



The Burden on Family Caregivers to the Patients with Alzheimer's Disease and Other Dementias in Nicosia, Cyprus

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Authors' contributions

This work was carried out in collaboration between all authors. Authors AI and EJ designed the study, wrote the protocol. Author AI collected the data. Authors AI, EJ, PK and P. Plotas wrote the first draft of the manuscript. Author KP performed the statistical analysis. Authors PK and P. Plotas contributed to the subsequent manuscripts. Authors PK, P Plotas and EJ managed the analyses of the study.

Authors P. Pappa and GC managed the literature searches. All authors contributed to the interpretation process, read and approved the final manuscript. Authors PK and P Plotas contributed equally to this work.

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ABSTRACT

Purpose: Dementia is a major problem in modern society of 21st century. The incidence and prevalence of dementia progressively increases with age. The impairment of cognitive functions in patients with dementia results in an increased burden for family caregivers. The objectives of this study were to investigate the burden on caregivers to patients afflicted with Alzheimer's disease

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and to estimate the factors affecting their quality of life.

Patients and Methods: The study involved 79 family caregivers of patients with dementia and was carried out from June to August 2014. The Greek version of 'The Zarit Burden Interview' was used, which included 22 questions/statements relating to the emotions of family caregivers. The questionnaire included 16 additional demographic and socio-economic questions. The statistical analysis was performed with SPSS 22 package.

Results: A total of 79 caregivers participated in the study, 65% were females and 69.6% were married. 74.7% stated that they were related to the patient. 81% felt a restriction in their personal life, and 58.2% felt stressed from the patient care. 81% expressed their fears for the patient's future. 65% responded that the patient was dependent on them. 65.8% felt burdened with the patient care, and 43% felt socially isolated. 49.4% had lost control of their personal life, while, 52.6% felt guilty about not caring enough. 47% of the caregivers to patients who have Alzheimer's disease stated that they have not attended any training program for home caring.

Conclusions: The study highlights the huge burden on caregivers. Therefore, it is imperative to diagnose these disorders in the early stages and thereby improving the quality of life for both patients and caregivers.

Keywords: Family caregivers; dementia; Alzheimer's disease; burden on caregivers.

1. INTRODUCTION

Dementia is a syndrome in which there is deterioration in memory, thinking, behavior and the ability to perform everyday activities [1]. According to the criteria DSM-IV-TR published by the American Psychiatric Association, in 2000, dementia is defined as a "severe disorder that causes a decline in the professional and social functioning of the individual".

Dementia is one of the biggest challenges for Public Health [2]. The incidence and prevalence of the disease increases with the age of the patient. Based on calculations of Alzheimer's Disease International (ADI), now-a-days, 47 million people are living with dementia worldwide, a figure that will expect to double by 2030 and tripled by 2050 [3]. In Europe, there are 10 million people with dementia and in Greece there are 200,000 people and 400,000 caregivers looking after them. These numbers will increase dramatically in the years to come [4]. At the age of 60, the prevalence of the disease is about 1% of the population and doubles every five years, reaching levels of 30% -50% at the age of 85 years old and over [5]. Despite the scientific advances in past 25 years, treatment of dementia is a major issue both nationally and internationally. The stigma, the denial and the lack of financial resources are the main obstacles to integrated care for people with dementia [6].

At the G8 Summit in London in December 2013, international financial experts, physicians and politicians called on the governments of all

countries, to render the prevention of dementia, a major public health objective in the coming years and founded the World Dementia Council, in order to achieve these objectives globally. Eleven countries are currently implementing National Action Plan policies in areas of intervention, priorities and actions, while highlighting the necessity and the importance of taking co-ordinated measures to meet the needs of people with dementia [7].

The term senile dementia -which is the most common type of dementia - is known to the broad population as Alzheimer's disease. It is a multifactorial syndrome which is characterized by a decline in the superior cognitive functions with a set of symptoms indicating that the reasoning process begin to degenerate [8]. Alzheimer's Disease was named by Dr Alois Alzheimer, who in 1906 gave a lecture on "A characteristic serious disease of the cerebral cortex," with the case of a 50 year old woman, Augusta, who died after an unusual mental illness. In this lecture, he described neurofibrillary degenerations or neurofibrillary tangles and senile plaques, which at present are the pathogenic neuropathological lesions of the disease [9]. These changes are now recognized as the characteristic brain lesions that Alzheimer's disease causes. The disease affects all population groups, regardless of social class, gender, race or geographical area, although it usually turns up in older people, however, it can also occur in younger population. Women are slightly more likely to be affected by Alzheimer's disease compared to men. This has been attributed either to the greater longevity

of women (and therefore they are more likely to develop the disease) or in the female hormones such as estrogen and progesterone [10].

1.1 The Burden on Caregivers of People with Dementia

Alzheimer's disease not only affects but poses many challenges for the entire family. The majority of people with dementia live in the community-family members being the major caregivers, particularly spouses, who are elderly themselves. One of the family members is considered the primary caregiver. In married couple, the spouses usually commit themselves as caregivers. In cases of widowhood, some children assume the role of the caregiver, based on the social criteria (sex, primogeniture, cohabitation). More often, however, daughters and daughters-in-law end up as the primary caregivers in these cases [11]. In other cases, the family employs a private caregiver or a qualified private caregiver from an institution to undertake the role of caring for the patient.

A broad population study of elderly families in Canada, resulted in the average age of caregivers to be 62 years, with 36% of them being older than 70 years. In Greece 89% of patients with Alzheimer disease are cared for at home and 77% of the caregivers are women. The main caregivers are children (50%) or spouses (32%) [12].

Family and private caregivers play an important role in supporting the elderly throughout the disease and are one of the largest resources of any health care system. Often members of families caring for a relative with Alzheimer's disease neglect their own health. They are so emotionally stressed due to this problem, that they are unable to perceive the mental pressure they are under [13]. The personal and emotional stress of the caregiver is enormous and, therefore it is necessary to design ways of coping with the consequences of the disease in the future. The results of a large number of investigations and interviews with caregivers show an increased mortality rate due to their burden [14]. The high demands for the caring of people with dementia affects the health of the caregivers, influencing their participation in social and professional activities, restricting their free time, undermining their social status and threatening their financial security [15].

Early detection and diagnosis of disorders caused by the disease is imperative so that the patient can receive the necessary care and treatment as soon as possible in order to slow down the progressive deterioration of the disease and to improve the quality of life for both the patients and caregivers [16].

The accumulation of problems arising from the care of a dependent family member usually is referred to as "burden" [13,17,18]. The term has prevailed internationally and concerns the physical, emotional or financial burdens that caregivers have to bare because of a person suffering from a chronic disease that causes disability. Spouses of the patients already carry the load of potentially poor health and the fatigue from life, as well as, having to reconcile with the fact of aging. The burden of caring for their partner, introduces them to a prolonged period of mourning, generating feelings of anger for the deprivation of a carefree old age period [19].

The concept of family burden was first introduced by Grad & Sainsbury, 1966 while they examined the care that was given to the mentally ill people in society, when the family became "the institution of choice" for the care of these patients [20]. Moreover, it is reported in the research, that women caregivers experienced greater stress when caring for the patient compared to men [19]. The literature describes several types of burden, in particular the specificities of Alzheimer's disease, the care of patients with dementia appears to be more difficult and burdensome than the caring of people with other chronic diseases [21]. Therefore, the huge cost for the family, sick people, health systems and society in general, the "burden of care" remains the dominant issue in gerontological research.

According to Given et al. [22], the burden is "the multidimensional biopsychosocial reaction to an imbalance of care requirements in relation to personal time, the social roles, the physical and the emotional states, the financial and support resources of caregivers, given the other multiple roles they have to fulfill" [22]. Other researchers, who have used different tools, also support the multidimensional nature of the burden [23]. In 1980, Zarit, Reever and Bach-Peterson analyzed this two-dimensional concept of the burden further, stating that the burden is the extent to which caregivers perceive their physical health, their social life and their economic status as a result of caring for their relative [24]. The concept

of burden as a research structure is one of the most frequently used variables in care research, both as a predictor and as a result [25].

The aim of this study was to investigate the level of burden on family caregivers to patients with Alzheimer's disease, as well as, other related dementias and factors affecting the quality of life for caregivers.

2. PATIENTS AND METHODS

100 family caregivers of patients with Alzheimer's disease or with other dementias, who were hospitalized in an institution or at home and living in the city of Nicosia in Cyprus, were invited to participate in the study. Of those, 21 did not respond. Therefore, the final sample of the study consisted of 79 family caregivers. Regarding the sample selection criteria, the main criterion for selecting the patients was the diagnosis of Alzheimer's disease or any other form of dementia was established by specialist physicians. The selection criteria for the caregiver were: Having more frequent contact with the patient than all other family members, having a greater responsibility in caring for the patient for at least one year and having no record of absenteeism or the existence of psychiatric illness, physical or mental disability and substance use, conditions that would prevent the undertaking of the caregivers role.

2.1 Questionnaire

A "self-completed questionnaire" was used, the first part of which consisted of 16 questions for the recording of the demographic and socioeconomic characteristics such as the gender, age, marital status, level of education, degree of relationship, income, employment characteristics, duration of care, care training program, etc. The second part of the questionnaire consisted of the Greek version of the Scale of Burden "The Zarit Burden Interview" [26-29]. This scale explore the sentiments of family caregivers and the importance of the burden. It features an ascending Likert-type arrangement from 0-4, with 0 = Never, 1 = Rarely, 2 = Sometimes, 3 = Quite often and 4 = Almost Always.

The total score of the scale shows the sum of the responses to the questions. The higher the rating is, the greater burden corresponding to the caregiver with the maximum being 88 (0-20 = low burden, 21-40 = moderate, 41-60 = moderate to severe burden, 61-88 = very severe burden).

The scale examine four dimensions of burden: a) the personal strain, b) the role strain c) the relational deprivation and d) the management of care [28].

Personal strain include questions on personal stressful feelings of chronic fatigue and about a sense of damaged health, which has been confirmed in other studies [30]. The role strain consist of questions which explore the burden felt by the caregiver due to care, patient dependency and the intensity of emotions that caring causes [31,32].

The relational deprivation describes the limited time for caregivers, resulting in limitations of personal development, reduced social contacts and interpersonal relationships [31].

The management of care include questions that assess the ability of the caregivers in providing care. Caregivers are experiencing serious doubts, whether they will be able to continue doing so.

All questions were coded and inserted into an electronic database for the purpose of the statistical analysis of the data. The descriptive and the deductive analysis were performed with the statistical package IBM SPSS Statistics, version 22.0.

The Cronbach internal consistency co-efficient of the questionnaire is 0.887 which indicates excellent internal consistency.

2.2 Moral Issues

For the purpose of this study, the researchers have obtained the relevant written permission required in Cyprus from the Cyprus National Bioethics Committee (No. 2014.01.86, 17/07/2014). Moreover, the written consent of the authors was obtained for the use of the questionnaire. The questionnaires were voluntarily and anonymously completed by their caregivers which were initially informed verbally and in writing about the purpose and methodology of the study. In this way, their informed consent was ensured.

2.3 Statistical Analysis

A Kolmogorov-Smirnov test was used (with the necessary Lilliefors correction) to ascertain if the data (quantitative variables) resulted from the normal distribution. This test was rejected at

a 5% significance level, so further analysis was performed using nonparametric methods. The non-parametric Mann-Whitney tests (for 2 factor levels) and the Kruskal-Wallis tests (when the factor levels were over 2) were used to check if the total burden and the burden of each factor separately were affected by the categorical variables. Also, for two quantitative variables we computed the correlation co-efficient of Spearman (nonparametric correlation coefficient).

In this case there was a statistically significant relationship between the independent variables and the burden (dependent variable), multiple linear regression was applied in order to select the best linear model as a result of action of these independent variables. In this case, backward stepwise regression was applied (backward stepwise linear regression). Regarding this multiple linear regression, the beta coefficients, the corresponding 95% confidence intervals and the p-values are presented.

3. RESULTS

3.1 Descriptive Analysis of Demographic and Socio / Economic Features

A total of 79 subjects participated, of which 64.6% were women and 35.4% were men, who met the criteria of family first-level caregivers with the average age being 50 years (minimum age 20 years and maximum 80 years). The majority of caregivers belong to the age group between 51-70 years (51.9%). The demographic characteristics of the participants are presented extensively in Table 1.

It is observed that the majority of people who provided care to people with dementia were married (69.6%), with secondary education (49.4%), lived in a different house from the patient (65.8%) and the average duration of care was 5 years. The relationship of the caregiver with the patient was analyzed, with 79.7% of caregivers stating a relative relationship with the patient and the children primarily undertaking the care of their ill parents (59.5%) and daughters outweighed (31, 6%).

The majority of caregivers (68.4%) did not suffer from any disease preventing them in caring for patients, the 46.8% reported that they were in a difficult financial situation and 74.7% of

caregivers had not attended a training course for home care.

3.2 Analysis of the Total Burden Using the Scale Zarit

According to the Zarit scale, the following data were found: The 5.1% of caregivers showed moderate burden, the 19% showed moderate to severe burden and the 75.9% showed very severe burden (Table 2).

Table 3 present the factors which are related to the total burden. We observed higher burden in married compared to unmarried, in caregivers with a higher number of children, with a lower level of education, living in the same house with the patient and in older caregivers with health problems. The relationship with care recipient affects the total burden. A person who is not related to the immediate patient's family is less burdened. It is impressive that those who have attended a training course present a higher total burden ($p = 0.006$).

The total rating of the burden of the four dimensions is presented in Table 4. It is observed that men had greater total burden (80.96%) than women (74.67%). Also men seem to be burdened more in the four dimensions, specifically in the role strain, the personal strain, the management of care and the relational deprivation, compared to women and the difference is statistically significant only in the dimension "Management of care" ($p = 0.047$).

The factors which are associated with the four different dimensions of the scale are the following: The "Personal Strain" is influenced by the marital status of the caregiver, the number of children, number of members living with the patient, residence and relationship with the patient.

The "Role Strain" correlates with the number of members living with the patient, educational level, relationship with the patient and caregiver's place of residence.

The "Relational Deprivation" is also influenced by marital status, by the number of children, by the income, and by the training program.

The "Management of Care" correlates with the gender, with the educational level and with the relationship degree with the patient.

Table 1. Demographic and socioeconomic characteristics of the population

Characteristics	N	%	Characteristics	n	%
Gender			Family Income (€)		
Male	28	35.4	< 6000	37	46.8
Female	51	64.6	6000≤12000	18	22.8
			> 12000	24	30.4
Age			Place of Residence	20	23.3
20-30	11	13.9	Same with the patient	5	6.3
31-40	7	8.9	Same building with the patient	22	27.8
41-50	8	9.1	Same neighborhood with the patient		
51-60	18	22.8			
61-70	23	29.1	Years of care		
71-80	12	15.2	< 5	55	74.3
Marital status			5≤10	15	20.3
Married	55	69.6	> 10	4	5.4
Not married	15	19	Relation with care recipient		
Widowed	1	1.3	Spouse	16	20.3
Divorced	2	2.5	Daughter	25	31.6
Legally Separated	1	1.3	Son	17	21.5
Children			Brother/Sister	5	6.4
0	3	3.8	Other	16	20.3
1	7	8.9	Health Problems of Caregiver		
2	18	22.8	No Problem	54	68.4
3	23	29.1	Hypertension	10	12.7
4	12	15.2	Musculoskeletal	4	5.1
5	5	6.3	Cardiovascular	4	5.1
Education level			Vision problems	3	3.8
Primary Education	16	20.3	Others	1	1.3
Secondary Education	39	49.4	Training Course of Care		
Higher education	23	29.1	Yes	20	25.3
Work Status			No	59	74.7
Unskilled Worker	3	3.8	Age of Patient		
Skilled Worker	3	3.8	60-70	23	29.9
Freelancer	11	13.9	71-80	27	35
Farmer	9	11.4	81-90	22	24.7
Private Employee	23	29.1	> 90	5	6.5
Civil Servant	16	20.3	Patient Disease		
Housekeeping	13	16.5	Parkinson	11	13.9
			Alzheimer	37	46.8
			Vascular Dementia	16	20.3
			Other Dementia	15	19
Gender of patient					
Male	47	57	Female	34	43

Table 2. Level of burden of the caregivers according to the scale Zarit

	Total N (%)	Men N(%)	Women N(%)
Low (0-20)	0	0	0
Moderate (21-40)	4 (5.1)	1 (3.6%)	3 (5.9%)
Moderate to severe (41-60)	15 (19%)	3 (10.7%)	12 (23.5%)
Very severe (61-88)	60 (75.9%)	24 (85.7%)	36 (70.6%)
Total	79 (100%)	28 (100%)	51 (100%)

Table 3. Factors affecting the total burden

Characteristics	N	Mean rank	P
Marital status			.008
Married	55	38.86	
Not Married	15	23.17	
Place of residence			.015
In the same house or in the same building with the patient	25	47.96	
Separately from the patient	52	34.69	
Educational level			.005
Primary Education (incl. no formal education)	16	52.50	
Secondary Education	39	38.85	
Higher education	23	31.57	
Income (in Euro)			.049
None	14	26.93	
Up to 6000 per year	23	44.52	
Up to 12000 per year	18	47.83	
Over 12000 per year	24	37.42	
Relation with care recipient			.000
Close Relationship (spouse, parents or children)	63	46.20	
Other	16	20.3	
Health problems of family caregiver			.017
No Problem	54	33.63	
Hypertension	10	49.00	
Diabetes	2	53.00	
Musculoskeletal	4	40.88	
Cardiovascular	4	61.63	
Vision problems	3	69.33	
Others	1	51.00	
Attendance at a training course about patient care			.006
Yes	20	52.10	
No	59	35.9	

Table 4. Total burden of the four dimensions

	Total Mean value* \pm SD	Women mean value* \pm SD	Men mean value* \pm SD	P
Total Burden	76.9 \pm 13.097	74.67 \pm 14.096	80.96 \pm 10.345	.100
Role Strain(7 questions, 0-28)	70.9 \pm 4.663	69.0 \pm 4.902	74.32 \pm 4.086	.227
Personal Strain (9 questions, 0-36)	79.3 \pm 6.494	76.5 \pm 6.975	84.55 \pm 5.064	.121
Management of care (2 questions, 0-8)	77.25 \pm 1.510	74.0 \pm 1.510	83.0 \pm 1.420	.047
Relational Deprivation (4 questions, 0-16)	82.9 \pm 3.176	80.75 \pm 3.285	86.8 \pm 2.913	.302

* mean value: The mean score of Zarit scale is here converted to the corresponding average percentage on a scale from 0 to 100% [33]

3.3 Multivariable Linear Regression

program. These variables explain the 50.5% of the variability of the total burden.

3.3.1 Burden rating

The results of multivariable linear regression are presented in Table 5. The factors affecting the total burden are the following: the age of the caregiver and the attendance of a training

3.3.2 Factor "Personal Strain"

Regarding "Personal Strain" the factors that appear to play a role are: the age of the caregiver and the age of patient and attending a training program (Table 6): These variables

explain the 59.8% of the variability of the rating in the factor "Personal Strain".

3.3.3 Factor "Role Strain"

With regard to the rating of the factor "Role Strain", the factors affecting this dimension are: the number of members living in the same house (at a significance level of 6.6%) and the age of the caregiver (Table 7). These variables explain the 27.5% of the variability of the rating in the factor "Role Strain".

3.3.4 Factor "Relational deprivation"

Concerning "Relational deprivation" the factors that play a role are: the income, the attendance at a training program and the age of the caregiver (Table 8). These variables explain the 36.8% of the variability of the rating in the factor "Relational deprivation".

3.3.5 Factor "Care Management"

The "Management of care" seems to be related with the gender and the level of education (Table 9). These variables explain the 14.3% of the variability of the rating in the factor of "Management of care".

4. DISCUSSION

This study confirms the magnitude of the problem of the burden on people who take care of patients with dementia in Cyprus. Our initial hypothesis, is the verification that the care of patients with dementia has a negative impact on the lives of the caregivers. The purpose of this study was to investigate the burden of caregivers, its dimensions and its accompanying consequences. The results are broadly consistent with the international literature. The surveys by Gruffydd E, et al. [34] and

Table 5. Multivariable linear regression with dependent variable being the total burden score

Characteristic	Coefficient B	95% CI for the B	P
Training Program	-10.833	-15.671 to -5.996	.000
Age of the Caregiver	.634	.444 to .824	.000

CI= Confidence Interval

Table 6. Multivariable linear regression with dependent variable being the factor "Personal strain"

Characteristic	Coefficient B	95% CI for the B	P
Training Program	-5.893	-8.147 to -3.638	.000
Age of the Caregiver	.301	.213 to .388	.000
Age of Patient	-.231	-.363 to -.099	.001

CI= Confidence Interval

Table 7. Multivariable linear regression with dependent variable being the factor "Role strain"

Characteristic	Coefficient B	95% CI for the B	P
Number of members living at the house	-1.389	-2.872 to .093	.066
Age of the Caregiver	.108	.034 to .181	.005

CI= Confidence Interval

Table 8. Multivariable linear regression with dependent variable being the factor "Relational deprivation"

Characteristic	Coefficient B	95% CI for the B	P
Income	.854	.291 to 1.417	.004
Training Program	-2.109	-3.439 to .778	.002
Age of the Caregiver	.103	.054 to .151	.000

CI= Confidence Interval

Table 9. Multivariable linear regression with dependent variable being the factor "Management of Care"

Characteristic	Coefficient B	95% CI for the B	P
Women compared to Men	-.738	-1.410 to -.067	.032
Level of Education	-.636	-1.099 to -.174	.008

CI= Confidence Interval

Papastavrou E, et al. [29] were conducted both in European countries, and in Cyprus, a significant increase in the burden of people who took care of patients with dementia [29,34]. The result of our study is in line with the Badia Llach X, et al. [35] study, in which the 46.5% of a sample of 268 Spanish caregivers presented a moderate to severe burden and the 34.7% presented a severe burden. This is also in line with the Mougias AA, et al. [36] study in which 41.61% presented a moderate to severe burden and 14.29% presented a serious burden. Also, the family relationship of the majority of the caregivers with the patient was highlighted, while most of the caregivers were women, mainly spouses and daughters, a fact which constitutes a constant finding in all studies [33]. Women are socially put in-charge of taking care of the people who are unable to treat themselves, especially within the family environment. This is reinforced by the fact that women's life expectancy is greater than men's and the fact that they are obligated to "caring" because of the social stereotype. Women are more exposed to the demands of caring and men are less [24]. The educational level seemed to affect the burden. Caregivers of higher level of education were associated with a lower burden, a fact in line with some studies in the international literature [37]. Education is a protective factor and caregivers with a higher level of education may have developed better skills for caring and for stress management.

Another factor that was evaluated is the impact of the burden related to the age of the caregiver. It is clear that older people cannot fully meet the demands of caring, with, over period of time, increases with the progression of the disease and the satisfaction of the patient's needs becomes even more difficult. At the same time the caregivers' age raises the limits for their ability to provide care.

Income was associated with a higher burden. The survey showed a higher burden on middle-income caregivers and less on those with a lower income, agreeing with some studies. In studies in the international literature, reduced

income has been associated with a higher burden, which may be explained by the fact that dementia generates a high financial burden due to the cost of medication, medical examinations and treatment programs. It is obvious that the economic hardship in a family environment without a fixed income is making the situation worse because of the high needs of the disease. The fact, that our study revealed contradictory results could be biased by the occupation of the caregivers who declared having no income, and were almost exclusively housewives taking care of their family.

The training of the caregivers is a key factor in providing quality care to dementia patients who are being treated. Interesting results found in this study was caregivers that attended a training program were more burdened than those who had not attended one. Caregivers had greater expectations for themselves, feelings of inadequacy, guilt about their effectiveness and efficiency. Additionally, they feel the need to be vigilant and ensuring that the relatives were satisfied. The result of this psycho-emotional and practical burden of the caregivers is their poor mental and physical health and the development of emotional disorders such as major depression and anxiety disorder [38].

5. CONCLUSIONS

The current survey highlights the high burden rates, thereby confirming the magnitude of the problem of the burden on people who take care of dementia patients. The study showed that many primary first-level family caregivers reported high levels of personal, physical, social and management burden and a multidimensional view of the issue. Taking care of a patient with Alzheimer's Disease affects the different aspects of each family's life. It is in this direction that this study, has shown that prevention and intervention are a social necessity. To reduce the stress and burden of the caregivers it would be wishful to organize and participate in suitable programs for example time and stress management seminars or caregiving trainings to respond appropriately

and effectively in the stress-charged situations and to improve the skills of the caregivers.

6. RESTRICTIONS

One of the limitations of this study was the difficulty encountered in finding caregivers, given that many of the patients with Alzheimer's disease or with other kinds of dementia are living in the community. Also the range of the sample as well as the percentage of losses, namely the unanswered questionnaires, limits the statistical power to a certain extent and the generalization of the conclusions.

CONSENT

As per international standard or university standard, patient's written consent has been collected and preserved by the authors.

ETHICAL APPROVAL

The study was performed in accordance with the ethical standards of the Cyprus National Bioethics Committee (No. 2014.01.86, 17/07/2014) and the Commissioner of Personal Data Protection (No 3.28.274/17/07/2014) and with the Helsinki Declaration of 1975, as revised in 2000.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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QUESTIONNAIRE

Questionnaire for Caregivers

- | | | |
|----|--|--|
| 1 | Sex | 1. Male
2. Female |
| 2 | Age | |
| 3 | Marital status | 1. Married
2. Single
3. Widowed
4. Divorced
5. Separated
6. Partnership |
| 4 | Number of Children | |
| 5 | Number of family members living in the same house | |
| 6 | Place of residence | 1. Same apartment with the patient
2. Same building with the patient
3. Neighborhood with the patient
4. Different home and neighborhood |
| 7 | Educational level | 1. No school
2. Primary school
3. Junior High School
4. High School
5. Technological Educational Institute
6. University
7. Postgraduate |
| 8 | Occupation (present or in the case of retirement, previous occupation) | 1. Unskilled worker
2. Qualified worker
3. Freelancer
4. Farmer
5. Private Employee
6. Civil Servant
7. Household |
| 9 | Income | 1. No income
2. Up to 6.000 euros per year
3. Up to 12.000 euros per year
4. More than 12.000 euros per year |
| 10 | Total years of taking care of the patient? | |
| 11 | Relationship with the patient | 1. Spouse
2. Daughter
3. Son
4. Sister
5. Brother
6. Partner
7. Other |

- | | | |
|----|---|--|
| 12 | Health problems of the caregiver | <ol style="list-style-type: none">1. No problem2. Hypertension3. Diabetes4. Musculoskeletal5. Cardiovascular6. Vision problems7. Other |
| 13 | Attendance of training programs for care giving | <ol style="list-style-type: none">1. Yes2. No |
| 14 | Age of patient | |
| 15 | Sex of patient | <ol style="list-style-type: none">1. Male2. Female |
| 16 | Patient's Disease | <ol style="list-style-type: none">1. Parkinson Disease2. Alzheimer Disease3. Vascular dementia4. Senile dementia |

The Zarit Burden Interview

0: NEVER 1: RARELY 2: SOMETIMES 3: QUITE FREQUENTLY 4: NEARLY ALWAYS

Please circle the response the best describes how you feel.

1. Do you feel that your relative asks for more help than he/she needs?
0 1 2 3 4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
0 1 2 3 4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
0 1 2 3 4
4. Do you feel embarrassed over your relative's behaviour?
0 1 2 3 4
5. Do you feel angry when you are around your relative?
0 1 2 3 4
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?
0 1 2 3 4
7. Are you afraid what the future holds for your relative?
0 1 2 3 4
8. Do you feel your relative is dependent on you?
0 1 2 3 4
9. Do you feel strained when you are around your relative?
0 1 2 3 4
10. Do you feel your health has suffered because of your involvement with your relative?
0 1 2 3 4
11. Do you feel that you don't have as much privacy as you would like because of your relative?
0 1 2 3 4
12. Do you feel that your social life has suffered because you are caring for your relative?
0 1 2 3 4

13. Do you feel uncomfortable about having friends over because of your relative?
0 1 2 3 4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?
0 1 2 3 4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?
0 1 2 3 4
16. Do you feel that you will be unable to take care of your relative much longer?
0 1 2 3 4
17. Do you feel you have lost control of your life since your relative's illness?
0 1 2 3 4
18. Do you wish you could leave the care of your relative to someone else?
0 1 2 3 4
19. Do you feel uncertain about what to do about your relative?
0 1 2 3 4
20. Do you feel you should be doing more for your relative?
0 1 2 3 4
21. Do you feel you could do a better job in caring for your relative?
0 1 2 3 4
22. Overall, how burdened do you feel in caring for your relative?
0 1 2 3 4

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