

Research article Ερευνητική εργασία

The burden of caring for patients with dementia and its predictors

A.A. Mougias,¹ A. Politis,² M.A. Mougias,¹ I. Kotrotsou,¹
P. Skapinakis,³ D. Damigos,³ V.G. Mavreas³

¹*Alzheimer Center of the Greek Psychogeriatric Association "Nestor", Athens,*

²*Department of Psychiatry, Eginition Hospital, School of Medicine, University of Athens, Athens,*

³*Department of Psychiatry, School of Medicine, University of Ioannina, Ioannina, Greece*

Psychiatriki 2015, 26:28–37

Dementia not only affects patients but also care providers. The assessment of Caregivers' Burden (CB) has grown exponentially in the dementia field, as studies have shown that it is higher in dementia than in other diseases. Dementia care in Greece is different compared to other developed countries, as most of the patients receive care at home from family members. The aim of the present study was to examine the level of burden in Greek caregivers who live in Athens, and its association with patient and caregiver factors. This was a cross-sectional study of 161 primary caregivers of dementia patients living in the community and attending a secondary clinic. CB was assessed with the Zarit Burden Interview (ZBI) and caregivers' depression with the Center for Epidemiological Studies Depression Scale (CES-D). Clinical characteristics of the patients were also assessed using validated scales (cognitive status, functional ability, neuropsychiatric symptoms). In order to find predictors of caregiver Burden, we conducted a 3-step hierarchical regression analysis. Most patients were suffering from Alzheimer's Dementia (n=101; 62.73%) and had moderate and severe dementia according to the MMSE score (mean MMSE=11.50), with patients being unable to perform 2 basic activities of daily living on average. 45 patients (27.95%) had depression according to the CSDD; only 5 patients didn't have any behavioral problem in the NPI, while patients had more than 5 behavioral problems on average. Caregivers were involved in their role for 3.6 years on average and the mean weekly caregiving time was more than 70 hours. Nearly half (n=80; 49.06%) of the 161 caregivers demonstrated high CB (ZBI >40) and nearly one fourth had depression according to the CES-D scale. All blocks of variables entered into the regression model independently predicted caregiver burden's variance (demographics, clinical factors and caregiving characteristics). Lower caregiver's age, high behavioral symptoms of dementia patients and caregivers' depression were found to be independently associated with CB. The final regression model explained 47.2% of the variance in CB. Dementia causes a great burden in caregivers. CB is a

complex issue that is associated with several patients and caregivers' factors. The level of CB should be assessed in everyday dementia clinical practice.

Key words: Alzheimer's disease, dementia, caregiver, burden.

Introduction

Dementia is a chronic deteriorating condition. Symptoms of dementia include cognitive and functional decline, behavioral problems, lack of insight, and personality change on the part of patients. As a result, all areas of daily life are hampered, not only for patients themselves but also for their caregivers.^{1,2}

The concept of burden has been developed in order to study the effects of caring. Caregiver burden is a term that includes all the consequences of caring for a chronically ill patient: economic, social, physical and psychological.³ It is divided into objective and subjective burden. Objective burden is the result of care on family life and includes items such as activities of daily living, economic and physical health of family members. Subjective burden refers to how caregivers perceive the burden of care and its emotional impact.⁴ Caregiver burden is increasingly recognized as a key component in dementia treatment. Its study has grown considerably in the past decade and has been used to evaluate the impact of pharmacological and non-pharmacological treatments in dementia and the effectiveness of social and health services.⁵

Caregivers of patients with dementia experience greater burden than caregivers of patients with other chronic diseases,⁶ for example compared to carers of patients with cancer.⁷ Caregivers of patients with dementia also report greater cost, less free time and more difficulty in working than similar aged matched caregivers of patients with physical disabilities.⁸ The same has been reported for depression⁹ and anxiety.¹⁰ Dementia care in Greece differs compared to many other countries in that the vast majority of patients (>95%) receive care at home from family members. Community services for dementia in Greece are developing and the need to establish these as policy priorities is urgent. We have highlighted the importance of caregiver factors in contributing patients' Quality of life in a companion study.¹¹

The main objective of this study was to evaluate the prevalence of burden experienced by caregivers of dementia patients in Greece and its association with the sociodemographic, psychological and clinical characteristics of patients and caregivers.

Material and method

Participants

The study took place in a memory clinic of the Psychogeriatric Association "Nestor", a Non-Profit Organization offering free of charge services for dementia patients and their families in Athens, Greece. 200 community residing patients and their primary caregivers were invited to participate in the study, when they contacted the service by phone for the first time. Patients were invited only if they had a dementia diagnosis and their primary caregivers were available. A total of 197 caregivers responded positively after one reminder. 11 patients did not show up at the interview, 24 patients did not meet the inclusion criteria of the study (most commonly, they didn't have dementia) and one caregiver stopped before the end of the study. Thus the study participants consisted of 161 patients and their primary

Table 1. Patient and caregiver demographic characteristics (n=161).

<i>Patients' demographics</i>	
Female gender (%)	109 (67.70)
Age (SD)	76.87 (7.03)
Married (%)	85 (52.80)
Years of education (SD)	8.24 (4.44)
<i>Caregivers' demographics</i>	
Female gender (%)	110 (68.32)
Age (SD)	59.18 (13.88)
Married (%)	123 (76.40)
Years of education (SD)	11.61 (3.96)
<i>Kinship relationship to the patient (%)</i>	
Adult child	72 (44.72)
Husband or wife	71 (44.10)
Other	18 (11.18)

Table 2. Disease and caregiving characteristics (n=161).

Age of dementia onset (SD)		72.97 (7.61)
Dementia type (%)		
AD		101 (62.73)
VD		32 (19.88)
DLB		13 (8.07)
FTD		13 (8.07)
PD		2 (1.24)
Severity of the disease (%)		
MMSE	20–30	40 (24.84)
»	10–19	56 (34.78)
»	0–9	65 (40.37)
Stay in relation to the patient (%)		
Same house (%)		107 (66.46)
Same building (%)		20 (12.4)
Same neighbourhood (%)		9 (5.6)
Same town (%)		24 (14.9)
Other town (%)		1 (0.6)
Years of caregiving (SD)		3.6 (2.61)
Weekly caregiving hours (SD)		73.11 (40.89)
Professional caregiver at home (%)		35 (21.75)
Health problems (SD)		1.38 (0.59)

AD=Alzheimer Disease, VD=Vascular Dementia, LBD=Lewy Body Dementia, FTD=Frontotemporal Dementia

caregivers. All patients met the diagnostic criteria for dementia according to DSM-IV-TR.¹² Caregivers were all primary, informal caregivers, involved in their role for at least two hours, twice a week.

Procedure

The study took place between May 2007 and April 2008. All caregivers and patients signed their written consent before their enrollment in the study, which

was approved by the Ethics Committees of both the Psychogeriatric Association and the Department of Psychiatry, Medical School of the University of Ioannina. Patients and caregivers were seen separately when they visited one of the consultation clinics for the first time. Demographic factors and scales on patients were completed by a neuropsychologist; caregiver demographic factors and scales were completed by a Psychiatrist. On the same day, the psychiatrist interviewed both patient and caregiver, in order to complete the Cornell Scale for Depression in Dementia and make the diagnosis of dementia (table 3). Both professionals received special training for scale administration and had at least 3 years of working experience with dementia patients.

Measures

Demographic data (gender, age, education and patient-caregiver family relationship) were collected for both patients and caregivers. Specific disease characteristics (age of dementia onset, dementia subtypes) were also assessed, as well as specific caregiving characteristics: whether the caregiver was living with the patient, weekly caregiving time, years of caregiving, presence of professional caregiver and subjective number of caregiver's diseases posing problems in the caregiving process.

Dementia type was diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders criteria (DSM-IV; American Psychiatric Association, 2000) for the diagnosis of Alzheimer's disease (AD) and vascular dementia (VD), consen-

Table 3. Patient and caregiver assessment variables (n=161)

Scale	Mean	SD	Range	alpha	Rater	Professional
Patient assessment variables						
MMSE	11.50	7.08	0–28	0.81	Patient	Neuropsychologist
Katz ADL	4.01	1.90	0–6	0.81	Caregiver	Psychiatrist
IADL	3.04	2.17	0–8	0.82	Caregiver	Psychiatrist
CSDD	5.43	4.55	0–21	0.76	Both	Psychiatrist
NPI	29.61	20.07	0–88	0.71	Caregiver	Psychiatrist
Caregiver assessment variables						
CES-D	14.31	11.61	0–54	0.86	Caregiver	Psychiatrist
ZBI	42.26	16.33	8–76	0.87	caregiver	Psychiatrist

MMSE=Mini Mental State Examination, Katz ADL=Katz Activities of Daily Living, IADL=Lawton's Instrumental Activities of Daily Living, CSDD=Cornell Scale for Depression in Dementia, NPI=Neuropsychiatric Inventory, CES-D=Center for Epidemiological Studies Depression Scale, ZBI=Zarit Burden Interview

Table 4. Hierarchical logistic regression analyses (n=161), with ZBI as the dependent variable.

	Step 1						Step 2 Step 3											
	β	95% CI	p	R ²	ΔF		β	95% CI	p	R ²	ΔF	β	95% CI	p	R ²	ΔF		
Patient's age	-0.11	-0.70	0.17	0.234	0.123		2.56**	-0.11	-0.69	0.17	0.239	4.32**	0.03	-0.32	0.44	0.740	0.472	8.69**
Patient's gender	-0.03	-10.54	8.19	0.805				0.01	-8.43	9.16	0.934		0.06	-5.82	9.95	0.605		
Patient's education	0.03	-0.60	0.85	0.734				0.03	-0.58	0.83	0.728		0.01	-0.57	0.69	0.856		
Caregiver's age	-0.35	-0.77	0.08	0.016*				-0.34	-0.74	0.09	0.012*		-0.31	-0.66	-0.09	0.011*		
Caregiver's gender	0.08	-4.94	10.80	0.463				0.04	-6.08	8.93	0.707		0.04	-5.28	8.38	0.654		
Caregiver's education	-0.10	-1.27	0.42	0.326				-0.09	-1.16	0.44	0.377		0.00	-0.72	-0.71	0.989		
Caregiver being a spouse	0.32	-1.14	22.22	0.076				0.32	0.34	21.60	0.057		0.23	-2.75	18.30	0.146		
AD or not								0.07	-8.43	3.74	0.447		0.08	-8.29	2.52	0.292		
MMSE								0.15	-0.14	0.86	0.158		0.06	-0.31	0.58	0.548		
KATZ ADL								-0.03	-2.50	1.89	0.785		0.06	-1.45	2.43	0.616		
IADL								-0.18	-3.59	0.77	0.204		-0.06	-2.50	1.60	0.663		
CSDD								0.04	-0.59	0.85	0.717		0.00	-0.63	0.66	0.965		
NPI								0.27	0.06	0.40	0.009**		0.21	0.23	0.32	0.024*		
Years of caregiving													0.05	-0.66	1.29	0.520		
Weekly caregiving time													-0.07	-0.11	0.05	0.494		
Professional caregiver													-0.16	-13.31	0.11	0.054		
Caregiver living with the patient													0.11	-4.22	11.60	0.357		
CES-D													0.48	0.46	0.93	0.000**		

AD=Alzheimer's Disease, VD=Vascular Dementia, MMSE=Mini Mental State Examination, Katz ADL=Katz Activities of Daily Living, IADL=Lawton's Instrumental Activities of Daily Living, CSDD=Cornell Scale for Depression in Dementia, NPI=Neuropsychiatric Inventory, CES-D=Center for Epidemiological Studies Depression Scale, ZBI=Zarit Burden Interview β =standardized regression coefficient CI=Confidence Interval, ΔF =partial F test

*p<0.01, **p<0.05

sus criteria by Mckeith et al¹³ for the diagnosis of dementia with Lewy bodies (DLB) and Neary et al¹⁴ criteria for the diagnosis of Frontotemporal dementia (FTD).

Caregiver burden and depressive symptoms were assessed as follows:

a. Zarit Burden Interview¹⁵ (ZBI), a 22 item scale. It was initially developed in 1986 in order to assess the subjective burden experienced by caregivers of dementia patients in USA. Since then it has been translated and validated in many languages. The 22 items assess various sources of burden and the caregivers are asked to respond using a 5-point Likert Scale (ranged from "never" to "nearly always") how often they feel that way. The questions are about caregivers' physical and mental health, economic status, social life and interpersonal relationships. Higher score means higher burden. The cutoff score of clinically significant burden is score >40. The scale was translated and validated in Greek by Papastavrou et al.¹⁶ The results from validity and reliability analysis in the Greek population have shown that the internal consistency reliability is exceptional ($\alpha=0.93$). Furthermore, validity and reliability analysis gave 4 factors which explain 63.92% of the variance and refer to "personal intensity", "intensity of role", "loss of relationships" and "care management". In a recent review on caregiver stressors and health by Pinguat and Sörensen,¹⁷ ZBI was used in 32 of 85 articles studied.

b. Center for Epidemiological Studies Depression Scale (CES-D),^{18,19} a 20-item measure, which has been extensively used in caregiver research.²⁰

Patients' clinical characteristics, namely cognition, disease severity, functioning, depression and neuropsychiatric features were assessed by the use of the following scales:

a. Mini Mental State Examination (MMSE),²¹ the most widely used instrument for measuring cognitive function. MMSE was translated and validated in Greek by Fountoulakis et al.²²

b. Katz ADL (Katz's Activities of Daily Living Scale),²³ a measure of six basic activities of daily living (bathing, dressing, toileting, transferring, continence, feeding).

c. Cornell Scale for Depression in Dementia (CSDD),²⁴ a 19-item instrument for measuring depressive symptoms in dementia. Both the patients and the caregivers are interviewed by a psychiatrist, but the scale is clinician-rated. Ratings >12 are strongly correlated with a psychiatric diagnosis of major depressive episode.²⁵

d. Neuropsychiatric Inventory (NPI)²⁶ assesses 12 non-cognitive, psychiatric symptoms of dementia: delusions, hallucinations, agitation, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep, and appetite and eating disorders. The caregiver rates each of the syndromes by frequency and severity. We included night-time behaviors and appetite/eating that are usually not counted in the total score of the NPI. The scale was translated and validated in Greek by Politis et al.²⁷

Statistical methods

The Statistical Package for Social Sciences (SPSS), version 13 for Windows, was used for the data analyses. To analyze demographic factors and to investigate the prevalence of cognitive and psychiatric symptoms in persons with dementia and their caregivers, mean scores and standard deviations were calculated. Cronbach's alpha was estimated to assess the internal consistency of all scales used. ZBI, the dependent variable in this study, was normally distributed (Kolmogorov-Smirnov test). We conducted a 3-step hierarchical regression analysis with Caregiver Burden as the dependent variable. Patients' and caregivers' demographic characteristics were entered at step 1, disease and clinical characteristics were entered at step 2 and caregiving characteristics were finally entered in the model. The possibility of multicollinearity was investigated in order to ensure the validity of our model.

Results

The demographic profiles of patients and caregivers are presented in table 1. Our sample represented a typical community dementia sample visiting a memory clinic: patients were elderly, mainly female with a low education level; caregivers were younger female (patients' daughters or wives) and highly educated. Clinical factors and caregiving characteristics

are presented in table 2. Most patients were suffering from Alzheimer disease and had moderate to severe dementia, according to the MMSE.

Most caregivers were living in the same house or building with the patients and were involved in caregiving on a daily basis. Caregivers had been involved in their role for 3.6 years on average and the mean time given to caregiving was more than 70 hours weekly. Finally, in every one in five cases, a professional caregiver was also present.

Cognitive function was severely impaired (mean MMSE=11.50), with patients being unable to perform 2 basic activities of daily living on average. 45 patients (27.95%) had depression according to the CSDD; only 5 patients didn't have any behavioral problem in the NPI, while patients had more than 5 behavioral problems on average. Nearly half (n=80; 49.06%) of the 161 caregiver were highly burdened (ZBI>44). Moreover, 36 caregivers (22.4%) had depression according to the CES-D scale (scores≥24). The mean scores of assessment scales in both patients and caregivers as well as internal consistency reliability (Cronbach's alpha) for all scales used are in table 3. Alpha coefficients were fair to good for all scales used.

Multivariate regression analysis

In the first block, patients' and caregivers' socio-demographic characteristics were entered into the regression equation (table 4). Demographics as a block were associated with caregivers' burden ($R^2=0.123$, $p=0.02$). Regarding single variables, caregivers' age was the only variable that was independently associated with ZBI. In the next step, clinical characteristics were entered into the equation. Their inclusion resulted in a significant increase in the R^2 ($p<0.001$), with NPI contributing independently to the CB variance. This shows that the percentage of CB variance explained by the model has increased; it means that clinical characteristics additionally explained CB variance after demographics have been taken into account. The R^2 was significantly increased ($p<0.001$), with caregivers' depression being independently associated with CB. In this third step of the regression analysis, lower caregiver's age was independently associated with CB. The R^2 of the final model was 0.472.

As we were concerned with the potential correlation between independent variables, it should be noted that intercorrelations among independent variables were below 0.80 with the exception of age of disease onset that showed a very high correlation with the patients' age (Spearman's $r=0.949$) and thus it was not used in the analysis. To further test for multicollinearity, the Variance Inflation Factor (VIF) was calculated for each independent variable. VIF values were between 1.35 and 6.82, indicating the lack of severe collinearity problem.

Discussion

In the current study, nearly half of the 161 caregiver were highly burdened (ZBI>40) and almost one fourth were depressed (CES-D scores ≥24). Lower caregiver's age, behavioral symptoms of dementia patients and caregivers' depression were found to be independently associated with CB.

The high percentage of highly burdened caregivers found in this study confirms previous findings reported in the literature.^{3,28} It is difficult to compare the amount of caregiver burden between different studies due to methodological differences. For example, the mean ZBI score in our study was higher than that found by Rymer et al.²⁹ or Davis and Tremont;³⁰ this may be explained by the fact that the former studied caregivers of Alzheimer Disease patients only, while the latter only included caregivers of patients with mild and moderate dementia. There is evidence that CB is lower in Alzheimer Disease patients and in patients with less severe disease.^{6,28} A study from Cyprus revealed higher mean caregiver burden than our study.²⁷ This may be due to the fact that the Cyprian sample derived from local Caregivers Association members. Cultural issues may also play an important role, as in both studies that used patients of Greek origin, the mean ZBI was much higher (42.26 in our study, even higher in the Cyprian study) than the average burden level of 29.9 found in the meta-analysis of Pinquart and Sorensen.⁶

Depressive symptoms are also common in caregivers of dementia patients. In our study, 22.4% of the caregivers had depression according to the CES-D scale (score≥24). Rates of depression in caregivers of patients with dementia range, among studies, from

10,5%³¹ up to 83%,³² while the rate of depression in elderly patients living in the community is estimated at only 7%.³² Caregivers' burden and depression are highly associated, although their association remains complex.³³ In general, although different methods are used, a common finding in all studies is the high prevalence of both burden and depression in caregivers of patients with dementia.

As concerning the associations of CB, all three blocks of variables entered in the hierarchical regression, were significantly associated with CB. That confirms that CB is a complex issue, resulting from multiple demographic, clinical, personal, social and specific caregivers' characteristics, as found in other studies.^{6,34}

Patients' and caregivers' demographics were associated with CB, explaining 12.3% of its variance. The younger age of caregivers independently predicted CB. This has been reported elsewhere³⁵ and may be linked to the fact that younger caregivers have more family and professional obligations, to which they cannot respond due to their caregiver role.

The only clinical characteristic that appeared to be associated with ZBI was patients' behavioral problems. Cognitive status (MMSE) and functional level (Katz ADL) did not appear associated with the ZBI. This is in agreement with other studies and reviews of the literature: only 2 of the 8 studies reviewed by Schulz et al³⁶ found an association between CB and patients' cognitive function. In their review, Pinquart and Sörensen⁶ noted the weak association between CB and functional decline. Finally, depressive symptoms seem to have a weaker role in CB than more positive patients' behaviors.⁵ In most studies, behavioral problems in dementia are the most important predictor of caregiver burden, with respect to patient characteristics.^{5,37-39} The Bédard et al⁴⁰ study reported that the neuropsychiatric symptoms of patients were the most important predictor of caregiver burden in 74% of the studies reviewed; moreover, the Almeida and Black⁴¹ review of the literature reported that neuropsychiatric symptoms could explain 5.6–71% of the CB variance. As concerning specific caregivers' characteristics, caregivers' depression predicted ZBI. However, the interrelationship between depression and burden is not yet fully understood.³²

Our final multivariate model explained 47.2% of the CB variance. In a meta-analysis by Pinquart and Sörensen,⁶ caregiver and patient's variables could only explain 28% of the variance of burden. As CB is a complex issue, other factors that were not studied here may contribute to the variance of CB: quality of patient-caregiver emotional relationship,³⁴ caregiver's sense of adequacy,⁴² family functioning,⁴³ caregiver's high expressed emotion⁴⁴ and coping strategies.¹⁶ A recent study on the associations of CB by Campbell et al³⁴ ended up in a 7 factor model which explained 80% of CB variance. Most of these factors (quality of patient-caregiver relationship, negative life experiences, neurotic caregiver's components, and caregiver's sense of adequacy and feeling of capture within caregiver's role) comprise components of the caregivers' personality.

There are several limitations in our study. Cross sectional studies cannot provide definitive answers regarding cause and effect and the possibility of reverse causality should be explored further in longitudinal studies. Our sample may not be representative of dementia community patients, as the study was conducted in a secondary clinic. Caregivers in the clinic may be particularly motivated or severely burdened; many patients were referred for a second opinion. Furthermore, most patients were suffering from moderate and severe dementia; neuropsychiatric symptoms are more common in the most advanced stages of the disease.¹¹ Functional status, behavioral competence, comorbidities and economic situation were measured based on the caregiver's report and the results might have been biased by caregivers' factors. Caregivers, especially those who are more burdened, are known to underestimate patients' abilities. Furthermore, factors such as caregivers' economic and health status weren't assessed. In addition to all these, the sample comes from the urban population of Athens. The level of burden may have been different if the sample had come from all over Greece including suburban and rural areas. Finally, the sample size, although large, did not allow us to differentiate predictive factors between subgroups of patients and caregivers. This is important, because the associations of CB may differ, for example, between dementia subtypes. For example, it is possible that caregivers of dementia patients with Lewy bodies and frontotempo-

ral dementia experience more burden than caregivers of AD patients, although in this study that couldn't be observed due to the small number of patients with LBD and FTD. Also, the impact of caregiving differs according to the caregiver's Kinship relationship to the patient.^{36,45}

Caregivers have a very important influence on the course of dementia. Their psychological status determines the time of patient's institutionalization.⁴¹ If we want to delay institutionalization of dementia pa-

tients, it is essential that interventions for dementia target both patients and caregivers. CB should routinely be assessed and novel caregiver interventions must be developed. This study highlights behavioral problems, as the first target of such interventions. Homecare services must be developed, especially for younger caregivers. Future research in caregiving must contain factors not studied in the current study and dementia interventions should also aim to diminish the burden of care.

Η επιβάρυνση από τη φροντίδα στην άνοια και οι παράγοντες πρόβλεψής της

A.A. Μούγιας,¹ A. Πολίτης,² M. Μούγιας,¹ E. Κοτρώτσου,¹
Π. Σκαπινάκης,³ Δ. Δαμίγος,³ Β.Γ. Μαυρέας³

¹Κέντρο Alzheimer Ψυχογηριατρικής Εταιρίας «Ο Νέστωρ», Αθήνα,

²Ψυχιατρική Κλινική, Αιγινήτειο Νοσοκομείο, Ιατρική Σχολή, Πανεπιστήμιο Αθηνών, Αθήνα

³Ψυχιατρική Κλινική, Ιατρική Σχολή, Πανεπιστήμιο Ιωαννίνων, Ιωάννινα

Ψυχιατρική 2015, 26:28-37

Η άνοια δεν επηρεάζει μόνο τους ίδιους τους ασθενείς, αλλά και τους φροντιστές τους. Η μελέτη της Επιβάρυνσης από τη φροντίδα στην άνοια έχει αναπτυχθεί τα τελευταία χρόνια, καθώς μελέτες δείχνουν πως η Επιβάρυνση από τη φροντίδα στην άνοια είναι μεγαλύτερη σε σχέση με άλλες νόσους. Ο βασικός σκοπός της παρούσας μελέτης είναι ο υπολογισμός της Επιβάρυνσης σε ένα δείγμα φροντιστών ασθενών με άνοια που διαμένουν στην Αθήνα, καθώς και η εύρεση των παραγόντων που την επηρεάζουν. Πρόκειται για συγχρονική μελέτη επισκόπησης και συσχέτισης σε 161 ασθενείς με άνοια και τους φροντιστές τους, οι οποίοι κατοικούν στην κοινότητα και επισκέφτηκαν ένα ιατρείο μνήμης. Η Επιβάρυνση από τη φροντίδα μετρήθηκε με το Ερωτηματολόγιο Επιβάρυνσης του Zarit (Zarit Burden Interview, ZBI) και η κατάθλιψη των φροντιστών με την κλίμακα του Κέντρου Επιδημιολογικών Ερευνών για την Κατάθλιψη (Center for Epidemiological Studies Depression Scale, CES-D), ενώ τα κλινικά χαρακτηριστικά των ασθενών υπολογίστηκαν με χρήση σταθμισμένων κλιμάκων (γνωσιακή κατάσταση, λειτουργικότητα, διαταραχές συμπεριφοράς). Για την εύρεση των παραγόντων που επηρεάζουν την Επιβάρυνση, πραγματοποιήθηκε μια ιεραρχική ανάλυση παλινδρόμησης τριών σταδίων. Οι περισσότεροι ασθενείς έπασχαν από νόσο του Alzheimer (n=101·62,73%) σε μέτριο έως σοβαρό στάδιο άνοιας σύμφωνα με το MMSE (μέση τιμή MMSE=11,50) και παρουσίαζαν αδυναμία στην πραγματοποίηση δύο βασικών δραστηριοτήτων της καθημερινότητας κατά μέσον όρο. Σύμφωνα με την κλίμακα CSDD, 45 ασθενείς (27,95%) έπασχαν από κατάθλιψη, ενώ σύμφωνα με το NPI οι ασθενείς παρουσίαζαν 5 προβλήματα συμπεριφοράς κατά μέσον όρο. Οι φροντιστές παρείχαν τις υπηρεσίες τους στους ασθενείς για μέσο χρονικό διάστημα 3,6 χρόνια και για περισσότερο από 70 ώρες την εβδομάδα. Σχεδόν οι μισοί (n=80· 49,06%) από τους 161 φροντιστές παρουσίαζαν υψηλή επιβάρυνση (ZBI>40) και 36 φροντιστές (22,4%) είχαν κατάθλιψη σύμφωνα με την κλίμακα CES-D (αποτέλεσμα≥24). Η ιεραρχική ανάλυση παλινδρόμησης κατέδειξε πως όλα τα

επίπεδα που εισήχθησαν ιεραρχικά στο μοντέλο συνέβαλαν ανεξάρτητα στη διακύμανση της επιβάρυνσης (δημογραφικά στοιχεία ασθενών και φροντιστών, κλινικά χαρακτηριστικά των ασθενών και χαρακτηριστικά της φροντίδας). Η μικρότερη ηλικία του φροντιστή, οι διαταραχές συμπεριφοράς στο πλαίσιο της άνοιας και η κατάθλιψη του φροντιστή παρουσίασαν ανεξάρτητη συσχέτιση με την Επιβάρυνση από τη φροντίδα. Το R^2 του τελικού μοντέλου ήταν 0,472. Η άνοια προκαλεί σημαντική επιβάρυνση στους φροντιστές των ασθενών. Η Επιβάρυνση από τη φροντίδα είναι μια πολύπλοκη έννοια, η οποία εξαρτάται από πολλούς παράγοντες των ασθενών και των φροντιστών. Στην καθημερινή κλινική πρακτική, η Επιβάρυνση των φροντιστών πρέπει να αξιολογείται.

Λέξεις ευρητηρίου: Νόσος Alzheimer, άνοια, φροντιστές, επιβάρυνση.

References

- Orgeta V, Sterzo EL. Sense of coherence, burden, and affective symptoms in family carers of people with dementia. *Int Psychogeriatr* 2013, 8:1-8
- Bullock R. The Needs of the Caregiver in the Long-Term Treatment of Alzheimer Disease. *Alzheimer Dis Assoc Disord* 2004, 18:S17-S23
- Dunkin J, Anderson-Hanley C. Dementia caregiver burden. A review of the literature and guidelines for assessment and intervention. *Neurology* 1998, 51:S53-S60
- Awad AG, Voruganti LN. The burden of schizophrenia on caregivers: a review. *Pharmacoeconomics* 2008, 26:149-162
- Meiland FJM, Kat MG, van Tilburg W, Jonker C, Dröes RM. The Emotional Impact of Psychiatric Symptoms in Dementia on Partner Caregivers. Do Caregiver, Patient and Situation Characteristics Make a Difference? *Alzheimer Dis Assoc Disord* 2005, 19:195-201
- Pinquart M, Sörensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2003, 58:112-128
- Papastavrou E, Charalambous A, Tsangari H, Karayiannis G. The burdensome and depressive experience of caring: what cancer, schizophrenia and Alzheimer's disease caregivers have in common. *Cancer Nurs* 2012, 35:187-194
- Ory MG, Hoffman RR, Yee JL, Tennstedt S, Schulz R. *Gerontologist* 1999, 39:177-185
- Cuijpers, P. Depressive disorders in caregivers of dementia patients: a systematic review. *Aging Ment Health* 2005, 9:325-330
- Cooper C, Balamurali TB, Livingston G. A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. *Int Psychogeriatr* 2007, 19:175-195
- Mougias AA, Politis A, Lyketsos CG, Mavreas VG. Quality of Life in Greek dementia patients. The role of caregiver factors. *Int Psychogeriatr* 2011, 23:395-403
- American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. 4th ed, text revision. Washington, DC, Author, 2000
- McKeith IG, Galasko D, Kosaka K. Consensus guidelines for the clinical and pathologic diagnosis of dementia with Lewy bodies (DLB): report of the consortium on DLB international workshop. *Neurology* 1996, 47:1113-1124
- Neary D, Snowden JS, Gustafson L, Passant U, Stuss D, Black S et al. Frontotemporal lobar degeneration: a consensus on clinical diagnostic criteria. *Neurology* 1998, 51:1546-1554
- Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980, 20:649-655
- Papastavrou E, Kalokerinou A, Papacostas SS, Tsangari H, Sourtzi P. Caring for a relative with dementia: family caregiver burden. *J Adv Nurs* 2007, 58:446-457
- Pinquart M, Sörensen S. Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2006, 61:33-45
- Radloff LS. The CES-D scale: A self report depression scale for research in the general population. *Appl Psych Meas* 1977, 1:385-401
- Fountoulakis K, Iacovides A, Kleanthous S, Samolis S, Gougoulas K, Tsiptsios I et al. Reliability, Validity and Psychometric Properties of the Greek Translation of the Center for Epidemiological Studies-Depression (CES-D) Scale. *BMC Psychiatry* 2001, 1:3
- Brodsky H, Green A, Koschera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. *J Am Geriatr Soc* 2003, 51:657-664
- Folstein MF, Folstein S, McHugh PR. Mini-mental state: a practical method for grading the cognitive status of patients for the clinician. *J Psychiat Res* 1975, 12:189-198
- Fountoulakis C, Tsolaki M, Chazi H, Kazis A. Mini Mental State Examination (MMSE): A validation study in demented patients from the elderly Greek population. *Encephalos* 1994, 31:93-102
- Katz S, Down TD, Cash HR, Grotz RC. Progress in the development of the index of ADL. *The Gerontologist* 1970, 10:20-30
- Politis A, Maillis A, Thomadaki O, Passa M, Stamouli E, Kotrotsou M et al. Validity and reliability of the newly translated Cornell Scale for Depression in Dementia (CSDD) applied to Greek outpatients with depression and depression and Alzheimer's disease. *Ann Gen Psychiatry* 2006, 5:245

25. Alexopoulos GS, Abrams RC, Young RC, Shamoian CA. Cornell Scale for depression in dementia. *Biol Psychiat* 1998, 23:271–284
26. Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology* 1994, 44:2308–2314
27. Politis AM, Mayer LS, Passa M, Maillis A, Lyketsos CG. Validity and reliability of the newly translated Hellenic Neuropsychiatric Inventory (H-NPI) applied to Greek outpatients with Alzheimer's disease: a study of disturbing behaviors among referrals to a memory clinic. *Int J Geriatr Psych* 2004, 19:203–208
28. Annerstedt L, Elmstehl S, Ingvad B, Samuelsson SM. Family caregiving in dementia: an analysis of the caregiver's burden and the "breaking point" when home care becomes inadequate. *Scand J Publ Health* 2000, 28:23–31
29. Rymer S, Salloway S, Norton L, Malloy P, Correia S, Monast D. Impaired awareness, behavior disturbance, and caregiver burden in Alzheimer disease. *Alzheimer Dis Assoc Disord* 2002, 16:248–253
30. Davis JD, Tremont G. Impact of Frontal Systems Behavioral Functioning in Dementia on Caregiver Burden. *J Neuropsychiatry Clin Neurosci* 2007, 19:43–49
31. Mahoney R, Regan C, Katona C, Livingston G. Anxiety and depression in family caregivers of people with Alzheimer's disease - the LASER-AD study. *Am J Geriatr Psychiatry* 2005, 13:795–801
32. O'Rourke N, Cappeliez P, Guindon SJ. Depressive symptoms and physical health of caregivers of persons with cognitive impairment: analysis of reciprocal effects over time. *Aging Health* 2003, 15:688–712
33. Clyburn LD, Stones MJ, Hadjistavropoulos T, Tuokko H. Predicting caregiver burden and depression in Alzheimer's disease. *J Gerontol B Psychol Sci Soc Sci* 2000, 55:2–13
34. Campbell P, Wright J, Oyebode J, Job D, Crome P, Bentham P et al. Determinants of burden in those who care for someone with dementia. *Int J Geriatr Psychiatry* 2008, 23:1078–1085
35. Brody EM, Litvin SJ, Hoffman C, Kleban MH. Marital status of caregiving daughters and co-residence with dependent parents. *Gerontologist* 1995, 25:78–85
36. Schulz R, Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry* 2004, 12:240–249
37. Mohamed S, Rosenheck R, Lyketsos CG, Schneider LS. Caregiver burden in Alzheimer disease: cross-sectional and longitudinal patient correlates. *Am J Geriatr Psychiatry* 2010, 18: 917–927
38. Machnicki G, Allegri RF, Dillon C, Serrano CM, Taragano FE. Cognitive, functional and behavioral factors associated with the burden of caring for geriatric patients with cognitive impairment or depression: evidence from a South American sample. *Int J Geriatr Psychiatry* 2009, 24:382–389
39. Levy K, Lanctôt KL, Farber SB, Li A, Herrmann N. Does pharmacological treatment of neuropsychiatric symptoms in Alzheimer's disease relieve caregiver burden? *Drugs Aging* 2012, 29:167–79
40. Bédard M, Pedlar D, Martin NJ, Malott O, Stones MJ. Burden in caregivers of cognitively impaired older adults living in the community: methodological issues and determinants. *Int Psychogeriatr* 2000, 12:307–32
41. Almeida OP, Black W. A systematic review of the association between behavioral and psychological symptoms of dementia and burden of care. *Int Psychogeriatr* 2004, 16:295–315
42. Gonyea JG, O'Connor M, Carruth A, Boyle P. Subjective appraisal of Alzheimer's disease caregiving: The role of self-efficacy and depressive symptoms in the experience of burden. *Am J Alzheimers Dis Relat Dement* 2005, 20:273–280
43. Mitrani VB, Lewis JE, Feaster DJ, Czaja SJ, Eisdorfer C, Schulz R et al. The role of family functioning in the stress process of dementia caregivers: a structural family framework. *Gerontologist* 2006, 46:97–105
44. Wagner AW, Logsdon RG, Pearson JL, Teri L. Caregiver expressed emotion and depression in Alzheimer's disease. *Ag Ment Health* 1997, 1:132–139
45. Savundranayagam MY, Orange JB. Relationships between appraisals of caregiver communication strategies and burden among spouses and adult children. *Int Psychogeriatr* 2011, 23:1470–1478

Corresponding author: A.A. Mougias, 22 Drosopoulou street, GR-112 57 Athens, Greece
 Tel: 6972 030 919
 e-mail: amougias@gmail.com