# **Original Article**

# Factors Associated with Anxiety and Depression among Family Caregivers of Patients Undergoing Palliative Radiotherapy

# Ourania Govina<sup>1</sup>, Eugenia Vlachou<sup>1</sup>, Ioannis Kalemikerakis<sup>1</sup>, Demetrios Papageorgiou<sup>2</sup>, Anna Kavga<sup>1</sup>, Theocharis Konstantinidis<sup>3</sup>

<sup>1</sup>Department of Nursing, University of West Attica, <sup>2</sup>Department of Chemotherapy, Euroclinic Hospital of Athens, <sup>3</sup>Department of Nursing, Technological Educational Institute of Crete, Athens, Greece



Corresponding author: Ourania Govina, PhD, RN, MSc

Department of Nursing, University of West Attica, Athens, Greece

Tel: +030-2106826629; Fax: +030-2106826629

E-mail: ugovina@teiath.gr

Received: August 06, 2018, Accepted: October 05, 2018

# ABSTRACT

**Objective:** The family caregivers of patients receiving palliative care experience high levels of anxiety and depression. The aim of the present study was to investigate the factors associated with family caregivers' anxiety and depression when caring for patients with advanced cancer in Greece. Methods: The sample consisted of 100 patients undergoing palliative radiotherapy and their respective caregivers. Patients completed the Hospital Anxiety and Depression Scale (HADS) and the MD Anderson Symptom Inventory. Their respective caregivers completed the Oberst Caregiving Burden Scale, the Bakas Caregiving Outcomes Scale, and the HADS. Correlational and multiple regression analyses were conducted to identify potential predictors of anxiety and depression. Results: The majority of patients were male (63.0%), whereas the majority of their caregivers were female (76.0%). The mean ages of patients and caregivers were  $63.9 \pm 10.8$  and  $53.3 \pm 12.6$  years, respectively. Caregiving anxiety and depression were associated with patients' variables, such as gender (P < 0.0005), primary cancer (P = 0.008), and past surgery

(P = 0.002), and caregiver's variables, such as gender (P = 0.001), co-residence (P = 0.05), previous care experience (P = 0.04), and means of transport (P = 0.038). In multiple regression analyses, caregiving anxiety and depression were significantly predicted by caregivers' and patients' characteristics, in a model that accounted for 48% of the anxiety variance (P < 0.0005). Conclusion: The caregivers who experienced more anxiety and depression shared the following traits: they were women, cared for men with lung cancer, cared for patients not undergoing surgery, lived together, were younger, went to the hospital by private means of transport, had previous care experience, and perceived an increased degree of general burden. Further investigation of the factors that may affect caregivers' psychological state is required to better identify parameters that may predict it.

Key words: Advanced cancer, anxiety, burden, depression, family caregivers

Access this article online		
Quick Response Code:	Website: www.apjon.org	
	<b>DOI:</b> 10.4103/apjon.apjon_74_18	

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

**Cite this article as:** Govina O, Vlachou E, Kalemikerakis I, Papageorgiou D, Kavga A, Konstantinidis T. Factors Associated with Anxiety and Depression among Family Caregivers of Patients Undergoing Palliative Radiotherapy. Asia Pac J Oncol Nurs 2019;6:283-91.

# Introduction

In the United States of America, it is estimated that 2.8 million people provide services to cancer patients as informal family caregivers.<sup>[1]</sup> The need for intensive caregiving by the family is due to an improvement in patients' survival rates, as a result of better treatment options, a shorter hospital stay, and the overall decrease in available financial resources.<sup>[2-4]</sup> A spectrum of caregiving roles, such as patients' management of the disease and treatment complications, handling of symptoms and medication, psychological support, and physical care, is usually undertaken after little or no training and with limited resources.<sup>[2,5,6]</sup> Therefore, family caregivers provide everyday support to the patients,<sup>[7]</sup> while often neglecting themselves and failing to address their own personal needs and feelings.<sup>[8,9]</sup> Given the importance of interaction between patients and their respective caregivers, where the former influences the health condition of the latter,<sup>[10,11]</sup> research on caregiving is continuously evolving and focusing even more on what we call the "patient-caregiver pair."<sup>[12]</sup>

The burden, as a result of caregiving, is a concept with physical, psychological, social, and financial dimensions.<sup>[2,3]</sup> Anxiety and depression are considered indicators of psychological burden or distress.<sup>[13,14]</sup> Kramer<sup>[15]</sup> suggests that the concept of "caregiver burden" may be considered the same as "psychological dysfunction," as are anxiety and depression. For some investigators, the difference lies in the fact that the "burden" refers to the more tangible aspects of care.<sup>[16]</sup> Although a number of studies have focused on the concepts of burden and depression, there is no consensus as to whether or not any distinction should be made between them.<sup>[17]</sup>

The distress experienced by caregivers comes as a result of the demanding care that accompanies patient health deterioration.<sup>[2]</sup> While patients' disease process and treatment affect the burden caregivers' experience,<sup>[18]</sup> courses of radiotherapy create new demands on them and new roles, such as accompanying the patient to the hospital on a daily basis for their treatments.

According to Thrush and Hyder,<sup>[13]</sup> the psychological or emotional burden of family caregivers of cancer patients is the most common type of burden. The intensive and burdensome tasks involved in caregiving often lead to distress, anxiety, and depression,<sup>[19]</sup> with incidences ranging from 52% to 94%. These effects are the most commonly reported findings.<sup>[13,20]</sup> Anxiety and depression are more severe in the case of advanced cancer patients.<sup>[21,22]</sup> More specifically, Trevino *et al.*<sup>[23]</sup> found that there is an increased risk of developing major depressive disorder and generalized anxiety disorder, which highlights the need for early prevention measures for caregivers of patients with advanced cancer.

The number of Greek families providing systematic oncology care is unknown, but it is thought to be large, given the strong family bonds and the inadequacy of the public health care services to cover the basic needs of patients and their caregivers. However, it is estimated that the scale of informal caregiving may have risen even more in recent years, because of the detrimental effects of the economic crisis on family budget and public services in Greece. This phenomenon is exacerbated by a dramatic reduction in the number of professional caregivers employed and hired in public hospitals. The family always was and still is a bastion of Greek society, and in most cases, families are willing to look after their members. They usually see the provision of care as an expression of love to their nearest and dearest, rather than as a burden. The factors that predict caregiver stress in Greece have some similarities to those in other European countries, but there are also cultural differences that need to be taken into account. In Greece, the acknowledged inadequacy of the health services, reduced resources, and the lack of palliative care structures are counterbalanced by Greece's special cultural characteristics, such a willingness to help, the obligation to provide care, the unofficial support network of distant relatives and friends, and the powerful familial bonds.

However, the demand for intensive and continuous care is likely to have an unexpected impact on caregivers' lives.<sup>[24]</sup> Only a few studies have been conducted in Greece of factors that may influence the psychological state of caregivers of patients with advanced cancer.<sup>[25,26]</sup> Hence, an exploration of these factors could contribute to identifying and developing specific interventions that would be politically and culturally relevant. On the condition that there is "mutual influence" between patients and caregivers,<sup>[10,27]</sup> the present study assumes that patient demographics, clinical characteristics, and psychological condition can be used as predictive factors for caregivers' anxiety and depression. The purpose of this study was to determine the factors associated with the anxiety and depression of family members caring for patients undergoing palliative radiotherapy.

# **Methods**

#### **Research design**

The present study was a cross-sectional, exploratory, and correlational study that used a prospective, consecutive sampling approach.

#### Participants and setting

The target population was a convenience sample of 100 adult patient–caregiver pairs. Patients suffered from advanced cancer and were undergoing palliative radiotherapy in two oncology centers in Athens. The respective family caregivers had been nominated by the patients themselves and they were the ones who, without receiving any payment, provided the patients with their main care. The inclusion criteria in this study were age >18 years, the absence of a psychiatric diagnosis, and good knowledge of the Greek language. Each pair participated in the study only once, regardless of the number of times they visited the department. The data were collected over a period of 18 months while the patients and caregivers were visiting the radiotherapy unit for the daily dose.

#### **Data collection**

Besides clinical and demographic data, patients were asked to complete (a) the Hospital Anxiety and Depression Scale (HADS) and (b) the MD Anderson Symptom Inventory (MDASI). At the same time and in another room, their respective caregivers completed (a) the HADS, (b) the Bakas Caregiving Outcomes Scale (BCOS), and (c) the Oberst Caregiving Burden Scale (OCBS).

Anxiety and depression were measured using the Greek version of HADS (G-HADS). G-HADS is a self-completed screening tool, designed for use in a hospital setting, that has been translated, validated, and widely used in the Greek population.<sup>[28]</sup> It consists of 14 questions that evaluate anxiety (7 questions) and depression (7 questions), with each question rated from 0 (none) to 3 (maximum). The Cronbach's alpha coefficients in the present study were 0.86 and 0.77, respectively.

Burden was measured using the Greek version of the BCOS. This is a questionnaire of 15 items that evaluate the caregivers' burden and thus changes in caregivers' lives as a result of providing care. More specifically, BCOS assesses the perceptions of social functioning, physical health, and subjective well-being on a 7-point scale, ranging from -3 (changes for the worst) to +3 (changes for the best). Answers are scored from 1 to 7, where a higher score indicates less burden, giving a range of possible total values from 15 to 105. The Cronbach's alpha coefficient for the Greek version was 0.83.<sup>[29]</sup>

The OCBS assesses caregivers' perceptions of the difficulty of care tasks (OCBS-D) and the time spent performing these tasks (OCBS-T). Each subscale consists of 15 questions.<sup>[30]</sup> All items are rated on a 5-point scale to indicate the amount of time spent (1 = none to 5 = a great amount) and the level of perceived difficulty (1 = not difficult to 5 = extremely difficult) for each task. Each subscale score is calculated by summing the responses for OCBS-T (time spent) and OCBS-D (difficulty) of each task. The range of possible values that each subscale can take ranges from 15 to 75, with a higher score showing more negative results. Cronbach's alpha coefficient in the present study was 0.87 for OCBS-D and 0.83 for OCBS-T.

The Greek version of the MDASI questionnaire measures symptomatology. More specifically, it evaluates the presence and severity of 15 symptoms experienced by

patients over the last 24 h, as well as the interference of these symptoms in their daily activities. Each symptom is scored on an 11-point scale (0–10), with 0 indicating that the symptom did not occur and 10 indicating that the symptom was the worst possible. The potential interference of a symptom on the functionality and on the life of the patient is also scored on a scale of 0–10, where 0 indicates that the symptom did not interfere and 10 indicates that it interfered completely. Translation and validation of the questionnaire were performed by Mystakidou *et al.*<sup>[31]</sup> in a Greek sample of patients with advanced cancer. Cronbach's alpha coefficient was 0.83 for the symptom severity subscale and 0.85 for the life interference subscale.

#### Statistical analysis

Continuous variables are expressed as mean values and standard deviations, while categorical variables are expressed as frequencies and percentages. The Kolmogorov-Smirnov statistical test was used to assess the normality of the continuous and categorical variables. Factor analysis between independent and dependent variables was performed using Student's t-test for independent samples, analysis of variance, and Pearson's r correlation coefficient to investigate the relationships between the outcome variables (anxiety and depression) and predictor variables (patient and caregiver data). All factors that had a statistically significant relationship to the outcome variable in univariate analysis were included in the multiple linear regression model (stepwise method) to determine the factors that affected the dependent variable. To apply multiple linear regression model, the assumptions of normality, variance, measurement independence, and noncollinearity of independent variables were all tested using the variance inflation factor of tolerance. Statistical significance was set to P < 0.05 (two-tailed), and data analysis was performed using SPSS 18.0 (Chicago: SPSS Inc., USA).

#### **Ethical** approval

The study was approved by the hospitals' Ethical Committee before data collection. Patients and their caregivers were verbally informed about the research, and their questions were answered as fully as possible. All patients then signed a written consent form that stated the purpose of the study, assured anonymity and confidentiality, and explained the usefulness of the expected results.

# Results

To achieve a sample of 100 pairs of patients and their informal caregivers, the investigators had approached 160 pairs. Out of those approached, 25 patients and 35 caregivers refused to participate because of the patients' burdened physical state, lack of time on their part, or fear of any additional discomfort imposed mainly on the patients (response rate 62.5%).

#### **Characteristics of participants**

The demographic characteristics of the caregivers as well as the characteristics of the patients (demographic and clinical) are presented in Table 1. The patients' mean age was 63.9 years (standard deviation [SD] = 10.8, range: 35-87). The majority of the patients in this study were male (63%), suffered from lung cancer (48%), had previously undergone operation for cancer (47%), had undergone chemotherapy (58%), and rated their Eastern Cooperative Oncology Group performance status as 2 (ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours). The average age of caregivers was 53.3 years (SD = 12.6, range: 26-88) and the majority were female (76%). The caregivers in this sample were married (88%) with adult children (69%), 76% of them lived with the patients, and 59% of them were spouses; 59% of the caregivers were experienced in caring for loved ones with chronic illness, while 38% of them also had professional employment.

#### Descriptive data of variables

The average total values of the questionnaires such as BCOS, OBCS (OBCS-T and OBCS-D), HADS, and MDASI are shown in Table 2. More specifically, the mean value of caregivers' anxiety was 12.31 (SD = 5.03) and the mean value of depression was 9.40 (SD = 4.70), i.e., the levels of anxiety surpassed the levels of depression. It should be noted that grades from 8 to 10 simply indicate the presence of anxiety or depression, while grades above 11 indicate probable mood disturbances.<sup>[32]</sup>

# Univariate analysis

The comparison between HADS-Anxiety and HADS-Depression variables showed statistically significant relationships for some characteristics of patients and caregivers.

Univariate analysis revealed that the male patients in this study had caused more anxiety to their caregivers than the female patients (P < 0.0005), while female caregivers experienced more anxiety than male caregivers (P = 0.001). Caregivers reported higher levels of anxiety: (a) when their patients had not undergone surgery to treat cancer (P = 0.002), (b) when they lived with their patients (P = 0.05), (c) when they had provided care for other loved ones in the past (P = 0.040), and (d) when they had to drive the patients to the hospital for their radiotherapy courses (P = 0.038). Regarding the HADS-Depression data, male patients reported higher levels of depression than women (P = 0.001), while female caregivers

Patients' and Caregivers' characteristics	Patients	Caregiver
Age (years)		
Mean±SD	$63.9 \pm 10.8$	53.3±12.6
Range	35-87	26-88
Gender, n (%)		
Male	63 (63.0)	24 (24.0)
Female	37 (37.0)	76 (76.0)
Family status, <i>n</i> (%)		
Married		88 (88.0)
Unmarried		12 (12.0)
Primary diagnosis, <i>n</i> (%)		
Lung	48 (48.0)	
Breast	22 (22.0)	
Urogenital system	20 (20.0)	
Other	10 (10.0)	
Educational level, n (%)		
Primary	52 (52.0)	36 (36.0)
High school	37 (37.0)	45 (45.0)
University	11 (11.0)	19 (19.0)
Past surgery, n (%)	( )	,
No	53 (53.0)	
Yes	47 (47.0)	
Past chemotherapy, <i>n</i> (%)	( )	
No	42 (42.0)	
Yes	58 (58.0)	
ECOG performance status, <i>n</i> (%)	, , , , , , , , , , , , , , , , , , ,	
1	27 (27.0)	
2	37 (37.0)	
3	36 (36.0)	
Minor child, n (%)	, , , , , , , , , , , , , , , , , , ,	
No	86 (86.0)	69 (69.0)
Yes	14 (14.0)	31 (31.0)
Residence, n (%)	( )	( )
Same as patient		76 (76.0)
Other		24 (24.0)
Care experience, n (%)		( )
No		41 (41.0)
Yes		59 (59.0)
Relationship with patient, <i>n</i> (%)		( )
Spouse		59 (59.0)
Child		27 (27.0)
Other		14 (14.0)
Daily working hours, <i>n</i> (%)		()
Not working/retired		62 (62.0)
4-16		38 (38.0)
Means of transport, <i>n</i> (%)		20 (0010)
Public transport		17 (17.0)
Private car		47 (47.0)
Taxi		36 (36.0)

ECOG: Eastern Cooperative Oncology Group, SD: Standard Deviation

experienced significantly greater depression (P < 0.0005). Greater depression was also noted in those who had previously treated other loved ones (P = 0.004). Patients with breast and urogenital cancer reported low-intensity depressive symptoms compared to those of lung cancer patients (P = 0.003). Comparisons between HADS-Anxiety,

Govina, et al.: Cancer Caregivers' Psychological Burden

Patients			Caregivers			
Patients' variables	Mean±SD	Minimum-maximum	Caregivers' variables	Mean±SD	Minimum-maximum	
HADS-Anxiety	8.11±3.97	0-17	BCOS	49.95±10.49	24-77	
HADS-Depression	$8.10 \pm 4.63$	0-19	OCBS-time	$39.03 \pm 9.10$	23-69	
MDASI-Symptoms	$2.51 \pm 1.18$	0.47-6.47	OCBS-difficulty	$33.48 \pm 10.70$	14-63	
MDASI-Interference	$6.15 \pm 1.94$	0-10	HADS-anxiety	$12.31 \pm 5.03$	1-21	
			HADS-D	$9.40 \pm 4.70$	0-21	

HADS: Hospital Anxiety and Depression Scale, MDASI: MD Anderson Symptom Inventory, SD: Standard Deviation, BCOS: Bakas Caregiving Outcomes Scale, OCBS: Oberst Caregiving Burden Scale

HADS-Depression and marital status, patient and caregiver educational level, chemotherapy history, juvenile children, degree of relationship, and employment of caregivers did not show any statistically significant differences [Table 3].

Statistically significant correlations were found between the age of caregivers and the HADS-Anxiety variable (r = -0.245, P = 0.014) and between the burden scales such as BCOS (r = -0.524, P = 0.0005), OBCS-T (r = 0.386, P = 0.0005), and OBCS-D (r = 0.470, P = 0.0005). Similarly, statistically significant correlations were found between the HADS-Depression variable and the BCOS (r = -0.533, P = 0.0005), OBCS-T (r = 0.303, P = 0.002), and OBCS-D (r = 0.476, P = 0.0005) scores.

#### **Multivariate analysis**

Multiple linear regression analysis for the depression variable revealed that model factors accounted for 48% of the variance ( $R^2 = 0.477$ , P < 0.0005). The factors that appeared to have such a significant effect on depression were as follows: BCOS-burden (B = -0.17, P < 0.0005), age (B = -0.10, P < 0.004), gender (B = 2.01, P < 0.049), primary diagnosis of breast cancer (B = 0.98, P = 0.056), and OBCS-D (B = 0.10, P = 0.024). On the other hand, multiple linear regression analysis for the anxiety variable revealed that model factors accounted for 39% of the variance ( $R^2 = 0.387$ , P < 0.0005), where the variables that had a significant effect on anxiety were the following: BCOS-burden (B = -0.14, P < 0.001), OBCS-D (B = 0.12, P = 0.004), and caregiver gender (B = -2.20, P < 0.009) [Table 4].

# Discussion

Cancer is a chronic illness with exacerbations and remissions that has a powerful effect on the lives of patients and their family caregivers. A recent study focuses on the "patient–caregiver" pair, as patients and caregivers seem to respond as an "emotional cluster."<sup>[12]</sup> Alarming symptoms of the patient's condition often demand intensive and long-term care, which seriously affects the caregivers' psychological situation.<sup>[33]</sup>

This study investigated factors in caregivers and patients that could have an impact on the caregivers' psychological state. Although data analysis highlighted many interesting correlations, the final regression models for the variables of anxiety and depression were mainly explained by caregiver factors. Anxiety and depression showed higher scores in those caregivers who had a higher perception of burden, in those who perceived the caregiving tasks as difficult and in those who were women. Caregivers of lung cancer patients and young cancer patients also reported higher anxiety levels.

There is a wealth of literature on caregivers' indicators of distress, which include anxiety and depression. Many studies have investigated the burden on caregivers, noting that this is one of the most significant predictive factors for anxiety and depression.<sup>[34-36]</sup> In most studies, there appeared to be a strong relationship between burden, anxiety, and depression in those caring for cancer patients.<sup>[26,36]</sup> The caregiver's psychological state can be negatively affected by difficult and stressful care tasks, such as limitations in their personal lives and uncertainty regarding the progression of the illness.<sup>[14]</sup> Therefore, caregiving as a stress factor can threaten the mental, physical, and social health of caregivers.<sup>[37]</sup>

In the final stage of the disease, when the patient's functionality is reduced, the increase in depression and burden is evident.<sup>[21]</sup> The moderate levels of anxiety and depression observed in caregivers in the present study were probably due to the patients' relatively good general condition and to a lack of information about the bad prognosis, which is very common in Greece.

In this study, univariate analysis revealed a number of factors that affected the anxiety and depression of caregivers, such as the gender of patients and caregivers, cancer detection, co-residence, transportation to and from the hospital, and previous care experiences. In terms of gender differences, male patients showed higher levels of anxiety and depression than women; thus, the caregivers' psychological condition was affected to a greater extent. A possible explanation is that in our sample, most male patients had been diagnosed with lung cancer and it is likely that the dramatic progression of the disease affected their psychological state. In addition, the traditional role of men as leaders in the Greek family is probably associated with

Table 3: Univariate qualitative analysis of anxiety anddepression variables				
Variables	Mean±SD	Р		
HADS-Anxiety				
Gender (P)				
Male	$10.78 \pm 4.65$	< 0.000		
Female	$7.05 \pm 3.81$			
Gender (C)				
Male	$6.63 \pm 3.94$	0.001		
Female	$10.28 \pm 4.60$			
Primary diagnosis				
Lung	$10.94 \pm 5.07$	0.008		
Breast	$7.05 \pm 3.34$			
Urogenital system	$8.60 \pm 3.89$			
Other	$8.80 \pm 4.78$			
Past surgery				
No	13.74±4.73	0.002		
Yes	$10.70 \pm 4.91$			
Residence (C)				
No	$7.79 \pm 4.61$	0.05		
Yes	$9.91 \pm 4.65$			
Care experience				
No	$8.24 \pm 4.26$	0.040		
Yes	$10.20 \pm 4.86$			
Means of transport				
Public transport	$9.00 \pm 4.78$	0.038		
Private car	$10.61 \pm 4.61$			
Taxi	$8.00 \pm 4.47$			
HADS-Depression				
Gender (P)				
Male	13.54±4.67	0.001		
Female	$10.22 \pm 4.97$			
Gender (C)				
Male	$8.42 \pm 4.15$	< 0.000		
Female	13.54±4.66			
Primary diagnosis				
Lung	14.17±4.42	0.003		
Breast	$10.05 \pm 4.80$			
Urogenital	10.85±5.19			
Other	11.30±5.36			

studies, it is argued that female patients experience greater discomfort than men<sup>[7,38]</sup> and that they seek more care.<sup>[2]</sup> In the current study, female caregivers experienced more anxiety and depression, and this finding is consistent with the results of many other studies.<sup>[7,26,39]</sup> In particular, female spouses appear to have the highest levels of discomfort, anxiety, and depression.<sup>[40]</sup> However, there are studies showing that male spouses experienced significantly greater discomfort than women.<sup>[41,42]</sup> Any differences between men and women in the experience of caring<sup>[39]</sup> may be due to cultural patterns of "absolute loyalty" and self-sacrifice imposed by society on women. Apart from the social rules and roles, women often use emotional strategies of coping, whereas men do not easily externalize their emotions.<sup>[9]</sup>

According to the findings of this study, caregivers of patients who had undergone surgery experienced less anxiety; this requires further investigation in the future. It is possible that past surgical treatment could have reduced the local disease, ameliorating respiratory symptoms, reducing care needs, and consequently limiting the negative effects of the illness on the lives of caregivers. In addition, surgical treatment is usually chosen for patients in earlier disease stages, who are usually still in a better overall health condition.

Another factor that seems to affect the anxiety of caregivers is the co-residence of patients and caregivers. Co-residence is associated with more demanding roles in prolonged care,<sup>[43]</sup> given the unlimited and around the clock availability of the caregiver, resulting in a loss of personal time, higher incidences of sleep disorders, and problems associated with possible work obligations,<sup>[33]</sup> although there are reports in the literature referring to a protective role of work against the psychological effects of caregiving.<sup>[44]</sup> In addition, previous experience of caregiving negatively affected the anxiety and depression of the caregivers in this study. It is likely that those who cared for their loved one for an extended period of time and had also taken care of other family members in the past were more anxious than those who assumed caregiving as a new role in their lives. The latter usually does not know the course of this long and difficult journey of caregiving. However, since there is no clear evidence of the effect of previous caregiving experiences on the outcomes of care, further investigation will be needed in the future.

In this study, the caregivers of lung cancer patients demonstrated higher anxiety and depression compared to the caregivers of breast cancer patients. In another study, female caregivers of lung cancer patients had higher levels of depression compared to male caregivers, both at the time of treatment and a year later.<sup>[45]</sup> It can be assumed that caregivers of lung cancer patients, who are mostly women,

increased obligations and with a breakdown in planning for the future because of the disease. In contrast, in most

C: Caregivers, P: Patients, NS: Non significant, SD: Standard Deviation, HADS: Hospital

 $10.17 \pm 5.17$ 

 $8.53 \pm 3.99$ 

 $12.33 \pm 4.91$ 

 $12.25 \pm 5.48$ 

 $10.59 \pm 4.45$ 

 $13.51 \pm 5.09$ 

 $11.88 \pm 5.22$ 

 $12.47 \pm 5.14$ 

 $12.31 \pm 4.92$ 

NS

NS

0.004

NS

Past surgery

Residence (C)

Care experience

Means of transport

Public transport

Anxiety and Depression Scale

Private car

No Yes

No

Yes

No

Yes

Taxi

Stepwise method	R <sup>2</sup> change	Reference category	В	SE	Р
Anxiety					
BCOS	0.278	-	-0.17	0.05	0.0005
Age (C)	0.110	-	-0.10	0.03	0.004
Primary diagnosis-breast	0.038	Lung	0.98	0.51	0.056
OCBS-difficulty	0.028	-	0.10	0.04	0.024
Gender (C)	0.022	Male	2.01	1.01	0.049
R <sup>2</sup> , F, P	0.477, (5.93)=116.96, <0.0005				
Depression					
BCOS	0.283	-	-0.14	0.04	0.001
OCBS-difficulty	0.58	-	0.12	0.04	0.004
Gender (C)	0.046	Male	2.20	0.83	0.009
$R^2, F, P$	0.387, (3.95)=20.00, <0.0005				

have high levels of mental disorders because of the severity of the symptoms of the illness and the poor prognosis. However, we cannot reach conclusions as there are no comparative studies looking at the severity and site of the cancer detected, which would probably reveal differences in the psychological state of the caregivers. Finally, regarding transportation to the hospital, caregivers escorting patients by private vehicle compared to those using a hired vehicle appeared to be going through a far more stressful process. This is probably due to the lack of parking spaces at hospital sites.

Factor analysis in relation to anxiety and depression showed that caregiving outcomes (care effects on caregivers' life), the perceived level of difficulty, and the time dedicated to care duties are significant predictors of caregivers' psychological condition. According to previous studies, care such as assistance in daily activities, management of symptoms, behaviors and feelings, and accompanying patients to their treatments adversely affects the psychological state of caregivers.<sup>[37,46,47]</sup> Similarly, Wagner et al.<sup>[48]</sup> reported that the low burden of care was associated with good psychological health in partners of breast cancer patients. The psychological health of caregivers can be adversely affected by factors such as difficult and stressful care tasks, personal life restrictions, social isolation, uncertainty about disease progression, and the duration of care.<sup>[14]</sup> The deterioration of a patient's functionality is associated with increased care demands, which is also a significant predictor of burden.<sup>[12]</sup> According to more recent studies, caregivers of patients with functional deterioration and advanced cancer experienced even higher levels of burden.<sup>[19,49]</sup> Another study showed that, as the "end of the journey" approaches, some caregivers reported symptoms close to cutoff points of depression, often associated with the patient's intense symptomatology.<sup>[17]</sup>

In the present study, multiple regression analyses also revealed that the younger age of caregivers is associated with increased anxiety. According to a relatively recent study, caregivers of younger age may experience more negative psychological effects.<sup>[50]</sup> However, extremely high depression rates are seen in middle-aged persons in developed countries, which may be explained by the fact that this generation of caregivers procreates at older ages and is likely to undertake dual care tasks simultaneously, looking after both parents and children.<sup>[13]</sup>

#### Limitations

It is difficult to generalize the results of this study, as it is likely that the small convenience sample, the inability to randomize the sample, and the heterogeneity of patient diagnoses render the population of the study non-representative. In retrospect, additional factors such as care duration, caregiver personality, and quality of relationship between patients and caregivers could probably be included in the study as potential mediators in causing emotional distress. Finally, studies with exclusively family caregivers (husbands or children or siblings) would probably lead to more useful conclusions about informal care and its effects on caregivers' anxiety and depression.

# Conclusion

We investigated the anxiety and depression of caregivers of advanced cancer patients. Negative psychological effects were reported by female caregivers, caregivers of male patients with lung cancer, caregivers who cared for patients who had not been surgically treated for their cancer, caregivers living together with patients (co-residence is associated with greater involvement in care), caregivers of younger age, caregivers who drove patients to the hospital, caregivers who had previously taken care of a loved one with a chronic illness in the past, and finally, caregivers who perceived a higher degree of burden imposed on them by their caregiving duties. There is a need for further investigation of the many factors that may contribute to negative caregiver outcomes, so as to determine the most significant predictive parameters.

Since the Greek National Health System has high expectations of family members who care for oncology patients, especially those with advanced and terminal stages of illness, there is an immense need to develop family support programs in the community by putting in place appropriate and efficient services and interventions. Caregivers who are identified as "functioning" and "healthy," without physical and, above all, without psychological distress, will be in a better position to help family members who have a serious and life-threatening illness, effectively managing not only the care needs of their loved ones, but also any deeper and personal problem that may arise.

#### Financial support and sponsorship

Nil.

#### **Conflicts of interest**

There are no conflicts of interest.

# References

- 1. National Alliance for Caregiving. Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience; 2016.
- 2. Given BA, Given CW, Kozachik S. Family support in advanced cancer. CA Cancer J Clin 2001;51:213-31.
- 3. Fletcher BS, Paul SM, Dodd MJ, Schumacher K, West C, Cooper B, *et al.* Prevalence, severity, and impact of symptoms on female family caregivers of patients at the initiation of radiation therapy for prostate cancer. J Clin Oncol 2008;26:599-605.
- 4. Teschendorf B, Schwartz C, Ferrans CE, O'Mara A, Novotny P, Sloan J, *et al.* Caregiver role stress: When families become providers. Cancer Control 2007;14:183-9.
- 5. Ferrell B, Hanson J, Grant M. An overview and evaluation of the oncology family caregiver project: Improving quality of life and quality of care for oncology family caregivers. Psychooncology 2013;22:1645-52.
- 6. Yun YH, Rhee YS, Kang IO, Lee JS, Bang SM, Lee WS, *et al.* Economic burdens and quality of life of family caregivers of cancer patients. Oncology 2005;68:107-14.
- 7. Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne JC. Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. Psychol Bull 2008;134:1-30.
- 8. Chung C, Hwang E. Couples' experiences of breast cancer in Korea: A descriptive qualitative study. Cancer Nurs 2012;35:211-20.
- 9. Lopez V, Copp G, Molassiotis A. Male caregivers of patients with breast and gynecologic cancer: Experiences from caring for their spouses and partners. Cancer Nurs 2012;35:402-10.
- 10. Sterba KR, Swartz RJ, Basen-Engquist K, Black PC, Pettaway CA. Long-term quality of life after radical prostatectomy in wives of men in the postoperative adjuvant androgen deprivation trial. Support Care Cancer 2011;19:1117-24.
- 11. Gilbar O, Zusman A. The correlation between coping strategies, doctor-patient/spouse relationships and psychological distress among women cancer patients and their spouses. Psychooncology 2007;16:1010-8.
- 12. Fletcher BS, Miaskowski C, Given B, Schumacher K. The cancer family caregiving experience: An updated and expanded conceptual model. Eur J Oncol Nurs 2012;16:387-98.
- Thrush A, Hyder AA. The neglected burden of caregiving in low- and middle-income countries. Disabil Health J 2014;7:262-72.
- 14. Sörensen S, Duberstein P, Gill D, Pinquart M. Dementia care: Mental health effects, intervention strategies, and clinical implications. Lancet Neurol 2006;5:961-73.
- 15. Kramer BJ. Gain in the caregiving experience: Where are we? What next? Gerontologist 1997;37:218-32.
- Parks SH, Pilisuk M. Caregiver burden: Gender and the psychological costs of caregiving. Am J Orthopsychiatry 1991;61:501-9.

- 17. Given B, Wyatt G, Given C, Sherwood P, Gift A, DeVoss D, *et al.* Burden and depression among caregivers of patients with cancer at the end of life. Oncol Nurs Forum 2004;31:1105-17.
- Li Q, Loke AY. A literature review on the mutual impact of the spousal caregiver-cancer patients dyads: 'communication', 'reciprocal influence', and 'caregiver-patient congruence'. Eur J Oncol Nurs 2014;18:58-65.
- 19. Rha SY, Park Y, Song SK, Lee CE, Lee J. Caregiving burden and the quality of life of family caregivers of cancer patients: The relationship and correlates. Eur J Oncol Nurs 2015;19:376-82.
- 20. Matthews BA. Role and gender differences in cancer-related distress: A comparison of survivor and caregiver self-reports. Oncol Nurs Forum 2003;30:493-9.
- 21. Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle CC, et al. Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. CMAJ 2004;170:1795-801.
- 22. Rumpold T, Schur S, Amering M, Kirchheiner K, Masel EK, Watzke H, *et al.* Informal caregivers of advanced-stage cancer patients: Every second is at risk for psychiatric morbidity. Support Care Cancer 2016;24:1975-82.
- 23. Trevino KM, Prigerson HG, Maciejewski PK. Advanced cancer caregiving as a risk for major depressive episodes and generalized anxiety disorder. Psychooncology 2018;27:243-9.
- 24. Govina O, Kotronoulas G, Mystakidou K, Katsaragakis S, Vlachou E, Patiraki E, *et al.* Effects of patient and personal demographic, clinical and psychosocial characteristics on the burden of family members caring for patients with advanced cancer in Greece. Eur J Oncol Nurs 2015;19:81-8.
- 25. Iconomou G, Viha A, Kalofonos HP, Kardamakis D. Impact of cancer on primary caregivers of patients receiving radiation therapy. Acta Oncol 2001;40:766-71.
- 26. Papastavrou E, Charalambous A, Tsangari H. Exploring the other side of cancer care: The informal caregiver. Eur J Oncol Nurs 2009;13:128-36.
- 27. Kim Y, Kashy DA, Wellisch DK, Spillers RL, Kaw CK, Smith TG. Quality of life of couples dealing with cancer: Dyadic and individual adjustment among breast and prostate cancer survivors and their spousal caregivers. Ann Behav Med 2008;35:230-8.
- 28. Mystakidou K, Tsilika E, Parpa E, Katsouda E, Galanos A, Vlahos L. The hospital anxiety and depression scale in Greek cancer patients: Psychometric analyses and applicability. Support Care Cancer 2004;12:821-5.
- 29. Govina O, Kotronoulas G, Mystakidou K, Giannakopoulou M, Galanos A, Patiraki E, *et al.* Validation of the revised Bakas caregiving outcomes scale in Greek caregivers of patients with advanced cancer receiving palliative radiotherapy. Support Care Cancer 2013;21:1395-404.
- 30. Carey PJ, Oberst MT, McCubbin MA, Hughes SH. Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. Oncol Nurs Forum 1991;18:1341-8.
- Mystakidou K, Cleeland C, Tsilika E, Katsouda E, Primikiri A, Parpa E, et al. Greek M.D. Anderson symptom inventory: Validation and utility in cancer patients. Oncology 2004;67:203-10.
- 32. Snaith RP. The hospital anxiety and depression scale. Health Qual Life Outcomes 2003;1:29.
- 33. Kotronoulas G, Wengström Y, Kearney N. Sleep and sleep-wake disturbances in care recipient-caregiver dyads in the context of a chronic illness: A critical review of the literature. J Pain Symptom Manage 2013;45:579-94.
- 34. Kim Y, Duberstein PR, Sörensen S, Larson MR. Levels of

depressive symptoms in spouses of people with lung cancer: Effects of personality, social support, and caregiving burden. Psychosomatics 2005;46:123-30.

- Kurtz ME, Kurtz JC, Given CW, Given BA. Depression and physical health among family caregivers of geriatric patients with cancer – A longitudinal view. Med Sci Monit 2004;10:CR447-56.
- 36. Grov EK, Dahl AA, Moum T, Fosså SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. Ann Oncol 2005;16:1185-91.
- 37. Vahidi M, Mahdavi N, Asghari E, Ebrahimi H, Eivazi Ziaei J, Hosseinzadeh M, *et al.* Other side of breast cancer: Factors associated with caregiver burden. Asian Nurs Res (Korean Soc Nurs Sci) 2016;10:201-6.
- Couper J, Bloch S, Love A, Macvean M, Duchesne GM, Kissane D, *et al.* Psychosocial adjustment of female partners of men with prostate cancer: A review of the literature. Psychooncology 2006;15:937-53.
- 39. Li Q, Loke AY. A spectrum of hidden morbidities among spousal caregivers for patients with cancer, and differences between the genders: A review of the literature. Eur J Oncol Nurs 2013;17:578-87.
- 40. Haley WE. The costs of family caregiving: Implications for geriatric oncology. Crit Rev Oncol Hematol 2003;48:151-8.
- 41. Baider L, Ever-Hadani P, Goldzweig G, Wygoda MR, Peretz T. Is perceived family support a relevant variable in psychological distress? A sample of prostate and breast cancer couples. J Psychosom Res 2003;55:453-60.
- 42. Goldzweig G, Hubert A, Walach N, Brenner B, Perry S, Andritsch E, *et al.* Gender and psychological distress among middle- and older-aged colorectal cancer patients and their

spouses: An unexpected outcome. Crit Rev Oncol Hematol 2009;70:71-82.

- 43. Brouwer WB, van Exel NJ, van Gorp B, Redekop WK. The CarerQol instrument: A new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual Life Res 2006;15:1005-21.
- 44. Mazanec SR, Daly BJ, Douglas SL, Lipson AR. Work productivity and health of informal caregivers of persons with advanced cancer. Res Nurs Health 2011;34:483-95.
- Pinquart M, Duberstein PR. Optimism, pessimism, and depressive symptoms in spouses of lung cancer patients. Psychol Health 2005;20:565-78.
- 46. Lambert S, Girgis A, Descallar J, Levesque JV, Jones B. Trajectories of mental and physical functioning among spouse caregivers of cancer survivors over the first five years following the diagnosis. Patient Educ Couns 2017;100:1213-21.
- 47. Given B, Sherwood PR. Family care for the older person with cancer. Semin Oncol Nurs 2006;22:43-50.
- Wagner CD, Bigatti SM, Storniolo AM. Quality of life of husbands of women with breast cancer. Psychooncology 2006;15:109-20.
- 49. Northouse LL, Katapodi MC, Schafenacker AM, Weiss D. The impact of caregiving on the psychological well-being of family caregivers and cancer patients. Semin Oncol Nurs 2012;28:236-45.
- 50. Viana MC, Gruber MJ, Shahly V, Alhamzawi A, Alonso J, Andrade LH, *et al.* Family burden related to mental and physical disorders in the world: Results from the WHO world mental health (WMH) surveys. Braz J Psychiatr 2013;35:115-25.