve after the AC treatment. Health, Anxiety and Depression have not been affected by the intervention. They are more resistant to change as the caregivers are aware of the inevitable evolution of the disease. In any case, these results suggest that the social/emotional care, the avoidance of isolation by empowering people to communicate with others who share a similar condition and informal discussions with trained members of the staff seemed to generally increase the perceived energy needed to cope with daily difficulties. This is a very important effect of the AC and its usefulness in helping caregivers cope with the burden of their care has been supported in this study. Despite the small size of the samples, large effect sizes [32] emerged for all of the significant findings reported, thus supporting the goodness of the results. The majority of variables showed large effect sizes which, although not reaching significance, encouraged us to investigate more in depth. Some authors maintain that improvement in caregivers' management of the disease has been associated with persons' with dementia better feelings of well-being [13]. This was not supported by our results, but the AC effects on caregivers did reflect on our persons with dementia, who actually perceived greater well-being and general satisfaction. As stated in "Materials and methods", all participants had been informed about the study, its objectives and procedures, making our study not blind and, as a result, the findings reported could have been affected by this methodological decision. However, we strongly believe that the regular exchange with a psychologist, who carried out individual interviews, the direct communication between different medical and health figures and the mutual self-help among participants may have been crucial elements for the successful outcome of the AC for caregivers. These aspects contribute to the existing literature about caregivers' interventions by suggesting that the AC is a valid and fairly efficient intervention for this population. The activities of our AC were chosen in the light of interventions reported as the most effective in reducing caregivers' burden associated with looking after persons with dementia. The AC can train caregivers and families of AD persons to better manage the disease and could also lead to postpone the institutionalization of these persons, which is certainly an ambitious goal (see the "National Plan of Dementia" [33]) for an incurable disorder such as Alzheimer's disease.

Limitations of the study

We are aware of some weaknesses in our study. First of all, our samples are small and, as this is in fact a pilot study, further research is needed to confirm our results. A limitation is also the lack of information about how long caregivers devoted to caring for their persons with dementia. It is reasonable to assume that the time spent caregiving might influence caregivers' perception of their burden. We did not originally collect this information and our results may be affected by this confounding factor. Furthermore, caregivers were included in our study after a clinical interview that attested normal psychiatric and cognitive functioning, without however the support of quantitative/psychometric measures. Finally, as already mentioned above, all participants had been informed about the objectives and procedures of the study, and this could have influenced our findings. Our data, therefore, should be considered with caution.

Acknowledgements We are grateful to the Humanitas Foundation-Project Elios Humanitas Gavazzeni, Bergamo, and to all the Volunteers. This research did not receive any specific Grant from funding agencies in the public, commercial, or not-for-profit sectors.

Compliance with ethical standards

Conflict of interest No potential conflict of interest was reported by the authors.

Statement of human and animal rights This study was conducted with respect of animals and humans rights.

Informed consent An Informed consent has been provided by all participants.

References

1. Marengoni A, Von Strass E, Rizzuto D et al (2009) The impact of chronic multimorbidity and disability on functional decline and survival in elderly persons. A community-based, longitudinal study. J Intern Med 265:288–295
2. Fratiglioni L, Launer LJ, Andersen K (2000) Incidence of dementia and major subtypes in Europe: a collaborative study of population-based cohorts. Neurol Dis Elder Res Group Neurol 54(Suppl 5):10–15
3. Vanacore N, Maggini M, Raschetti R (2005) Centro Nazionale di Epidemiologia, Sorveglianza e Promozione della Salute, ISS "Epidemiologia della demenza di Alzheimer in Italia". BEN-Notiziario ISS, vol 18, n. p 2
4. Elliott AF, Burgio LD, DeCoster J (2010) Enhancing caregiver Health: findings from the resources for enhancing Alzheimer's caregiver Health II intervention, vol 58, p 30
5. Donaldson C, Burns A (1999) Burden of Alzheimer's disease: helping the patient and caregiver. J Geriatr Psychiatry Neurol 12:21–28
6. Butcher HK, Holkup PA, Buckwalter KC (2001) The experience of caring for a family member with Alzheimer's disease. West J Nurs Res 23:33–55
7. American Psychiatric Association (2013) Diagnostic and statistical manual of mental disorders, fifth edition, DSM-5. American Psychiatric Publishing, Arlington
8. De Rotrou J, Cantegreil I, Faucounau V et al (2011) Do patients diagnosed with Alzheimer's disease benefit from a psycho-educational programme for family caregivers? A randomised controlled study. Int J Geriatr Psychiatry 26:833–842
9. Kitwood T (1997) The concept of personhood and its relevance for a new culture of dementia care. In: Caregiving in dementia research and applications, vol II. Routledge, London, pp 3–13
10. Brodaty H, Donkin M (2009) Family caregivers of people with dementia. Dialogues Clin Neurosci 11:217
11. Sörensen S, Pinquart M, Duberstein P (2002) How effective are interventions with caregivers? An updated meta-analysis. Gerontologist 42:356–372
12. Beinart N, Weinman J, Wade D et al (2012) Caregiver burden and psychoeducational interventions in Alzheimer's disease: a review. Dement Geriatr Cogn Disord Extra 2:638–648
13. Brodaty H, Green A, Koschera A (2003) Meta-analysis of psychosocial interventions for caregivers of people with dementia. J Am Geriatr Soc 51:657–664
14. Knight BG, Lutzky SM, Macofsky-Urban F (1993) A meta-analytic review of interventions for caregiver distress: recommendations for future research. Gerontologist 33:240–248
15. Martin-Carrasco M, Ballesteros-Rodríguez J et al (2013) Interventions for caregivers of patients with dementia. Actas Esp Psiquiatr 42:300–314
16. Woods RT, Bruce E, Edwards RT et al (2009) Reminiscence groups for people with dementia and their family carers: pragmatic eight-centre randomised trial of joint reminiscence and maintenance versus usual treatment: a protocol. Trials 10:64
17. Eggenberger E, Heimerl K, Bennett MI (2013) Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. Int Psychogeriatr 25:345–358
18. Capus J (2005) The Kingston Dementia Café: the benefits of establishing an Alzheimer café for carers and people with dementia. Dementia 4:588–591
19. Mather L (2006) Memory Lane Café: follow-up support for people with early stage dementia and their families and carers. Dementia 5:290–293
20. Heyn P (2003) The effect of a multisensory exercise program on engagement, behavior, and selected physiological indexes in persons with dementia. Am J Alzheimer's Dis Other Dement 18:247–251
21. Dubois B, Feldman HH, Jacova C et al (2007) Research criteria for the diagnosis of Alzheimer's disease: revising the NINCDS–ADRDA criteria. Lancet Neurol 6:734–746
22. Folstein MF, Folstein SE, McHugh PR (1975) Mini-mental state. A practical method for grading the cognitive status of patients for the clinician. J Psychiatr Res 12:189–198
23. Katz S, Ford AB, Moskowitz RW (1963) Studies of Illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. Jama 185:914–919
24. Lawton MP, Brody EM (1969) Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist 9:179–186
25. Lawton MP (1988) Scales to measure competence in everyday activities. Psychopharmacol Bull 24:609–614
26. Barberger-Gateau P, Commenges D, Gagnon M et al (1992) Instrumental activities of daily living as a screening tool for cognitive impairment and dementia in elderly community dwellers. J Am Geriatr Soc 40:1129–1134
27. Cummings JL, Mega M, Gray K et al (1994) The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. Neurology 44:2308–2314
28. Grossi E, Mosconi P, Groth N (2002) Il Questionario Psychological General Well-Being. Versione Italiana.: Edizioni "Mario Negri"
29. Novak M, Guest C (1989) Application of a multidimensional caregiver burden inventory. Gerontologist 29:798–803
30. Bursac Z, Gauss CH, Williams DK et al (2008) Purposeful selection of variables in logistic regression. Source Code Biol Med 3:17
31. Velentgas P, Dreyer NA, Nourjah P et al (2013) Developing a protocol for observational comparative effectiveness research: a user's guide. Agency for Healthcare Research and Quality (US), Rockville
32. Cohen Jacob (1988) Statistical power analysis for the behavioral sciences. Routledge, US. ISBN 1-134-74270-3
33. Fargo KN, Aisen P, Albert M et al (2014) 2014 Report on the milestones for the us national plan to address Alzheimer's disease. Alzheimers Dement 10:S430–S452