The Burden of Informal Caregivers of the Chronically Ill: A Hospital-Based Survey

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Abstract

Background: A significant proportion of the care needs of the chronically ill are covered by the informal caregivers. These needs can create the conditions for the physical and psychological burden of the informal caregiver.

Aims: The aim of this study was to investigate the degree of burden of chronically ill caregivers, as well as possible correlations between demographic and clinical characteristics of caregivers and patients with the degree of burden on caregivers.

Methodology: A cross-sectional study was performed using a structured questionnaire. The studied population was the informal caregivers of chronically ill patients, who were hospitalized in a general provincial hospital in Greece. The duration of the study was from 10th to 31st December, 2020. A total of 150 informal caregivers were enrolled and 148 agreed to participate (response rate 98.6%).

Results: The average age of caregivers was 54 years, most were children (62.2%) or spouses (33.1%) of the patients and the average hours of daycare was 14.1. The fifty per cent of caregivers had a mild burden (overall score from 21 to 40), 31.8% had a moderate (overall score from 41 to 60), 10.1% had a very low (overall score from 0 to 21) and 8.1% had a severe burden (overall score from 61 to 88). According to the findings of the multivariate linear regression, the gender of the patient (female), the increased daily hours of care provision, the existence of chronic health problems of caregivers and patients, unemployed/domestic/retired caregiver relative to employees and caregivers increased level of education were statistically significantly related to a higher burden of caregivers.

Conclusions: Every year the prevalence of chronic diseases increases and therefore the need for informal caregivers will increase, making it imperative to improve their quality of life so that they will be able to provide health care.

Key Words: Burden, caregiver, chronical ill, informal.

Introduction

Chronic diseases have a high incidence and are responsible for the high rates of disability and death internationally (World Health Organization, 2021; Busse *et al.*, 2010). In fact, a significant number of people suffer from more than one chronic disease (Hajat and Stein, 2018). The continuously increasing number of patients with chronic disease is also creating increasing care needs for these patients. A significant proportion of the care needs, both when patients visit or are hospitalized in health service structures and at home, are covered by the informal caregivers. Informal care may be defined as "*the provision of health care to dependent persons by family, friends, neighbors or others in the patient's immediate social network, who do not receive financial compensation for the assistance they provide*"(Govina *et al.*, 2020). Informal caregivers have the role of partner and/or assistant, can provide emotional support, personal care, transport services to and from health care structures and generally facilitate the patient's adaptation to the disease and the needs or limitations that arouse from it (Govina *et al.*, 2020).

A study carried out on informal caregivers of patients with dementia in Greece showed that the majority of informal caregivers (70%) resided with the patient who they cared for and in their entirety caregivers came from close family environment (Dimakopoulou, Efthymiou and Karpathiou, 2015). According to the same study, the average age of caregivers was 63.16 years, providing daily an average of 13.6 hours of care for patients, while 38.7% provided care 24 hours a day. A study also in Greece, in caregivers of patients with advanced cancer, found that the majority of informal caregivers (86%) had an affinity of husband or child with the patient, with the average age of caregivers being 53.3 years (Govina *et al.*, 2015). The average duration of the informal care provided was relatively short (14.4 months) and 59% already had experience of previous chronic care (Govina *et al.*, 2015).

The family and professional obligations of informal caregivers, combined with the obligations to cover the care needs of chronic patients, for which many caregivers declare ignorance, as well as the cohabitation of the caregiver with the patient along with the several

hours of care, can create the conditions for the physical and psychological burden of the informal caregiver. In the above care conditions, the needs of the chronic patient outside his home, which include traveling to health structures for examinations, visiting the attending physician, admission and hospitalization for the treatment of the chronic disease or the treatment of its complications, should not be overlooked. Depression and anxiety are two psychologically important consequences of informal care. A study in family caregivers of patients diagnosed with lung cancer in Taiwan found high levels of depression and anxiety even before patients received treatment (Lee *et al.*, 2013). Factors found to be associated with anxiety and depression were age and effectiveness in managing the patient's symptoms. In particular, younger caregivers, and those with a greater knowledge of managing patient symptoms, were less likely to experience anxiety and depression. An extensive study involving 1635 cancer caregivers was conducted in the US, which evaluated the quality of life of caregivers and investigated the factors that affect them. The study was conducted two years after the diagnosis of their patient relative with cancer (Kim and Spillers, 2010). Regarding the mental health of caregivers, those who were elderly, male, relatively affluent and cared for patients with less serious diagnosed cancer with good mental and physical function, reported better mental health. The physical burden of chronic caregivers is also important. In a systematic review of 192 studies regarding the burden of family caregivers for patients diagnosed with cancer, pain was one of the major problems that caregivers experienced (Girgis *et al.*, 2013). In particular, caregivers reported back pains, leg pains, muscle tensions as well as headaches. Caregivers also reported sleep problems. More specifically, caregivers reported sleep disorders, poor sleep quality and restless sleep as well as reduced sleep time. Many caregivers said they were also experiencing insomnia. Fatigue, loss of energy and physical exhaustion are included in the burden of caregivers. Finally, according to the same systematic review, many caregivers found themselves facing loss of appetite, indigestion, weight loss and physical strength.

The informal caregivers of chronically ill patients systematically offer valuable care to chronic patients, supporting them both physically

and psychologically. Investigating the degree of burden of informal caregivers and the factors contributing to this burden, contribute to the creation of support services by the state to meet the above needs.

The aim of this study was to investigate the degree of burden of chronically ill caregivers, as well as possible correlations between demographic and clinical characteristics of caregivers and patients with the degree of burden on caregivers.

Methodology: A cross-sectional study was performed using a structured questionnaire. The studied population was the informal caregivers of chronically ill patients, who were hospitalized in the clinics of a general provincial hospital in Greece. Initially, the study protocol was approved by the Ethical Committee and then by the administration of the Hospital. The researchers conducted the interview with the caregivers of chronically ill patients. Convenience sampling was applied. The duration of the study was from 10 to 31 December, 2020. A total of 150 informal caregivers were enrolled and 148 agreed to participate (response rate 98.6%).

Instrument and Data collection: The Zarit Burden Interview, which has been translated and validated in Greek (Papastavrou, Kalokerinou-Anagnostopoulou, *et al.*, 2006), was used to collect the data. Permission was sought and given by the Greek researchers who translated the questionnaire. The Burden Scale consists of 22 questions and was initially designed to assess the subjective burden on American caregivers of dementia patients. The 22 sentences reflect the feelings of caregivers of elderly people with dementia. For each point, the participants are asked to indicate how often they have felt this way, on a Likert scale with ascending order (from 0 = never to 4 = almost always). The summary index (total score) of the scale is the sum of the reactions at the individual points. Higher grades are indicative of a higher burden for the caregivers with a maximum value of 88. The 22 proposals of the Scale are divided into four sub-scales (factors), which are Personal strain (9 proposals), Role strain (7 proposals), Relational deprivation (4 proposals) and Management of care (2 proposals).

Data Analysis: The categorical variables are presented as absolute (n) and relative (%) frequencies, while the quantitative variables are presented as mean, standard deviation, median, minimum value and maximum value. Kolmogorov-Smirnov testing and normality charts were used to control the normal distribution of quantitative variables. The independent variables were the demographic characteristics and professional characteristics of the caregivers as well as the demographic and clinical characteristics of the patients. The dependent variable was the burden on the caregivers. Because of the limited variability, family relationships with the patient and diagnoses could not be used in correlations.

The analysis of variance was used to investigate the existence of a relationship between a quantitative variable and a dichotomous variable using the t-test (student's t-test), while analysis of variance was used to investigate the existence of a relationship between a quantitative variable and a categorical variable with >2 categories. Pearson's correlation coefficient was used to investigate the existence of a relationship between two quantitative variables following the normal distribution. Spearman's correlation coefficient was used to investigate the existence of a relationship between a quantitative variable following the normal distribution and an ordinal variable. In the case that >2 independent variables were obtained statistically significant at the level of 0.2 (p<0.2) in the bivariate analysis, multivariate linear regression was applied with the burden scores as dependent variable. In this case, the multiple linear regression method was applied by backward stepwise linear regression. For multiple linear regression, the coefficients' beta, the corresponding 95% confidence intervals and the p-values are presented.

The two-sided statistical significance level was set at 0.05. The data was analyzed with the IBM SPSS 21.0 (Statistical Package for Social Sciences).

Results

The studied population included 148 informal chronically ill caregivers. Demographic and professional characteristics of caregivers are shown in Table 1. The average age of caregivers was 54 years, while most were women (77%), married (83.8%) and high school graduates (64.2%). Also, 49.4% of caregivers were working, while 39.2% had chronic health problems. Most were children (62.2%) or

spouses (33.1%) of the patients. The average hours of daycare were 14.1 and the average number of years of care was 5.4.

The patients' demographic and clinical characteristics are presented in Table 2. The mean age of the patients was 76 years, most of them were men (61.5%), married (93.9%) and elementary graduates (56.8%). Also, 43.2% of patients were ambulatory, 36.5% were on stretcher, 13.5% were on cane and 6.8% were on wheelchair. The most common main diagnoses were cancer (42.6%), chronic renal failure (18.9%) and stroke (10.1%). Also 84.5% of patients had co-morbidity.

The descriptive results and the Cronbach's alpha internal consistency factor for Zarit scales are shown in Table 3. The Cronbach's alpha internal consistency factors for Zarit scales were between 0.74 and 0.84 and 0.9 for the total scale, which indicates excellent reliability. The fifty per cent of caregivers had a mild burden (overall score from 21 to 40), 31.8% had a moderate (overall

score from 41 to 60), 10.1% had a very low (overall score from 0 to 21) and 8.1% had a severe burden (overall score from 61 to 88).

Bivariate correlations between demographic and clinical characteristics of caregivers and patients with the total score and with the score of the 4 sub-scales of the questionnaire were initially performed. After the bivariate analysis, for those independent variables that resulted in a statistical relationship at the level of 0.20 (p<0.20), multivariate linear regression was applied, the results of which are presented in Table 4. According to the findings of the multivariate linear regression, the gender of the patient (female), the increased daily hours of care provision, the existence of chronic health problems of caregivers and patients, unemployed/domestic/retired caregiver relative to employees and caregivers increased level of education were statistically significantly related to a higher burden of caregivers.

Table 1. Demographic and working characteristics of the caregivers (n=148).

Characteristics	N	%
Sex		
Male	34	23
Female	114	77
Age	54[a]	9.2[b]
Educational Level		
Primary School	22	14.9
High Schools	95	64.2
University	31	20.9
Marital Status		
Unmarried	16	10.8
Married	124	83.8
Widower	2	1.4
Divorced	6	4.1
Number of Children	2[a]	1[b]
Profession		
Unemployed	8	5.4
Housework	42	28.4
Retired	25	16.9
Civil Servant	22	14.9
Private Servant	32	21.6
Freelancer	17	11.5
Farmer	2	1.4
Family relationship with the patient		

Parent	2	1.4
Child	92	62.2
Sibling	5	3.4
Spouse	49	33.1
Caregiver's Residence		
Same as patient	67	45.3
Different home, in the patient's building	48	32.4
Different area	33	22.3
Hours of Daily Care	14.1[a]	7.4[b]
Years of Care	5.4[a]	4.9[b]
Chronic Health Problems		
No	90	60.8
Yes	58	39.2

[a] mean   [b] standard deviation

Table 2. Demographic and clinical characteristics of the patients (n=148).

Characteristics	N	%
Sex		
Male	91	61.5
Female	57	38.5
Age	76[a]	11.8[b]
Educational Level		
None	10	6.8
Primary School	84	56.8
High School	50	33.8
University	4	2.7
Marital Status		
Unmarried	4	2.7
Married	139	93.9
Widower	2	1.4
Divorced	3	2.0
Number of Children	2[a]	1[b]
Mobility Status		
Ambulatory	64	43.2
Cane	20	13.5
Wheelchair	10	6.8
Stretcher	54	36.5
Main Diagnose		
Stroke	15	10.1
Cancer	63	42.6
Chronic Obstructive Pulmonary Disease	9	6.1
Chronic Renal Failure	28	18.9
Dementia	10	6.8
Other	23	13.5
Co-morbidity		
Hypertension	58	39.2

Cardiovascular Disease	53	35.8
Diabetes	48	32.4
Dementia	27	18.2
Chronic Obstructive Pulmonary Disease	10	6.8
Co-morbidity		
No	23	15.5
Yes	125	84.5

[a] mean   [b] standard deviation

Table 3. Descriptive statistics and Cronbach's alpha for the subscales and the overall Zarit Scale.

Scale	Mean	Standard deviation	Median	Minimum value	Maximum value	Cronbach alpha
Personal strain	16.7	6.4	16	3	34	0.81
Role strain	10.7	4.4	10	3	23	0.82
Relational deprivation	8.6	4.1	8	0	16	0.84
Management of care	3.2	1.9	4	0	8	0.74
Overall score	39.2	13.7	37	12	74	0.90

Table 4. Multivariate linear regression analysis with the demographic and clinical characteristics of caregivers and patients as the independent variables and the scores of the subscales as the dependent variables.

Dependent variable *Independent variable*	Coefficient beta	95% confidence interval for beta	p-value	Adjusted R2
Overall Zarit scale				34%
Female patients versus men	4.1	0.3 to 7.9	0.033	
Daily hours of care	0.5	0.2 to 0.7	<0.001	
Chronic health problems of caregivers	13.8	10.1 to 17.5	<0.001	
Personal strain				42%
Unemployed/domestic/retired caregiver relative to employees	4.1	2.1 to 6.1	<0.001	
Daily hours of care	0.2	0.02 to 0.3	0.027	
Chronic health problems of caregivers	5.7	4 to 7.4	<0.001	
Caregivers' level of education	1.8	0.4 to 3.3	0.015	
Role strain				20%
Daily hours of care	0.1	0.03 to 0.2	0.01	
Chronic health problems of caregivers	3.1	1.8 to 4.5	<0.001	
Relational deprivation				30%
Daily hours of care	0.2	0.1 to 0.3	<0.001	
Chronic health problems of caregivers	3.9	2.7 to 5.2	<0.001	
Caregiver's age	-0.1	-0.2 to -0.002	0.046	
Female patients versus men	1.3	0.1 to 2.4	0.03	
Patients' co-morbidity	0.7	0.2 to 1.3	0.007	
Management of care				5%
Chronic health problems of caregivers	0.8	0.2 to 1.4	0.011	

Discussion

According to the findings of this study, informal caregivers experience a moderate burden, with the sub-scale of personal strain achieving the highest score and therefore the greater burden. The sub-scale of personal tension describes the personal feelings of despair and chronic fatigue experienced by the caregivers and the possible damage to their health when caring for a chronic patient. This sub-scale also highlights the burden felt by the caregiver due to the care needs, the patient's dependence and the feelings of tension caused by this care (Papastavrou, Kalokerinou-Anagnostopoulou, *et al.*, 2006). The statistically significant findings related to this subscale in this study, i.e. caregivers who are not working and therefore spend much more time with patients, increased daily hours of care and chronic health problems of caregivers interpret the high score of the subscale. These findings are consistent with the findings of studies on a sample of Greek informal caregivers with cancer and multiple sclerosis (Argyriou *et al.*, 2011; Govina *et al.*, 2015) and the corresponding findings of international studies (Thana *et al.*, 2021). In a systematic review of 192 studies regarding the burden of caregivers for patients with a diagnosis of cancer, the significant effect of care on the physical and mental health of caregivers was highlighted (Girgis *et al.*, 2013). In particular, the burden experienced by informal caregivers includes back pain, leg pain, headaches, as well as muscle tensions. Problems have been recorded with the sleep of caregivers, as they indicate sleep disturbances, poor quality and restless sleep and reduced sleep time or insomnia. Also, fatigue, loss of energy and physical exhaustion are included in the burden of caregivers. Finally, according to the same systematic review, many caregivers were found to face loss of appetite, indigestion, weight loss and physical strength.

The degree and extent of the burden of caregivers make it necessary to create a supportive environment of the care framework for chronic patients, through the interconnection of hospital and primary care. In Greece there is primary care service for chronic or elderly patients who need health care at home. The service is called "Help at Home", is active with the responsibility of the Municipalities and takes care of patients or elderly people in their home. The services provided include treatment for trauma, decubitus ulcers, stomas, psychological support for patients and families, as well as the training of patients and caregivers in the management of their disease or condition. Through this service we avoid patient movements for services and reduce the burden on the patient, the caregiver and the health system (Frengidou *et al.*, 2019; Alexias and Flamou, 2007). The training of the patient and caregiver in the management of the condition and the disease is an important factor which can alleviate the burden of caregivers. The lack of knowledge regarding coverage of physical and psychological problems of chronic patients has been found to be associated with a greater burden on caregivers (Whitlatch and Orsulic-Jeras, 2018; Dimakopoulou, Efthymiou and Karpathiou, 2015). Therefore, the development and expansion of patient support services at primary level is fundamental for the multiple benefits of their implementation.

Limitations: This study has some limitations that should be assessed when interpreting the results. The limitations pertain to the small size of the sample and to carrying out the study in a single hospital.

Conclusions: The informal caregivers of chronically ill patients offer valuable care and can help both when visiting patients in health structures and during their stay at home. This care can last from 8 hours a day and extend to 24 hours a day. This care can also last for years and with the passage of years it can be more demanding in some chronic patients, especially when they are already elderly. This study highlighted many factors associated with the burden of informal caregivers. Informal caregivers should be appreciated by the state, who should try to cover them. Every year the prevalence of chronic diseases increases and therefore the need for informal caregivers will increase, making it imperative to improve their quality of life so that they will be able to provide health care.

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