

Original Article

## Exploration of the Relationship between the Burden and Family Support among Family Caregivers of Older Adults with Chronic Diseases: A Cross- Sectional Study

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### Abstract

**Background:** Most chronic patients receive some level of care and support by their families. The burden of family caregivers comprises any factor that disrupts their lives and affects their health, interpersonal relationships, work, finances, social life and leisure. The burden is related to the experience as a result of the patient's daily care, possibly dependent on the feeling of family support.

**Aim:** To investigate the relationship between burden and family support in family caregivers of older adults with chronic diseases.

**Methods:** A cross sectional study was carried out involving 150 family caregivers of patients with chronic diseases. A questionnaire of socio-demographic and other data was used as well as the Zarit Burden Interview (ZBI) and the Family Support Scale (FSS).

**Results:** The sample consisted of 150 people, with a mean age of 57, with the majority being women (70.7%). Most caregivers were married (48.7%) with 21.3% having a child-father relationship and with 22% having a child-mother relationship. Regarding the score on the ZBI Charge Rating Scale, the caregivers of the sample recorded high caregiver burden rates from the lowest (not at all to mild 25.3%) to the moderate and severe rating (mild to

moderate 38.7% and moderate to severe 33.7%). Women appeared to experience higher levels of burden than men, while caregivers with reported health problems suffered more burden. On the Family Support Scale (FSS), women reported an increased sense of family support compared to male caregivers ( $75 \pm 19$  vs.  $29 \pm 7$ ,  $p = 0.001$ ). Finally, scores of the ZBI scale were found to be negatively related to the scores of FSS scale ( $r = -0.288$ ,  $p = 0.008$ ). These findings supported the main research hypothesis since carers who received higher levels of family support, were experiencing lower levels of burden.

**Conclusions:** The positive correlation found between the burden of caregivers of patients with chronic diseases and the family support they receive indicates that health professionals ought to provide all necessary educative and counselling measures of relief for caregivers indicating the importance of asking and receiving support by other family members so as to be able to carry out the difficult and burdensome task of care.

**Key words:** burden, family caregiver, care, chronic patient, chronic illness, family support, informal caregiver

## Introduction

Disease is a source of intense stress and involves the whole family; not just the patient. Adaptation to a new health condition is a complex process and depends on multiple factors, such as: the disease itself and its characteristics (acute, chronic, severe or not), whether family was functional in the past and various factors that are related to family members and the environment (Choliq et al, 2020; Suksatan et al, 2021).

In most countries, both formal and informal networks are responsible for meeting the care needs of chronic patients. Typical health and welfare systems include public and private networks. Informal care is provided by family members, friends and relatives. In a care system for chronic patients, these two parts complement each other (Farahani et al, 2020).

Internationally, formal health care providers and community health policy makers are trying to adopt strategies to prevent the re-admission of patients with chronic illness because of chronic illness care needs, in hospitals, care and rehabilitation centers as well as to decrease the expenses due to disease complications (Alam et al, 2020).

Therefore, families taking over the main responsibility of patient care after discharge is a common strategy applied in communities with a lack in public rehabilitation centers and enormous costs in private ones (Rouch et al, 2021). However, social systems internationally provide inadequate support for these chronic patients and their family caregivers (Farahani et al, 2020).

Although the education of families and patients is an important indicator of quality in clinical centers and is considered a right worldwide, in

practice, chronic patients and their family caregivers lack specialized training (Lolaty et al, 2018, Kazemi et al, 2021). This has forced family caregivers to deal with different health problems in different aspects of patient care. Family caregivers take over an excessive burden of care because of a lack of awareness about how care is provided, how to receive help, or because of false cultural beliefs that force them to reject any help offered by other family members or relatives (Choliq et al, 2020).

Studies show that the burden of caregivers can often be due to problems of physical, emotional and psychological nature, which are accompanied by feelings of withdrawal, shame, social isolation or even occupational problems, sadness, poor communication, etc. The result can be the appearance of a feeling of discomfort and dangerous behaviors (sleep and eating disorders) (Lolaty et al, 2018, Ashrafizadeh et al, 2021).

International literature suggests that society is dependent on family caregivers for the ongoing care of their chronically ill relatives, but does not develop formal or informal services for teaching and support in this stressful task.

Health professionals constitute a team that can recognize and respect the efforts of family caregivers, assess their needs, provide specific guidance on the care they provide (eg medication, clothing changes, etc.) and refer to potential continuing care services in the community.

With the support and motivation by health professionals, family caregivers can increase their feelings of control over care, their sense of personal well-being, and adherence to treatments for the benefit of the chronic patients they care for

(Hopwood et al, 2018, Beauregard & Miller, 2020).

## Background

Studies investigating the relationship between family support of patients with various types of acute or chronic diseases and its effect on the treatment of the disease have been identified in the international literature (Christensen et al, 1989; Christensen et al, 1992; Okkonen and Vanhanen, 2006). The association of family support with the occupational fatigue of health professionals such as nurses has also been studied (Ogus, 1990). In addition, the effect of social support on family caregivers of people with chronic diseases has been investigated (Sautter et al, 2014).

In Greece, the burden and the sense of family support of family caregivers of patients with major mental disorders has been evaluated and it was found that family support is an important protective factor against the negative consequences of care (Evmolpidis et al., 2019). However, the relationship between the burden and the family support of family caregivers with chronic diseases has not been studied in Greece.

The present research study aims to investigate the relationship between burden and family support in family caregivers of patients with chronic illnesses, but also to explore caregivers' feelings about the care and support they receive from their family, in an effort to provide the scientific community with new results and conclusions about a population group, which needs further thorough investigation.

**Research questions and hypothesis** The main research questions of this study were:

A. Is there a correlation between the socio-demographic data of carers such as: educational background, marital status, financial status as well as health problems they face and the burden they experience?

B. Is there some kind of correlation between burden and clinical factors such as years since disease diagnosis and duration of patient care?

The main research hypothesis was that caregivers who experience greater family support experience a lower burden of caring for a relative with a chronic illness.

## Methodology

**Study design and Participants:** The current research study was a cross-sectional study which

involved 150 caregivers of patients with chronic diseases. The study population consisted of participants of both sexes who cared for their relatives for a period of more than 6 months. The study was conducted at the 417 NIMTS Veterans Hospital located in Athens. During the convenience sampling procedure, the chronic patients' caregivers, who constituted the sample, were approached during the treatment of their patients in various clinics of the specific tertiary hospital.

**Data collection tools:** A questionnaire of socio-demographic data which was distributed to family caregivers was constructed after a study of the international literature and included questions about the educational and socio-economic level of the caregiver, the duration of patient care, supportive structures and other data that may affect the burden experienced. The second tool of the present study was the Greek version of Zarit Burden Interview (ZBI) (Zarit, 1980) which assesses the subjective burden experienced by patient caregivers. The ZBI questionnaire consists of 22 questions that reflect how people who care for a relative feel, whether they feel angry, lack time, whether they feel stressed, whether their health has been negatively affected, whether they feel they cannot offer enough, or whether they feel that they can offer more quality care to their relative. The total score of the tool ranges from 0–88 (0-21 = low or no burden, 21-40 = moderate burden, 41-60 = severe burden). The Greek version of the scale has been examined for its validity and reliability by Parpa et al, 2017. Permission for use of ZBI was given by Mapi Research Institute.

The third questionnaire used, was the Greek version of the Family Support Scale (FSS) (Julkunen and Greenglass, 1989), which has been translated and validated by Tselebis et al (2011). The Greek version of the scale consists of 13 items referring to the family. The family support scale does not aim at the objective examination of the family support but at the feeling that the person has about how much he is supported by the people with whom he lives with (e.g. My family supports me in all my efforts or our family sticks together despite any difficulties). The increased score on the scale corresponds to an increased sense of family support. Permission to use the questionnaire was granted to the first researcher by Dr Julkunen.

**Ethical considerations:** The main researcher was granted a written permission to conduct the study

by the Scientific Council of NIMITS Hospital. The signed consent of the respondents was also requested for their participation in the research before the completion of the questionnaires and after detailed information about the study was given. The confidentiality of the information concerning the respondents was ensured and the anonymity of the respondents was ensured by coding the data that could only be accessed by the main researchers.

**Statistical analysis:** The data analysis was performed using IBM's SPSS Statistics program. In the analysis of the variables, the linear correlations (bivariate correlation) were examined by pairs, with the significance level being set at 0.05 (Pearson's  $r$ ).

## Results

Table 1 shows the main characteristics of the 150 participants. The average age was 57 years while the majority of participants were female with a percentage of 70.7% ( $n = 106$ ). Regarding the relationship with the patient, it was found that the majority were caregivers who cared for their mother. Regarding their place of residence, the majority answered that they live in the same house / apartment with the patient, 44% ( $n = 66$ ). Regarding the existence of a support network for their chronic patient, both in the community and with regard to home care, 107 out of 150 answered negatively with a percentage of 71.3%, suggesting the lack of a support network to provide help in the care of their chronic patient.

Table 2 shows that 114 people (76%) did not use a day care center, in contrast to 21 participants, who chose to use a day care center (14%), while 15 participants stated that it was not available at their place of residence (10%). In addition, out of the 150 people who participated in the study, 137 (91.3%) stated that they do not receive any allowance for the care of their chronic patient.

In Table 3 we see data on chronic patient care. Regarding the number of years that have passed since the diagnosis of the chronic disease, most of the answers fall into the category of 2 to 3 years (35.3%) and the length of time they were taking care of their chronic patient, falls in the category of 2 to 3 years of care (34.6%). Regarding the hours of care per day, the highest percentages fall into the range of 2 to 8 hours of care (72.7%). The mean value on the ZBI Burden Rating Scale for participating caregivers was 28.20 (SD = 12.3831), with 2.3% of carers presenting a severe

burden, 33.7% moderate to severe, 38.7% mild to moderate, 25.3% not at all to a mild burden, with a score from 0–20. The caregivers who showed minimal to no burden were mainly men, did not live in the same house as the patient and had a high level of education and income. The majority of those with moderate to severe burden, were women. Most of them were married with an average of 4.9 years of care, with most having a basic education and a moderate to poor financial situation.

On the Family Support Scale (FSS), the mean value was (mean  $\pm$  SD)  $48.6 \pm 8.8$ , with women reporting an increased sense of family support compared to male caregivers ( $51.2 \pm 8.4$  vs.  $46 \pm 9.2$ ,  $p = 0.05$ ).

With regard to the use of other agencies and/or therapists, it was found that it has a large and positive correlation ( $r = 0.236$ ) with the variable of receiving allowance for the care of the relative. The use of agencies and therapists for the care of the relative was found to be positively related to the feeling of lack of money for the simultaneous coverage of both the needs of the patient and the personal expenses of the caregiver himself ( $r = 0.216$ ). The negative impact on the caregiver's health was found to be directly and positively related to whether he/she feels pressured by his relative ( $r = 0.470$ ). The negative pressure created by helping the chronic patient seems to push the family caregiver to think that it would be preferable to entrust the care of the relative to another person/caregiver ( $r = 0.499$ ). The care provided to the chronic patient has a direct negative effect on the caregiver's psychology when he returns home after a difficult day ( $r = -0.267$ ). Moreover, the behavior of the relative/patient in front of strangers seems to contribute negatively to the psychology of the family caregiver, increasing the pressure they feel ( $r = 0.542$ ). According to the results of the multivariate linear regression (table 4), women appeared to experience higher levels of burden than men and caregivers with reported health problems were suffering more burden than caregivers who did not report health problems ( $p = 0.01$ ).

Finally, the scores on the ZBI scale were found to be negatively correlated with the scores on the FSS scale ( $r = -0.228$ ,  $p = 0.008$ ) (table 5). Therefore, as family support decreases, so does the caregiver's burden increases.

**Table 1:** Caregivers characteristics

		Mean (SD)	N	%
<b>Age of the caregiver</b>		57±12		
<b>Caregiver gender</b>	female		106	70.7
	male		44	29.3
<b>Relationship to patient</b>	father		32	21.3
	mother		33	22
	daughter		9	6
	son		10	6.7
	sister		11	7.3
	partner		22	14.7
	other		33	22
<b>Marital status</b>	single		56	33.7
	married		73	48.7
	widowed		2	1.3
	divorced		8	5.3
	separated		4	2.7
	living together		7	4.7
<b>Number of children</b>	0		71	47.3
	1		23	15.3
	2		34	22.7
	3		18	12
	4		1	0.7
	5		3	2
<b>Educational background</b>	didn't attend to school		3	2
	primary school		2	1.3
	high school		10	6.7
	lyceum		59	39.3
	university		69	46
	postgraduate studies		7	4.7
<b>Employment</b>	unskilled worker		1	0.7
	skilled worker		1	0.7
	self employed		17	11.3

	farmer		5	3.3
	public servant		61	40.7
	employee (private sector)		36	24
	housewife		12	8
	retired		11	7.3
	student		6	4

**Table 2:** Support network

		N	%
<b>Supportive services of chronic patient in community and home health care</b>	Yes	38	25.3
	No	107	71.3
	Not Available	5	3.3
<b>Use of other agencies/therapists</b>	Yes	40	26.7
	No	99	66
	Not Available	11	7.3
<b>Daily care center</b>	Yes	21	14
	No	114	76
	Not Available	15	10
<b>Care allowance for the chronic patient</b>	Yes	13	8.7
	No	137	91.3

**Table 3:** Data related to chronic patient's care

		N	%
<b>Time from the chronic illness diagnosis</b>	1 - 5	87	57.9
	6 – 10	46	30.7
	11 – 15	8	5.3
	16 – 20	8	5.3
	21 - 25	1	0.8
<b>Duration of care of the chronic patient</b>	1 - 5	98	65.2
	6 – 10	44	29.2
	11 – 15	5	3.4
	16 – 20	3	2.1
<b>Hours of chronic patient's care per day</b>	0 - 5	72	47
	6 – 10	55	36.6

	11 – 15	10	6.7
	16 – 20	2	1.7
	21 - 24	12	8
<b>Do you think you should take more care of your relative?</b>	YES	47	31.3
	NO	59	39.3
	SOMETIMES	44	29.3
<b>Caregivers' comorbidities</b>	None	84	56
	Hypertension	11	7.3
	Diabetes	5	3.3
	Myoskeletal problems	27	18
	Cardiovascular	5	3.3
	Eye problems	3	2
	Other	15	10

**Table 4.** Linear Regression analysis results for Zarit Burden Interview scale (ZBI)

	$\beta$	95% CI	P value
Women vs men	8.0	1.9 to 14.2	0.01
Health issues vs absence of diseases	12.9	5.5 to 20.3	0.01

**Table 5:** ZBI & FSS scales' association

		FSS
<b>ZBI</b>	Pearson's r	-0.288
	P	0.008
	N	150

## Discussion

The aim of the current study was to investigate the relationship between burden and family support in family caregivers of older adults with chronic diseases. The results showed that the more family support decreases, the more the family caregiver's burden increases. The caregivers who showed minimal to no burden were mainly men, did not live in the same house as the patient, had a high level of education and income. Of those with moderate to severe burden, the majority were

women, spouses with elementary education and moderate to poor financial status, who reported though an increased sense of family support compared to male caregivers. The present study also showed that the care provided to the chronic patient has a direct negative effect on the caregiver's psychology when he returns home after a difficult day and directly links the relative / patient's behavior in front of strangers to the family caregiver's psychology, which negatively increases the pressure that the caregiver feels.

The current study revealed a positive correlation between the care of the chronic patient and the carer's burden. 35% of the participants stated that they care for their relative for a period of 2-3 years, 72% stated that care takes 8 hours per day while the carer experiences a burden by the care provided to the chronic patient ( $r=0.267$ ). With regard to the scores of ZBI, women presented a higher burden compared to male caregivers. With regard to Family support Scale the burden of the family caregiver seemed to increase as family support decreased ( $r=0.288$ ,  $p=0.008$ ).

Moreover, the behavior of the relative / patient in front of strangers seems to contribute negatively to the psychology of the family caregiver, increasing the pressure he feels ( $r = 0.542$  which confirms previous results of similar studies regarding the positive relationship between the burden of caregivers and the level of functionality of caring patients (Yazici et al, 2016; Souza et al, 2017; Hsiao et al, 2020). Literature shows that people with chronic illness face a range of discrete and intense stressful events that can affect even a person with increased strength. Adapting to a chronic disease is extremely complex and affects almost all areas of human functioning, but, at the same time, affects almost everyone.

Multiple parameters of adaptation to chronic disease and the relationship between the chronic patient and his family caregiver that were found, show the multiple and interrelated changes that take place. The family caregiver seems to be negatively burdened by the care he provides to his relative. The negative impact on the caregiver's health was found to be directly and positively related to whether he/she feels pressured by his relative ( $r = 0.470$ ). The negative pressure created by helping the chronic patient seems to push the family caregiver to think that it would be preferable to entrust the care of the relative to another person / caregiver ( $r = 0.499$ ), which is a basic sign of burden. Combined with the feeling that the caregiver is the only person on whom the patient can rely, but also the caregiver's feeling of uncertainty about the future and how to deal with the situation, the feeling of a lack of personal time and the opinion that his social life has been negatively affected by caring for the chronically ill, often seems to lead to a sense of loss of control over the caregiver's life at the time of the relative's illness. These results are recorded in the international literature, as the necessary factors that must be regulated to reduce the feeling of

burden of family caregivers (Bakas et al, 2014, Araújo et al, 2018, Riffin et al, 2019, Fields et al, 2020, Rouch et al, 2021)

Moreover, the behavior of the relative / patient in front of strangers seems to contribute negatively to the psychology of the family caregiver, increasing the pressure he feels ( $r = 0.542$ ). The role of the family caregiver in caring for the patient seems to depend greatly on the degree of adaptation to the patient's own illness and personality. Difficult patients, with excessive demands, who put their family caregivers in a bad position, burden them additionally both psychologically and socially, as shown in our study, a finding that is consistent with other studies (Limpawattana et al, 2013; Mosquera et al, 2016; Riffin et al, 2019; Rouch et al, 2021).

The results of the current study showed that caregivers felt that the chronic patient depended on them and were concerned about both their personal financial situation and the financial condition of the chronic patient, fearing that they would not be able to cope with care and management of chronic disease in general and emerging requirements from it. The caregivers who participated in our research seemed to be worried about their patient's future, but their concern also included the fact that their family and friendships were negatively affected by the care of their chronic patient. Despite these results, the caregivers of our sample record the higher rates of burden on the ZBI Scale from the lowest (not at all to mild 25.3%) to the moderate to severe score (mild to moderate 38.7% and moderate to severe 33.7 %). Family caregivers usually take care of their patients for emotional reasons, mainly due to their relationship with the chronic patient. The Greek culture and attachment to the tradition of family institutions often prompts them to feel that they are morally obliged to offer their care to the member who is in need due to his chronic illness. Of course, many times the family caregiver derives benefits from this care, such as the feeling of satisfaction and contribution, which possibly "lighten" the burden he feels. Similar findings are recorded in international studies, the differences lie mainly in cultural characteristics (Campos-Puente et al, 2019, Palacio et al, 2020, Rezaei et al, 2020, Spatuzzi et al, 2020).

In addition, the scores of the FSS Scale showed that women reported an increased sense of family support, a finding that was not correlated with any



other independent variable. Also, this finding contradicts the majority of surveys both in Greece and internationally, not only in terms of the population of family carers, but also in terms of the general population, in similar surveys. The reduced sense of family support on the part of women is a common finding in previous and recent studies and is often interpreted as defining the traditional roles and responsibilities of women in the family structure and the wider social context (Yildiz et al, 2016, Tan et al, 2018, Yuen et al, 2018, Spatuzzi et al, 2020). The contradictory finding of our study is probably due to the special characteristics of the female caregivers in the specific hospital who belong in a fairly high socioeconomic status probably receiving help in their responsibilities.

A most important element that the current study highlighted is the strongly positive relationship between financial assistance to chronic patients, in the form of benefits and the use of special care by specialized centers. In addition, the use of special structures or treatment groups for the care of the chronic patient is positively related to the feeling of not having enough money to cover the personal expenses of the family caregivers and, consequently, increases the hours of care provided to the chronic patient daily. The financial burden of chronic illness on both the patient and the caregiver and the family budget, is an important factor on the one hand of the care provided to the patient and on the other hand has a positive or negative effect - depending on the financial balance - on the caregiver's burden, the ability or not to cover other family and personal expenses, the required working hours and, consequently, the provided care hours. This important element that emerges from the present research, is in agreement with many international studies (Girgis & Lambert, 2017; Sadigh et al, 2021).

**Limitations:** One of the imitations of the study is the synchronous nature of the research, as it limits the possibility of investigating the relationship between cause and effect. Also, the sample of the study accidentally had a high level of education and financial assistance, a fact that cannot represent all family caregivers in Greece. In addition, the limited ability of extending the study to other hospitals in Athens and the region, limits the generalizability of the results.

**Conclusion:** The results of the present study supported the research hypothesis that the more

family support decreases, the more the family caregiver's burden increases. The caregivers who showed minimal to no burden were mainly men, did not live in the same house as the patient, had a high level of education and income. Of those with moderate to severe burden, the majority were women, spouses with elementary education and moderate to poor financial status, who reported though an increased sense of family support compared to male caregivers. The present study also showed that the care provided to a relative with a chronic disease has a direct negative effect on the caregiver's psychology when he returns home after a difficult day and directly links the patient's behavior in front of strangers to the family caregiver's psychology. When his/her psychology is negative increases the pressure the caregiver feels.

In the future, more studies will need to consider different time points that may better reflect the course of chronic disease, such as the time of initial diagnosis, changes in treatment protocols, and the signs of chronic disease exacerbation or recovery. Also studies should be related to the types of ongoing treatment, the caregiver and patient needs and self-care assistance, and the chronic patient's ability to perform some routine daily activities, facilitating the caregiver's work. Particular emphasis should be placed on safety, the risk of adverse outcomes and adverse effects for both the caregiver and the chronic patient (Michels et al, 2016; Chan et al, 2018).

Studies are also needed to investigate family caregivers coming from social minorities and economically disadvantaged groups, in order to better understand their needs and design interventions to support the provision of safe care. In addition, it is necessary to make the necessary adjustments to minimize the burden on the caregiver related to socio-economic parameters and culture (Siouta et al, 2016, Qualls, 2016, Grotti et al, 2019).

The identification and positive development of psychological factors such as family support could help reduce the stress and burden of the caregiver and promote the well-being of both the family caregiver and the chronic patient under his care. This could indirectly affect the way caregivers treat and manage the physical problems of their patients that require early recognition and treatment, as well as their emotional and physical needs. Increasing the caregiver's ability makes

him/her more resilient and improves his psychological and emotional well-being, positively affecting various personal aspects related to the feeling of optimism, personal development and spirituality, in terms of defining personal meaning in relation to experience of the disease.

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