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Research Article

Assessing the Burden of Family Caregivers of People with Dementia Living in the Community of a Greek Island

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Abstract

Introduction: The family caregiver's role is crucial in providing care for people with dementia, but equally important is the burden accompanying such care.

Purpose: To assess the burden of family caregivers of elderly with dementia who live in the community, as well as to investigate the determinants of the burden.

Patients and Methods: The cross-sectional study was conducted using the "Zarit Burden Interview", in which the demographic details were included. The questionnaires were completed through personal interviews. Responses from a sample of 114 family caregivers of elderly with dementia living in urban and rural areas of a Greek island were examined. Statistical analyses included t-test, chi-square test and ANOVA. Multiple linear regression was applied to analyse the factors affecting caregiver's burden. The level of statistical significance was set at 0.05.

Results: The majority of the family caregivers were women, daughters mainly, with a low income and mean age 58 years. Mean total burden of caregivers is characterised as moderate to severe. The burden is not correlated with gender, while younger age, high income and high educational level of the caregiver is related to low burden score. The multivariate analysis demonstrated that the number of caregivers' health problems is the primary variable related to the burden score. Caregiver›s own health state with chronic health problems (hypertension, respiratory problems, diabetes) is correlated with higher burden score. The duration of caregiving is proportional to the caregivers' burden. Social support of the family and the availability of community facilities are both requested by the caregivers themselves.

Conclusions: Design and implementation of targeted actions to create dementia-friendly communities will support family caregivers and will contribute to the strengthening the institution of the family, to avoid institutionalization and thus enhance the health and well-being of the caregiver and the care recipient.

Keywords: Burden; Community; Dementia; Determinants; Family caregiver

Introduction

The care of elderly people with dementia by the family has increased significantly in recent years due to the increase in life expectancy and integration into a society of older people. Because of the high levels of dependence and morbidity related to dementia, family members, usually one of them, become responsible for the care of the person with dementia. The family caregiver should assume various roles, the most difficult of which is decision-making about the patient while caring for him/her. If this care is not provided, the patients are quickly admitted to institutional care [1,2]. The family caregiver's role is crucial in providing care for people with dementia [3,4], but equally important is the burden accompanying such care, because providing care for people with dementia is a stressful and exhausting process. Family caregivers report feelings of despair, discomfort and confinement, loss of control, isolation from society and pressure at work [5,6]. Insufficient management of the burden of care can lead to caregiver burnout, with obvious signs of burden at physical, mental and psychological levels [7-10]. This burden has a negative impact on the quality of life of caregivers and their family members, as well as on their social and professional lives, financial status, relationships and family cohesion.

In Greece, which is by strong family institutions and traditions, there is a widespread feeling that the care of elderly patients with dementia is the sole responsibility of their families. The family is the first one to provide care to patients with dementia. Secondarily and at the same time care is provided by health care professionals, with institutional long-term care in rehabilitation centres, clinics or hospitals or institutional care of social inclusion at local-regional level in the form of retirement homes and nursing homes being the final choice. In recent years, social facilities and services play an important role in providing services to the patient and the family caregiver, such as day care centres for the elderly and/or clinics of non-profit associations, which have been founded by relatives and caregivers of individuals with dementia and health care professionals. Nevertheless, the gradual loss of functionality and autonomy, as well as behavioural disorders, including aggressiveness, suspicion and unexplained anxiety of the person with dementia, lead to impaired quality of life of both the care recipient and those who provide care, either family caregivers or health care professionals. Caregivers of elderly patients with dementia report physical and psychosocial burden. Studies demonstrate that these caregivers suffer more frequently from depression, perceive their workload as greater and their health as worse because of receiving more medicines in comparison with their counterparts [11]. Therefore, it is evident that the caregiver requires immediate care too, similar to that of a person who is ill.

The purpose of the present research study is to assess the burden of family caregivers of patients with dementia who live in the community, as well as to investigate the determinants of caregiver-perceived burden. It is thus sought to collect information about the needs of family caregivers, which can form the basis to design and develop protection and support programmes for family caregivers and, indirectly, for patients, through the improvement of care provided.

The Burden of Caring for People with Dementia

The Profile and Role of the Caregiver of a Patient with Dementia

Increasing life expectancy is one of the most important risk factors for dementia. There are many types of dementia, including vascular dementia, senile dementia or Lewy body dementia. Alzheimer's disease is the most common type of dementia, which represents 50-60% of dementia in the elderly. It is a neurodegenerative brain disorder characterised by chronic and gradual impairment of cognitive / mental functions. It affects memory, spatial and temporal orientation, attention, speech, critical reasoning and thinking, and it has an impact both on the patient's everyday activities, and on his/her personality and interpersonal relationships. Dementia's staging is as follows [12,13]:

- Mild disease, in which the patient has short-term memory loss, difficulty in decision-making, restlessness and symptoms of depression and he/she is not interested in usual everyday activities.
- Moderate disease, in which the person requires assistance forself-care, logical sequential thinking and speech are impaired, and confuses persons and situations.
- Advanced disease, in which the patient is completely dependent, as in addition to mental impairment, the physical consequences of the disease occur.

As the disease progresses, the patient's level of dependence on others, and particularly from the members of his/her family, increases [14]. Zarit and Edwards [15] defined caregiving as an interaction in which one family member is helping another on a regular basis with tasks that are necessary for independent living. This care, with or without payment, aims to meet the daily functional needs of the elderly, but also to offer a sense of companionship [16]. Usually, the caregiver for the elderly with dementia is a member of his/her family or wider social network (friend, neighbour). In most cases, the spouse takes on the role of caregiver. When the spouse is not alive, one of the children depending on various social criteria (gender, cohabitation, free time), takes over [14,17]. Family caregivers are informal caregivers as they provide non-specialised care, typically unpaid. Formal caregivers are nurses, social workers, and the physician either as an individual healthcare professional or as part of a health group or at an institution or a care centre for the elderly, who receive payment for their services. Caregivers' duties and responsibilities, as well as the care plan, are determined based on each patient's needs, as the disease progresses. The type of care provided by a family caregiver includes, among others, the following:

- Support in everyday activities, such as cleaning - housekeeping, shopping, and food preparation, getting up, moving, personal care, etc.
- Procedural assistance, such as payment of bills, purchase of medicines, nutrition and other expenses.
- Pain management: such as adjusting the dosage or changing the type of medication administered, and using devices for the administration of medicines.
- Communication with the elderly care interdisciplinary team (physician, physiotherapist, etc.).

- Emotional help and support, such as keeping company and talking with the elderly.

The above show the vital role of caregivers in protecting the well-being of care recipients. Caregivers develop a special interest, commitment, deeper awareness and understanding of the care recipient's deteriorating health condition. A complex, emotionally charged relationship develops between the caregiver and the care-recipient, based on which both the duties and concerns of caregivers can be understood. Nevertheless, the most important for all caregivers is to realise that to be able to care for the dependent person in the best possible way, they should deal with their own feelings and not neglect themselves as the needs of caregivers and care recipients are interdependent.

The Concept of Dementia Patient Caregiver Burden

Caring for elderly people with dementia is a long-term and difficult process, which is usually undertaken by the close relatives of the patient and, secondarily, friends, neighbours and health care professionals. Only 1% of people aged over 65 years live in institutions [17]. Grad and Sainsbury [18] introduced the concept of family burden while studying the care of the mentally ill in the community. Zarit, et al. [19] and George and Gwyther [20] refer to the burden of caring for a dependent family member. Hoening and Hamilton [21] discriminated between subjective and objective burden. Subjective burden concerns the psychological burden of caregivers and the feelings they experience because of the provision of care. Objective burden is the result of care and concerns the changes in the life of both the caregiver and his/her family, such as the limited free time, changes in relationships among family members and increased family expenses. Given, et al. [22] define burden as a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, and financial resources, given the other roles they have to fulfil.

Caregivers of elderly individuals, while providing care to them have to play various roles: be friends, spouses, supporters and protectors of the patient, while being responsible for decision-making on issues concerning the patient. As a result of this, the quality of life of both the caregiver and his/her family members is negatively affected, while the same also applies to social and professional life, financial situation, the cohesion of the family and the relationships among family members. A significant number of research studies has focused on the effects of care on caregivers' health and quality of life, confirming that their family members also experience increased physical and psychiatric morbidity [9,23]. Caregiver burden is a multidimensional problem, and it does not depend only on the nature of the disease, the level of patient functionality, the characteristics and the problems of the patient. It extends to the subjective perception of the caregiver, his/her personality, the dynamic change of the situation and the multidimensional character of care [11,24-26]. It is also worth noting the financial burden for the family that provides care to an elderly patient with dementia, as family members have to manage the household, cover expenses for eating as well as medical and pharmaceutical expenses and anything else that may be required. In this framework, the Health System is in advantageous position by saving money, as the family has to provide care to the patient.

Burden can be measured using various tools. Some are classified as one-dimensional because they focus strictly on the caregiver's emotions and experience. Other are multidimensional, reflecting various aspects of caregiver's well-being and functionality, which may be affected in different levels by the care provided to a patient with dementia. Poulshock and Deimling [27] developed a multi-dimensional tool for subjective and objective burden, which measures burden in relation to the actual problems that occur during care. Another multidimensional tool to measure burden is the Caregiver Burden Inventory (CBI) [28], which provides information about the profile of the caregiver. Similarly, to "The Zarit Burden Interview" [19], it refers to emotional as well as practical difficulties of care, thus including both subjective and objective burden. Despite the information provided by the existing tool for designing therapeutic approaches for people working in the field of care, there is still need for reliable and valid tools to measure separately, if possible, subjective and objective burden of caring for patients with dementia.

Material and Methods

Questionnaire and Data Collection

The present cross-sectional research study was conducted the first semester of 2019. The study population consisted of family caregivers of dementia patients who live in urban and rural areas in the largest big Greek island by area, Crete, and are registered in four Day Care Centres for the Elderly (K.I.F.I) of the Municipality of Heraklion, as well as in facilities-clinics of the non-profit Alzheimer's Association. To be eligible, the caregiver had to be the person providing care to another person, who is dependent exclusively on the caregiver for support. Therefore, caregivers who were the patients' immediate and extended family members, had the most frequent contact with the patient compared to all other family members, and were either exclusively responsible for the patient or responsible to organise the provision of care participated in the study. The sample size amounted to 114 family caregivers. The sample used in the analysis represents 58.5 percent of the similar cases based on the number of elderly people that are registered in the day care facilities and visit them on a systematic basis accompanied by their caregiver.

The study was conducted using "The Zarit Burden Interview" (ZBI or BI) [10], which was used with the permission of Dr. Steve Zarit. The Greek translated version [29] was used with permission. The burden scale consists of 22 questions that reflect the feelings of the caregivers of elderly with dementia, and the effect of patient's disability on their lives. It includes indicators of objective and subjective caregiver burden, translating into both facts and emotions [30]. According to Gallagher, et al. [31], the internal consistency of ZBI was very good with Cronbach's alpha value of 0.91 and test-retest reliability was over 0.70.

The questionnaire consists of two sections with questions, while an open-ended question was also added, allowing the caregivers-responders to express themselves freely. The first section includes questions for the demographic data of the caregivers, from which it is possible to gather information about gender, age, marital status, educational level, income, years of providing care, the degree of kinship, health problems, and whether they have attended an education programme for patient care. The second section includes the 22 questions of the Zarit Interview, grouped into four dimensions: role strain, personal strain, relational deprivation and management of care. The 22 questions focus on assessing mental health, financial status, social life of the caregiver and the relationship between the caregiver and the patient with dementia. In each question, the responders should state the frequency that they had felt in a certain way in a scale with ratings from "Never" (score 0) to "almost always" (score 4). The total score, ranging between 0-88, is calculated by adding the scores obtained for each answer. According to Zarit, et al. [32], estimates of the burden score are as follows: little or no burden (score 0-20), mild to moderate burden (score 21-40), moderate to severe burden (score 41-60) and severe burden (score 61-88).

The questionnaires were filled in through personal interviews, as most of the responders were elderly and they could not write the answers of the questions on their own. The interviews were conducted at scheduled dates convenient to the participants at the premises of the four Day Care Centres for the Elderly, as well as at the clinics of the non-profit association. When the caregivers could not visit the aforementioned areas due to the constant care of their relative-the patient, the interview was scheduled at their home. The choice of conducting the interviews in the above places was based on the criterion of finding places familiar to the caregivers, where they would feel comfortable to respond to the questions of the interview. Approximately one hour was required to fill in each questionnaire, as each question had to be repeated for most caregivers and they felt emotionally charged, they started crying and they were talking about what they are experiencing asking for understanding and support. It should be noted that apart from obtaining permission to use the Zarit Burden Interview, a permission to conduct the study was also obtained from the competent parties of the centres/clinics where the interviews were conducted. In addition, the consent of the population of caregivers under study was also obtained. In particular, the caregivers were informed about the aim of the study through a letter, which stressed the fact that their details will be kept anonymous and confidential in the results. The caregivers who participated in the interview and were the sample of the study provided their written consent to participate in the study, based on the guidelines for bioethical and ethical research for the protection of participants.

Methods of Analysis

Descriptive statistical analysis (mean, standard deviation and frequency) was used to describe the sample. Test of normality was carried out on all variables of the sample, while internal consistency was evaluated using Cronbach's alpha coefficient of reliability. The differences of the mean values of the continuous variable "burden score" and the binary categorical variables (such as gender, health problem) were tested with the independent samples t-test. For the comparisons of the means between a continuous variable and categorical variables with more than two levels (such as kinship, educational level, income, place of residence, number of health problems), one-way Analysis of Variance (ANOVA) was applied. The relationships between qualitative variables (such as gender, caregivers' health problems, and seminar attendance) were tested using the chi-square (χ^2) test. Spearman (r) correlation coefficient was used to assess the correlation between the burden score and age (in years) and the number of family members, while Pearson's (r) correlation coefficient was used to assess the correlation between burden score and absolute number of health problems and years of care. Backward stepwise multiple linear regression was used to study the factors affecting caregiver's burden. Moreover, multiple logistic regression was used with dependent variable the binary form of the variable "burden score" (above or below the median score) and the same explanatory variables (such as gender, caregiver's age, caregiver's health problems). The statistical package IBM SPSS Statistics 22.0 was used to carry out the analyses. The two-sided level of statistical significance was set at 0.05.

Results

Sociodemographic Characteristics of the Sample

The sample consisted of 114 family caregivers of patients with dementia, 81 women and 33 men. (Table 1) presents the sociodemographic characteristics of the population under study. People of various ages were included, the majority of whom belonged in the 45-60 years old age group, with a median age of 58.9±12.4 years old. Caregivers' educational levels covers all educational levels, with the highest percentage, 43.9%, being primary school graduates or having attend some years in the primary school. Twenty-three respondents have attended higher education institutions, and two of them have a post-graduate degree. Most caregivers have low income, with 61.9% of them having an annual income of less than €10,000.

Variable	F(%)
Gender	
Male	33(28.9%)
Female	81(71.1%)
Age	
<=45	9(7.9%)
45-60	65(57.0%)
60-75	28(24.6%)
>75	12(10.5%)
Degree of kinship with the patient	
Spouse	28(24.6%)
Child	56(49.1%)
Daughter	39(69.6%)
Son	17(30.4%)
Brother/sister	9(7.9%)
Brother	5(55.6%)
Sister	4(44.4%)
Other	21(18.4%)
Educational Level	
Primary Education	50(43.9%)
Secondary Education	41(36.0%)
Higher education	23(20.2%)
Income (€)	
<10,000 €	71(62.3%)
10,000-20,000 €	40(35.1%)
>20,000€	3(2.6%)
Place of residence	
The same household with the patient	78(68.4%)
The same building with the patient	10(8.8%)
The same neighbourhood with the patient	10(8.8%)
Different household and neighbourhood from the patient	16(14%)
Attendance of training programme on providing care to patients with dementia	
Yes	22(19.3%)
No	92(80.7%)
Health problems	
Number	
None	46(40.4%)
1	46(40.4%)
2	10(8.8%)
3	8 (7%)
4	4(3.5%)
Hypertension (Yes/No)	27(23.7%)
Diabetes Mellitus (Yes/No)	18(15.8%)
Musculoskeletal (Yes/No)	16(14.0%)
Cardiovascular (Yes/No)	17(14.9%)
Respiratory (Yes/No)	12(10.5%)
Visual (Yes/No)	4(3.5%)
Other (Yes/No)	13(11.4%)
Whether the patient is alive	
Yes	75(65.8%)
No	39(34.2%)

Table 1: Sociodemographic characteristics of the sample (n=114).

The mean time of caring for the elderly persons is 4.9 years, while the mean number of persons living in the same households approximately three persons (Table 2). In total, 19.3% of the sample had attended a training course for providing care to patients with dementia.

	Mean	Standard Deviation	Median	Minimum	Maximum
Years of care (years)	4.9	6.4	3	1	61
Family members in the same household	3.1	1.3	3	1	7

Table 2: Years of care and number of people living in the same household.

The majority of caregivers live with the patient, while only 10 caregivers live in the same building (8.8%). Figure 1 presents the distribution of caregivers' responses in relation to the place of residence.

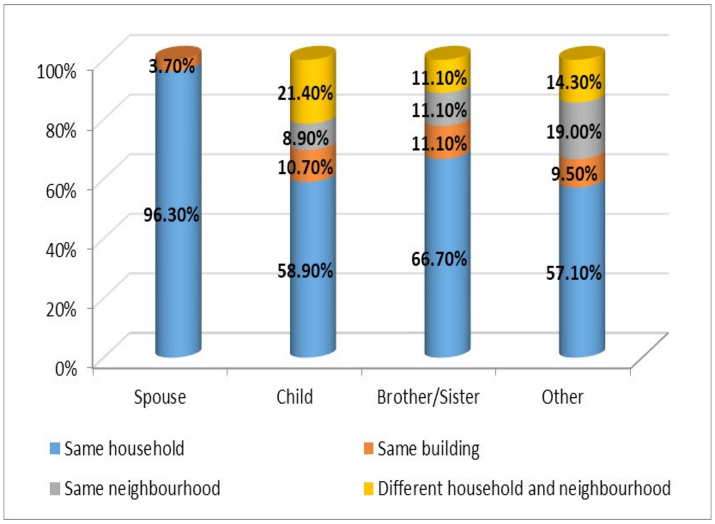

Figure 1: Distribution of caregivers based on kinship with the relative and place of residence.

From the 114 participants, 46 did not mention any health problem, while 46 of them stated just one. Among the reported health problems, hypertension has the highest percentage (23.7%), while percentage frequency of health problem by gender is presented in Figure 2.

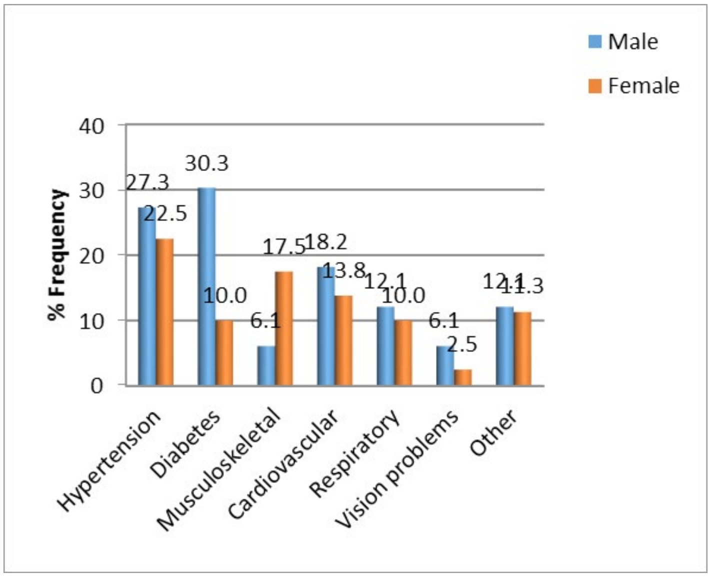

Figure 2: Caregivers' health problems by gender.

Caregivers' Characteristics as Determinants of Burden

(Table 3) presents the responses in each of the 22 questions of the Zarit Burden scale. The number of unanswered questions ranges from 0-4 (0.0-3.5%) and therefore no specific approach was employed for the missing cases. Question "Do you feel you have lost control of your life since your relative's death?" is an exception, as a large number of missing cases was excepted (75 caregivers) whose relative with dementia is alive. Internal consistency coefficient, Cronbach alpha, for all questions is 0.929.

S/N	Question of the Zarit Burden Scale		Never	Rarely	Sometimes	Quite frequently	Nearly always	No answer
Role strain								
Q1	Do you feel that your relative asks for more help than he/she needs?	N	14	20	30	28	20	2
		%	12.5	17.9	26.8	25	17.9	
Q2	Do you feel embarrassed over your relative's behaviour?	N	8	12	21	31	40	2
		%	7.1	10.7	18.8	27.7	35.7	
Q3	Do you feel angry when you are around your relative?	N	22	27	37	19	9	0
		%	19.3	23.7	32.5	16.7	7.9	
Q4	Do you feel that your relative currently affects your relationships with other family members?	N	15	9	26	32	32	0
		%	13.2	7.9	22.8	28.1	28.1	
		%	12.3	5.3	48.2	20.2	14	
Q14	Do you feel you have lost control of your life since your relative's death?	N	9	8	10	6	6	75
		%	23.1	20.5	25.6	15.4	15.4	
Q15	Do you wish you could leave the care of your relative to someone else?	N	18	18	46	22	9	1
		%	15.9	15.9	40.7	19.5	8	
Q16	Overall, how burdened do you feel in caring for your relative?	N	4	10	22	39	38	1
		%	3.5	8.8	19.5	34.5	33.6	
Relational deprivation								
Q17	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	N	11	9	21	26	45	2
		%	9.8	8	18.8	23.2	40.2	
Q18	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	N	5	7	23	31	47	1
		%	4.4	6.2	20.4	27.4	41.6	
Q19	Do you feel that you don't have as much privacy as you would like because of your relative?	N	6	9	22	33	44	0
		%	5.3	7.9	19.3	28.9	38.6	

Q20	Do you feel that your social life has suffered because you are caring for your relative?	N	6	11	18	34	45	0
		%	5.3	9.6	15.8	29.8	39.5	
Management of care								
Q21	Do you feel you should be doing more for your relative?	N	13	26	53	12	9	1
		%	11.5	23	46.9	10.6	8	
Q22	Do you feel you could do a better job in caring for your relative?	N	19	28	41	17	7	2
		%	17	25	36.6	15.2	6.3	

Table 3: Distribution of answers in the 22 questions (n=114).

(Table 4) presents the percentage distribution of the burden score in each group. The mean score of burden for the population under study that includes 114 caregivers is 50.7, with a median of 53.5, and is characterised as moderate to severe (score 41<50.7<60). Data distribution is symmetrical around the median with a maximum value of 85 and a minimum value of 14, while an outlier (11) is also observed.

Burden (score)	**Frequency**	**%**	**Valid Percent**	**Cumulative Percent**
Little or No (0-20)	5	4.4	4.4	4.4
Mild to Moderate (21-40)	23	20.2	20.2	24.6
Moderate to Severe (41-60)	53	46.5	46.5	71.1
Severe (61-88)	33	28.9	28.9	100
Total	114	100	100	

Table 4: Percentage distribution of the burden score.

The statistical analysis of correlations between burden score and demographic characteristics showed a statistically significant correlation only between burden score an age as a categorical variable (χ^2=8.726, p=0.033) and as a continuous variable (Spearman's r=0.286, p=0.002) (Figure 3). Furthermore, a statistically significant correlation was identified between gender and diabetes mellitus (Pearson's x^2=7.191, p=0.007) with men caregivers showing a greater percentage of the disease (30.3%) in comparison to women caregivers (10.0%), while no statistically significant relationship (p>0.05) was found between the gender and the other health problems of the caregivers. Increasing number of years of providing care is correlated significantly with the burden experienced by the caregivers (Pearson's r=0.201, p=0.034). The result did not change when the outlier (61 years of care) was removed (Figure 4).

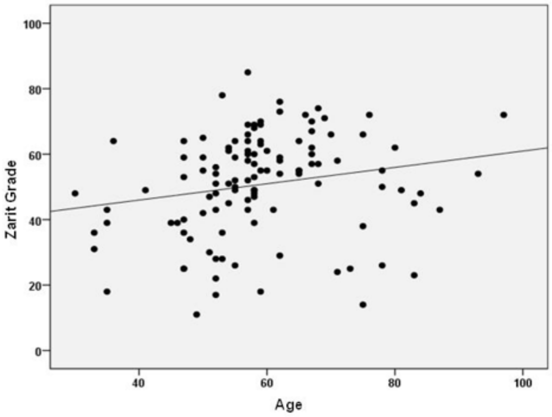

Figure 3: Scatterplot of caregiver's age and burden score.

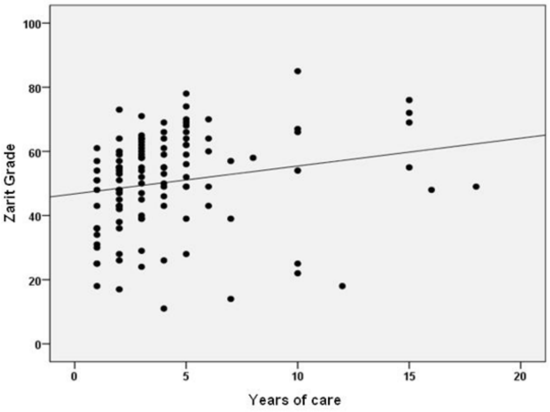

Figure 4: Scatterplot of years of care and burden score.

The analyses of the means revealed no statistically significant difference in terms of total mean burden between men and women caregivers (t=0.204, p=0.839>0.05), between the number of family members living in the same household (Pearson's r=-0.051, p=0.067) and between the degree of kinship of the caregiver with the patient (F=2.223, df=3.109, p=0.090). Nevertheless, caregivers who were brothers/sisters of the patient had the greatest burden score 57.8±14.3, irrespectively of their gender. Similarly, no statistically significant difference was identified in the total mean burden between attendance and no attendance of an education course by the caregivers (F=0.336, 112, p=0.563) and when the comparison was based on the caregivers' place of residence (F=2.26, p=0.89). The burden for caregivers living in a different household and neighbourhood is lower (41.9±1.4) in comparison to caregivers living in the same household (52.7±15.6), same building (51.5±10.9) and same neighbourhood 51.3±16.7). When considering health problems, the comparison of the means showed no statistically significant difference in terms of total mean burden. Similarly, no statistically significant difference was observed between those with or without musculoskeletal problems (t=-1.341, p=0.183); between those with or without cardiovascular problems (t=-1.261, p=0.210); and between those who reported other health problems and those who do not have any problems (t=-0.147, p=0.883).

The analysis of the means showed a statistically significant difference in total mean burden experienced by the caregivers by their educational level (ANOVA F=5.188, p=0.007). In particular, caregivers with high educational level had quite lower burden score (41.9±17.2) in comparison with those who had completed secondary education (51.6±14.2) and primary education (54.0±14.9). Similarly, a statistically significant difference was found in total mean burden experienced by the caregivers by annual income categories (ANOVA test F=3.639, p=0.029). Caregivers with an income>20,000€ had significantly lower burden score (29.7±5.7) in relation to those with an income between €10,000-20,000 (49.6±15.2) and those with an income below €10,000 (52.7±15.2). When health problems were examined, a statistically significant difference in total mean burden was found by type of health problem (F=8.529, p<0.001), between those with or without hypertension (t=-2.915, p=0.004) with a mean burden score of 58.1±12.7; between those with or without diabetes (t-test: t=-4.075, p<0.001) with a mean burden score of 63.7±11.0; between those with or without vision problems (t=-3.702, p<0.001) with a mean burden score of 77.8±5.4; and between those with or without respiratory problems (t=-3,186, p=0,002) with a mean burden score of 55.1±16.9. Caregivers with 4 and 3 health problems have high burden scores, 76.8±5.7 and 59.1±10.1, respectively, with a statistically significant difference in mean burden score as compared to caregivers with 0, 1 and 2 health problems (F=8.529, p<0.001).

Furthermore, a multivariate analysis (enter and backward method) was carried out using two techniques (Table 5). In the first analysis, the multiple linear regression model was applied with burden score as the dependent variable and the other variables (gender, age, educational level, annual income, degree of kinship with the elderly, place of residence, number of problems and years of care) as independent variables. The number of caregiver's health problems interpret statistically the burden score, p<0.001 and goodness of fit R^2=0,420. Similar result was obtained using the second technique, multiple logistic regression with the same independent variables and the burden score as the dependent binary variable, with values above and below the median 53.5. The possibility of high burden score (dependent variable) can be predicted by the number of caregiver's health problems (p=0.011<0.05).

Multiple Linear Regression	**B**	**95%LL**	**95%UL**	**p**
Number of health problems	6.246	-3.656	8.837	<0.001
Multiple Logistic Regression	Odds Ratio	95%LL	95%UL	p
Number of health problems	2.104	1.183	3.743	0.011

Table 5: Results of the multivariate analysis, with the burden score as the dependent variable (continuous or binary).

Finally, it is worth noting that in the open-ended questions, in which the caregivers could write any additional information or remark, the majority of them pointed out the need for information, education and support from social services.

Discussion

The present research study focuses on the burden score and the factors that affect it, aiming at highlighting areas for action to better support caregivers and, indirectly, the care recipients, i.e., elderly with dementia. The use of the Zarit Burden Interview was selected. In the population under study, which included 114 caregivers living in the wider area of Heraklion, Crete, burden is characterised from moderate to severe (score 41<50,7<60). This moderate burden score could be explained by the fact that caregivers are registered in day care social facilities for individuals with dementia, the aim of which is to support both patients and caregivers in everyday activities. Therefore, the present study investigates both the burden and its parameters in a sample of caregivers who receive social services.

According to the results of the analysis, it is evident that women (spouses and daughters) are the majority of caregivers who provide care to elderly people with dementia, experiencing severe burden to a greater extent, a finding that is consistent with the relevant findings [24,25,29,33]. The fact that mainly women undertake the role of care can be explained by the prevailing culture, which considers her (the wife or daughter) accountable to provide care to any family member unable of self-care. A large number of women undertake the care of a relative, rationalising their involvement through role stereotypes [34,35]. Nevertheless, according Rudd et al. [36] women have a longer life expectancy than men, get married to older men the responsibility for the care they take on is getting more intense. However, the analysis did not show a statistically significant difference between caregiver's gender and reported burden score. McConaghy and Caltabiano [37] and Iatraki [29] demonstrate similar findings. This can be explained by the fact that women learn to distance themselves emotionally and, as many men, to behave in a more organisational manner. Women, as compared to men, are more exposed to the demands of caring for people with dementia, and usually undertake a difficult task, requiring skills that they lack in many cases. Therefore, women, daughters in particular, are a "Vulnerable" group for the provision of specialised support services and strengthening to be able to cope with the demanding task of providing care to dementia patients. Any kind of support programme design for family caregivers should take into account that over time, the number of men caregivers is expected to rise, as dementia is more frequently diagnosed among women [38]. According to our study, 30.4% of caregivers have a parent-son relationship and 23.9% consists of husbands, both of which are far from insignificant.

The ages of the caregivers who were included in the sample are correlated with the burden experienced by caregivers, while older caregivers show greater burden. Similar findings are confirmed by a large number of researchers [10,39-42]. For older caregivers, the burden of care is often heavier due to their own physical limitations and the fear of having to leave their relative behind when they die [11]. Further evaluating the responses of the sample's caregivers, it is worth noting that burden shows a slightly decreasing trend in those over the age of 75 years, because of the fact that the caregiver cannot offer help and additional support is required by another person. Moreover, the increasing years of care are statistically significantly correlated with burden. The duration of caregiving affects caregivers' burden [24,25,43]. Indeed, according to Parks and Novielli [23] the amount of time spent to provide care to the care recipient does not correlate with caregiver's burden. Further research into the caregivers'' profiles in relation to patient's gender and severity of the disease may clarify the correlation of burden with years of care. The degree of kinship between caregiver and patient, living in the same household, and seminar attendance did not demonstrate statistically significant correlation with the burden experienced by the caregivers. The profile of the caregivers at the particular time of data collection may explain the above findings.

The educational level and income of caregivers are highlighted as significant factors that affect the level of burden that the caregiver experiences. Vitaliano, et al. [44] report income as the most important predictor of burden for caregivers of patients with Alzheimer's disease. Furthermore, the theory of vulnerable populations that was formulated by Flaskerud & Winslow [45] is confirmed; according to this theory, socio-economic factors, such as income and education, are correlated with increased morbidity, like burden. Caregivers with low income cannot pay for the medical and pharmaceutical treatment of the patient, while because of the time spent to provide care to the patient cannot meet their professional obligations, which aggravates further the financial situation and thus the burden experienced. Seltzer et al. [46] note that low burden of caregivers with high educational level and income can be explained by the fact that they request support by specialised services to provide care to their relatives. Education seems to be a protective factor and caregivers with higher educational level develop better care and stress management skills, and they request help by supporting services when they cannot provide care. According to Sansoni et al. [47] caregivers with a higher level of education show low levels of depression, while Vellone, et al. [48] suggested that caregivers with a lower level of education have limited knowledge on dementia to be able to manage the patient's reactions and the consequences of care.

Caregiver's health status is a predictor of the level of burden experienced. The number and type of caregivers' health problems are statistically correlated with the reported burden. Hypertension, respiratory problems, diabetes and vision problems of the caregivers are statistically correlated with the level of burden. The same result is demonstrated with the multivariate analysis, which showed that the number of caregiver's health problems is a predictor of burden. According to Atienza, et al. [49], female caregivers experience greater blood pressure reactivity to caregiving-related stress. However, as the effect of burden on health status has been studied more than the effect of pre-existing health problems on burden, it is not possible to draw safe conclusions.

In the context of the above, the information, education and empowerment of caregivers emerges as a field in health policy- and strategy-making. Family caregivers themselves require to be informed about the existing support and educational programmes and social facilities. It has been argued that empowering dementia patients' caregivers contributes in minimising their burden [3,17,50,51]. Counselling and educational programmes for caregivers focussing on the care of patients with dementia and the management of the burden experienced can have a positive impact on both caregivers and care recipients' quality of life. Besides, such information can enhance their willingness to participate in self-support groups, through which they will meet other caregivers in their community to exchange experiences, tips, or even for emotional support. In addition, as also stated by Marriott et al. [52], family therapy helps caregivers in managing the burden of care, but also the patients themselves in expressing their needs and concerns (if possible, depending on their health status).

Management of dementia in the community is a primary goal. Primary health care services can contribute in achieving this goal through psycho-educational interventions, as well as specialised facilities in the community. According to Colvez et al. [8], supporting the family through specialised programmes and services aiming at keeping the elderly in their homes is essential. In Greece, such facilities include the Day Care Centres for the Elderly (K.I.F.I) and the programme "Help at Home" of municipalities. The main aim of the provided services is to support caregivers, keep patients with dementia at their familiar natural and social environment for as much as possible, avoid institutionalisation and social exclusion, maintain family cohesion, and ultimately improving the quality of life of their families. Special memory and dementia clinics operate within the neurological departments of the Hospitals that support care recipients and caregivers, while non-profit associations for Alzheimer's disease, founded by relatives and caregivers of individuals with dementia, doctors, psychologists and other health care professionals offer comprehensive services in the community for individuals with dementia and their caregivers. The need of caregivers for social services and counselling and support programmes is reasonable, as they can contribute in improving their own quality of life, as well as the quality of life of both their family members and the patient with dementia [12,53]. Information and awareness raising at community level to enhance familiarisation with the problem and enhancing the quality of life of both people with dementia and their families aim at reducing the social, financial and emotional burden of family caregivers due to long-term care of people with dementia. It is, thus, essential to find ways to relieve family caregivers of the burden of caring, as well as targeted actions planning that aim at enhancing the health and well-being of the caregiver, care recipient, and the society as a whole.

Conclusions and Administrative Implications of the Study

The present research study aims at investigating the determinants of burden of family caregivers of people with dementia living in a community and registered in social day care facilities for people with dementia that support everyday both caregivers and care recipients using the Zarit Burden Interview (ZBI ή BI). The analysis of the results confirmed the findings of various international studies and supports the assumption that family caregivers' burden is influenced by the characteristics of the caregivers and the duration of caring. The mean burden of caregivers is moderate to severe. The majority of the caregivers are women, live in the same household with the elderly and provide care for approximately 5 years. According to the data analysis, there is no correlation between gender and burden, while on the contrary the age of the family caregiver plays a crucial role. High income and high educational level of the caregiver is related to low burden score. Moreover, according to the results of the multivariate analysis, there is a positive statistically significant association between the number of caregivers' health problems and the burden score. The burden of caregivers who have health problems is higher because of caring the elderly with dementia; the greater the number of caregivers' health problems the higher the burden they experience. The results of the present study provide a comprehensive picture of the need to support and educate both families and the caregivers of the elderly with dementia in the community.

Nevertheless, the present study has some limitations, the most important of which being that is a cross-sectional study, and therefore it is not possible to determine the causal relationships and the conclusions and how these relations change over time. However, this study design was selected based on the aim of our study, i.e., to investigate the factors affecting the burden experienced by caregivers in the community of a big Greek island. Furthermore, despite possible concerns about the representativeness of the sample, the results help in showing the main actions that can be undertaken at the community level. The conclusions highlight the need for measures aiming at informing, educating and empowering the caregivers, which will contribute positively in reducing their burden.

In summary, the most important conclusion that is drawn concerns the need to further investigate the consequences of burden on family caregivers of elderly patients with dementia, as well as the strategies adopted to cope with it. The same questionnaire can be applied to a larger sample of caregivers throughout Greece to further confirm the correlations revealed in the present study. Further, research should be focus on the burden caregivers and care recipients experience in the time of COVID-19 pandemic. A comparative analysis between caregivers living in rural areas, in the islands and in urban areas of the country would be also interesting to investigate possible differences by area of residence. It would be also useful to study the caregiver's personality characteristics, the burden experienced, and the effectiveness of various services provided by current facilities and services to support family caregivers.

A well-organized guidance, social support of the family and investing on both the current and new care facilities are among the requests of the caregivers, as also confirmed by our study. Providing accessible and documented information, training programmes, support services and other services adjusted to the needs of caregivers to improve their knowledge and skills in managing people with dementia to be able to live in the community and avoid stress and health problems of the caregivers are critical points to create dementia-friendly communities. Establishing hospitality and long-term stay facilities for the elderly with dementia can also contribute in relieving the burden of caregivers. Design and implementation of targeted actions in the community, supporting the caregivers and the care recipients are fields of action that will contribute in keeping the person with dementia in the familiar environment, maintaining family cohesion, and avoiding institutionalisation. This becomes of major importance the current period of the novel Coronavirus (COVID-19) pandemic where both caregivers and care recipients experience a lot of psychological and physical distress [50]. Such actions will aim at improving the lives of people with dementia, their caregivers and their families, while reducing the impact of dementia on communities and countries.

Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

Author Contributions

Both authors contributed equally in the manuscript from the literature research and the conception of the study to the protocol development, to ethical approval gaining, caregiver recruitment and data analysis. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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