

Original Article

Investigation of Caregiver Burden, Anxiety, and Depression in Caregivers of the Palliative Patients According to Certain Variables

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Abstract

Background: Caring for patients receiving palliative care can cause physical, psychological, and economic difficulties for their relatives. For this reason, it should be emphasized that in palliative care, attention should be paid to patients' relatives as well as patients.

Aims: The aim of this study is to determine the burden of care, anxiety, and depression levels in caregivers of palliative patients and the factors affecting these parameters.

Methods: This descriptive study was carried out in Gülhane Training and Research Hospital in Ankara, Turkey. A total of 100 relatives of the patients, who provided care to the inpatients in the palliative care department, were included in the study. Data were collected using Caregiver Information Form, Hospital Anxiety and Depression Scale (HADS), and Zarit Caregiver Burden Interview (ZBI).

Results: According to our study results; caregivers were at risk for depression and anxiety, and their levels of care burden were moderate.

Conclusions: According to the results of this study, it was found that caregivers were at risk for anxiety and depression, and they had moderate levels of care burden. Care burden was found to be a determinant for the development of anxiety and depression. These results suggest that it would be appropriate to evaluate the care burden in caregivers for palliative care in terms of the development of anxiety and depression.

Key Words: Anxiety, caregiving, care burden, depression

Introduction

Palliative care is a holistic approach, which involves specialized medical and nursing care for individuals with progressive diseases. It aims to improve the quality of life of the patients and their families. Therefore, palliative care focuses on symptom management, providing physical, psychosocial, and moral support to the patients and their relatives, and supporting the relatives of the patient during the grieving period after the patient dies (Ahluwalia et al., 2018; Dahlin et al., 2018).

Patients under palliative care have chronic and progressive diseases; therefore, it is inevitable for their relatives to get involved in caregiving. Relatives of the patients play an active role in

palliative care, as well as healthcare professionals. Palliative care is a multidimensional concept that requires continuity involving professional assistance and family support (Singer et al. 2016; Alam et al. 2020). This concept involves positive attainments (self-improvement, satisfaction, finding meaning in life through the caregiving experience, improvement of love and sincerity) and challenges (meeting the needs of the patients, loss of economic, physical, and psychological roles, impairment of balance in the family). These difficulties that are experienced during caregiving cause the caregiver burden (Kavalieratos et al. 2016). In palliative care, formal caregivers are healthcare professionals, while informal caregivers are the family, relatives, friends, or neighbors of the patient (Alam et al. 2020).

Studies have demonstrated that caregiving may cause physical, psychological, social, and economic difficulties in caregivers and that wide-ranging emotional distress and psychological symptoms may be observed in caregivers such as depression, anxiety, anger, hopelessness, guilt, and shame (Ghane et al., 2016; Ullrich et al. 2017; Alam et al. 2020). This indirectly and negatively affects patient care (Krug et al. 2016; Alam et al. 2020). Anxiety and depression were determined to be common in caregivers according to many studies conducted with caregivers of patients under palliative care (Kuo et al. 2017; Götze et al. 2018; Guclu et al., 2018; Govina et al. 2019; Oechsle et al. 2020). In a study conducted in 2018 with the relatives of patients with cancer hospitalized in a palliative care center, depression was observed by 43.1% and anxiety was observed by 66.7% among the caregiving relatives of the patients (Guclu et al., 2018). In another study conducted in 2020 with the caregiving relatives of patients under palliative care, moderate/severe anxiety and depressive symptoms were observed in 27% and 35%, respectively (Oechsle et al. 2020). The impairment of the psychological well-being of the caregivers also affects the patient (Krug et al. 2016; Aoun et al. 2017).

Palliative care is a holistic procedure involving the patients and their relatives. The aims of palliative care include decreasing the levels of hopelessness, anger, burnout, anxiety, and depression and increasing the quality of life in caregivers (Aoun et al. 2017; Götze et al., 2018). The literature includes studies conducted to determine the psychological problems in caregivers of patients under palliative care (Götze et al., 2018); however, the number of studies determining the predictors of anxiety and depression in caregivers is limited in our country (Duran et al. 2019; Özdemir et al. 2020). The study sought answers to the following questions:

- What is the anxiety and depression level of caregivers of palliative patients?
- What is the care burden level of caregivers of palliative patients?
- What is the relationship between anxiety, depression and care burden of caregivers of palliative care patients?

It is believed that the results of this study would guide the planning of interventions for the relatives of the patients.

Methodology

Participants and settings: This descriptive study was carried out in the palliative care department of Gülhane Training and Research Hospital in Ankara. The study was conducted with the caregiving relatives of the patients hospitalized in the palliative care department between March 2018 and February 2019. A total of 100 caregiving relatives of patients, who were between 18-65 years of age, had no vision or hearing problems, and volunteered to participate in the study, were included in the study. No sample selection was performed in the study, and all caregivers, who volunteered for the study, were included in the sample. To conduct the study, ethics committee approval was obtained from the ethics committee of (University of Health Sciences Turkey, Gülhane Non-Interventional Ethical Committee, No: 18/48 46418926, Date: 28.02.2018). Written permission was obtained from the hospital and the palliative care department where the study was conducted. The participants were informed about the objective and subject of the study, and they were explained that participation was on a voluntary basis. Informed consent was obtained from the participants. Data were collected using the Caregiver Information Form, Hospital Anxiety and Depression Scale, and Zarit Caregiver Burden Interview.

Research tools

Caregiver Information Form: It was developed by the researchers in line with the literature to determine the sociodemographic (age, gender, daily caregiving time, chronic diseases, etc.) characteristics of the participants and their characteristics related to caregiving. The form contained questions regarding caregiving including whether the participant was knowledgeable about caregiving, presence of other individuals they had to care for at home, presence of chronic diseases, whether the other responsibilities were affected due to caregiving, mean number of daily hours allocated to caregiving, and evaluation of their medical condition before and after caregiving.

Hospital Anxiety and Depression Scale (HADS): This scale was developed by Zigmond et.al (1983) and tested for validity and reliability in Turkish by Aydemir et al. (1997). The scale does not aim to make a diagnosis; it aims to determine the risk group by screening anxiety and depression in a short period. In addition, the scale can be used to evaluate the change in the

emotional state of the person. It is a four-point Likert-type scale scored between 0 and 3. It consists of 14 items and two sub-dimensions (anxiety and depression). The minimum score that the participants can obtain from both sub-dimensions is 0, and the maximum score is 21. The cut-off value for the anxiety sub-dimension (HADS-Anxiety) is 10, and it is 7 for the depression sub-dimension (HADS-Depression). When the mean scores obtained from the sub-dimensions are higher than the cut-off values, this indicates increased levels and risk of anxiety and depression in caregivers. Aydemir et al. (1997) found the Cronbach's alpha coefficient of the scale as 0.85 for the anxiety sub-dimension and 0.78 for the depression sub-dimension. In this study, the Cronbach's Alpha coefficient was 0.82 for the anxiety sub-dimension and 0.78 for the depression sub-dimension.

Zarit Caregiver Burden Interview (ZBI): This scale determines the caregiver burden perceived by caregivers. It was tested for validity and reliability in Turkish by İnci (2006). It is a five-point Likert-type scale consisting of 22 items and a single sub-dimension. The minimum score to be obtained from the scale is 0, and the maximum score is 88. High scores indicate a high level of caregiver burden. İnci (2006) calculated the Cronbach's Alpha coefficient of the scale as 0.95. In this study, the Cronbach's Alpha coefficient of the scale was found to be 0.77.

Data collection tools were administered to the participants in the resting room of the palliative care department using the face-to-face interview method. Completing the forms took approximately 15-20 minutes.

Statistical Analysis: The data were analyzed using Statistical Package Program for Social Science (SPSS Inc, Chicago, IL) 21.0 software. Skewness and kurtosis coefficients were used for testing the normality of the data, and it was determined that the data were distributed normally. Independent t-test and ANOVA were used to compare the variables. When significant differences were observed in the ANOVA, the LSD post hoc test was used to determine the groups with differences. The relationship between variables was evaluated with the Pearson correlation test, and the effect of caregiver burden on depression and anxiety was evaluated using regression analysis. The confidence interval was determined as 95% in the analyses ($p < 0.05$).

Ethics Committee Approval: Ethical approval was obtained from the Institutional Review Board ((University of Health Sciences Turkey, Gulhane Non-Interventional Ethical Committee, no: 18/48 46418926 date: 28.02.2018).

Informed Consent: The participants were informed about the research and their consent was obtained.

Results

The descriptive statistics for participants were presented in Table 1. The mean age of the participants was 45.96 ± 9.96 ; 41% were male, and 59% were female. Among the participants, 61% reported good medical conditions, and 39% reported a moderate level of medical conditions before starting caregiving. Among the participants, 35% reported good medical conditions, 52% reported a moderate level of medical conditions, and 13% reported poor medical conditions after starting to provide care; and 31% had chronic diseases. Among the participants, 45% provided care for the patients for 20 hours or longer per day. The mean scores obtained by the participants from the sub-dimensions of HADS and ZBI were presented in Table 2. The mean HADS-Anxiety score of the participants was found as 10.14 ± 4.24 , and the mean HADS-Depression score of the participants was found as 8.75 ± 4.34 . According to the HADS-Anxiety and HADS-Depression scores, it was observed that caregivers were at risk for anxiety and depression. The mean ZBI score was 57.33 ± 10.44 and the caregivers were determined to have moderate levels of caregiver burden.

Scores obtained from the sub-dimensions of HADS and ZBI were compared according to the demographic characteristics of the patients in Table 3. It was concluded that the scores obtained by the participants in the ZBI did not have statistically significant differences according to the gender, age groups, medical condition before and after starting to provide care, duration of caregiving provided per day, and the presence of chronic diseases ($p > 0.05$).

It was found that the HADS-Anxiety and Depression scores obtained by the relatives of the patients did not have statistically significant differences according to gender and age groups ($p > 0.05$). The HADS-Anxiety scores obtained by the participants had statistically significant

differences according to the medical conditions before starting to provide care ($t=-2.56$; $p<0.05$). HADS-Anxiety scores of the participants, who defined their medical conditions as moderate before starting to provide care, were significantly higher compared to the scores obtained by the participants, who defined their medical conditions as good before starting to provide care. It was determined that the scores obtained from the depression sub-dimension did not have statistically significant differences according to the medical conditions before starting to provide care ($p>0.05$).

It was concluded that the scores obtained by the participants in the HADS-Anxiety ($F=8.51$; $p<0.05$) and HADS-Depression ($F=17.69$; $p<0.05$) sub-dimensions had statistically significant differences according to the medical conditions after starting to provide care. According to the results of the LSD post hoc test, which was administered to determine the groups with differences,

- HADS-Anxiety Scores of the participants, who defined their medical conditions as moderate and poor before starting to provide care, were significantly higher compared to the scores obtained by the participants, who defined their medical conditions as good after starting to provide care.

- HADS-Depression scores of the participants, who defined their medical conditions as moderate and poor after starting to provide care, were significantly higher compared to the scores obtained from the participants, who defined their medical conditions as good after starting to provide care. Depression scores of the participants, who defined their medical conditions as poor after starting to provide care, were significantly higher compared to the scores obtained from the participants, who defined their medical conditions as moderate after starting to provide care.

It was found that the HADS-Anxiety scores obtained by the participants had statistically significant differences according to the duration of care provided per day ($F=9.14$; $p<0.05$). According to the results of the LSD post hoc test, which was administered to determine the groups with differences, HADS-Anxiety Scores of the participants, who provided care for 8-12 hours per

day, were significantly higher compared to the scores obtained by the participants, who provided care for 18 hours or longer per day.

It was found that the HADS-Depression scores obtained by the participants did not have statistically significant differences according to the duration of care provided per day ($p<0.05$) and there were statistically significant differences according to the presence of chronic diseases ($t=2.87$; $p<0.05$). HADS-Depression scores of the participants with chronic diseases were significantly higher compared to the scores obtained by the participants with no chronic diseases. HADS-Anxiety scores obtained by the participants did not have statistically significant differences according to the presence of chronic diseases ($p>0.05$).

The correlation between the scores obtained by the participants HADS-Anxiety, HADS-Depression, and ZBI was presented in Table 4. A positive and significant correlation was found between HADS-Anxiety and HADS-Depression ($r=0.57$; $p<0.05$) scores, and between HADS-Anxiety and ZBI ($r=0.39$; $p<0.05$) scores. A positive and significant correlation was also found between HADS-Depression scores and the ZBI scores ($r=0.34$; $p<0.05$).

The results of the regression analysis performed to determine the effect of caregiver burden on anxiety and depression were presented in Table 5. It was determined that the model displaying the effect of the caregiver burden on anxiety was appropriate ($F_{(1,98)}=17.34$; $p<0.05$), and the caregiver burden was found to explain approximately 14% of the difference in anxiety ($\Delta R^2=0.610$). According to the standardized regression coefficient (β) and the significance of the coefficient (t), caregiver burden was found to have a positive and significant effect on anxiety ($\beta=0.39$; $t=4.16$; $p<0.05$).

It was determined that the model displaying the effect of the caregiver burden on depression was appropriate ($F_{(1,98)}=12.67$; $p<0.05$), and the caregiver burden was found to explain approximately 11% of the difference in depression ($\Delta R^2=0.105$). According to the standardized regression coefficient (β) and the significance of the coefficient (t), caregiver burden was found to have a positive and significant effect on depression ($\beta=0.34$; $t=3.56$; $p<0.05$).

Table 1. Descriptive Statistics for Participants (N = 100)		
	Mean	SD
Age	45.96	9.96
	n	%
35 years and under	14	14.0
36-45 years	33	33.0
46-55 years	38	38.0
56 years and older	15	15.0
Gender		
Female	59	59.0
Male	41	41.0
Medical Condition Before Starting Caregiving		
Good	61	61.0
Moderate	39	39.0
Medical Condition After Starting to Provide Care		
Good	35	35.0
Moderate	52	52.0
Poor	13	13.0
Daily Caregiving Time		
8 hours	15	15.0
12 hours	25	25.0
18 hours	15	15.0
20 hours and above	45	45.0
Chronic Diseases		
Have	31	31.0
Have not	69	69.0

SD: Standard deviation

Table 2 Descriptive Statistics of the Scales				
Scales	Mean	SD	Skewness	Kurtosis
HADS				
HADS- Anxiety	10.14	4.24	0.33	-0.73
HADS- Depression	8.75	4.34	0.86	0.23
Zarit Caregiver Burden Interview	57.33	10.44	0.41	0.92

SD: Standard deviation

Table 3: Comparison of Scale Scores of Participants According to Their Descriptive Characteristics

	Zarit Caregiver Burden Interview		HADS- Anxiety		HADS- Depression	
	Mean±SD	p	Mean±SD	p	Mean±SD	p
Gender						
Male (n=41)	59.15±7.90	0.148 ¹	11.00±4.18	0.091 ¹	9.24±4.42	0.346 ¹
Female (n=59)	56.07±11.79		9.54±4.22		8.41±4.30	
Age						
A-35 years and under	58.14±9.91	0.573 ²	9.36±3.65	0.417 ²	7.36±4.13	0.122 ²
B-36-45 years	56.52±11.43		10.94±4.41		10.06±5.18	
C-46-55 years	56.45±9.68		10.21±4.56		7.97±3.05	
D-56 years and older	60.60±10.84		8.93±3.45		9.13±4.88	
Medical Condition Before Starting Caregiving						
Good	57.67±11.26	0.684 ¹	9.30±4.20	0.012¹	8.25±4.40	0.148 ¹
Moderate	56.79±9.13		11.46±4.02		9.54±4.19	
Medical Condition After Starting to Provide Care						
Good	56.83±10.59	0.873 ²	8.00±3.58	0.000²	6.00±2.59	0.000²
Moderate	57.35±9.62		11.02±4.40	B.C>A	9.63±4.13	B.C>A
Poor	58.62±13.64		12.38±2.75		12.62±4.77	C>B
Daily Caregiving Time						
A-8 hours	59.20±9.29	0.231 ²	12.53±5.42	0.000²	10.80±6.48	0.093 ²
B-12 hours	58.00±11.79		12.60±4.29	A.B>C.D	9.52±4.29	
C-18 hours	52.27±11.71		8.33±2.26		7.73±3.67	
D-20 hours and above	58.02±9.36		8.58±3.24		7.98±3.47	
Chronic Diseases						
Have	57.06±13.17	0.866 ¹	10.61±4.54	0.458 ¹	10.55±5.05	0.005¹
Have not	57.45±9.06		9.93±4.12		7.94±3.75	

1: t test 2: Anova test

SD: Standard deviation

Table 4: Correlation Between HADS- Anxiety, HADS- Depression and Zarit Caregiver Burden Interview Scores of The Participants

Scales	2	3
1-HADS- Anxiety	0.57**	0.39**
2-HADS- Depression	1	0.34**
3- Zarit Caregiver Burden Interview		1

**p<0.01 Pearson Correlation

Table 5. The Effect of Caregiving Burden on Anxiety and Depression

Model	Independent variable	Dependent Variable	B	SH _B	β	t	p
1	Constant		1.106	2.205		0.501	0.617
	Caregiving Burden	Anxiety	0.158	0.038	0.388	4.165	0.000
R ² =0.150			ΔR ² =0.142		F _(1, 98) =17.344		p=0.000
2	Constant		0.678	2.305		0.294	0.769
	Caregiving Burden	Depression	0.141	0.040	0.338	3.559	0.001
R ² =0.114			ΔR ² =0.105		F _(1, 98) =12.668		p=0.001
Regresyon analysis							

Discussion

This study was conducted to investigate the relatives of the patients providing care for the inpatients in the palliative care department in terms of caregiver burden, levels of anxiety and depression, factors affecting these parameters, and the effect of caregiver burden on anxiety and depression. In the study, it was found that the relatives of the patients were at risk for anxiety and depression. The literature contains studies where different scales were used to measure psychiatric symptoms in caregivers (Kuo et al. 2017; Oechsle et al. 2020). In the studies where the same measurement tool was used, the relatives of the patients were found to have moderate levels of anxiety and depression (Egici et al., 2019; Ozdemir et al. 2020). In their study on caregivers of patients with cancer, Sari (2017) found that 64% of the participants had depressive symptoms. Similar to the results of our study, these results demonstrated that caring for a patient under palliative care caused anxiety and depression.

In the study, it was found that the relatives of the patients had moderate levels of caregiver burden, and the caregiver burden did not differ according to the demographic characteristics (gender, age, medical conditions before and after starting to provide care, duration of daily care, and presence of chronic diseases). In other studies that were conducted with the relatives of patients under palliative care, the caregiver burden of the relatives of the patients was found to be moderate or high (Krug et al. 2017; Oechsle et al. 2020). In line with the literature, the results of our study demonstrated that caring for a patient under palliative care caused caregiver burden.

In this study, it was concluded that the medical condition was effective on anxiety; however, it was not effective on the level of depression. Relatives of the patients, who had poor medical conditions before starting to provide care, had higher levels of anxiety. Relatives of the patients, who had poor medical conditions after starting to provide care, had higher levels of anxiety and

depression. These results were consistent with the knowledge in the literature that caregiving could affect the physical and psychological health of individuals (Ghane et al., 2016; Ullrich et al. 2017; Alam et al. 2020).

In our study anxiety levels of the participants, who provided care for 8-12 hours per day, were significantly higher compared to the participants, who provided care for 18 hours or longer per day. It is believed that the high level of anxiety despite the short duration of caregiving was because the caregiver observed multiple conditions related to the patient, spent more time, and shared more with the patient as the duration of caregiving prolonged. This made them get used to the process and conditions; therefore, they could cope with the challenges more easily and had less anxiety. We found that the duration of daily care provided did not affect the level of depression. The literature contains studies indicating that variables such as the duration of caregiving, the time spent with the patient, or living in the same house increase the risk of depression (Krug et al. 2016; Ullrich et al. 2017; Govina et al. 2019). This difference may have stemmed from the characteristics of the sample group.

The depression levels of caregivers with chronic diseases in our sample were found to be high. This result suggested that the caregivers with chronic diseases may have experienced medical problems during care because of their diseases, and the risk for depression may have increased due to the increased fatigue, tension, and insomnia caused by their chronic diseases. The result of our study was consistent with the knowledge in the literature that the prevalence of depressive disorder was high in individuals with chronic diseases (Bademli 2017; Airaksinen et al. 2020; Liu et al. 2021).

In this study, it was found that anxiety, depression, and caregiver burden were interrelated, and as the level of depression increased, the caregiver burden also increased. In a similar study, it was determined that as the caregiver burden increased in the caregivers of elderly patients, their anxiety levels also increased (Ay et al., 2017). The results of our study were similar to the knowledge that individuals may experience physical, economic, and psychological difficulties and feelings such as caregiver burden, guilt, anger, and hopelessness due to caregiving, and that these factors may lead to the development of anxiety and depressive

symptoms in individuals (Krug et al. 2017; Alam et al. 2020; Oechsle et al. 2020).

Strengths and limitations: This study had some limitations. The limitations of the study were being conducted in a single palliative care department and the fact that the data collection tools were administered based on self-reporting.

Conclusion: Caregivers in our sample were at risk for depression and anxiety, and their levels of caregiver burden were moderate. According to the results of the study, the medical conditions of the caregivers before starting to provide care affected the levels of anxiety, and the medical conditions after starting to provide care affected levels of anxiety and depression. Levels of depression were found to be high in caregivers with chronic diseases. In addition, caregiver burden was found to be a determinant for anxiety and depression. These results suggested that it would be appropriate to evaluate the caregiver burden in caregivers for palliative care in terms of the development of anxiety and depression. Palliative care is a holistic process involving the patient and the caregiver. Therefore, nurses need to include caregivers in their care plans. In the light of the results, it is believed that determining psychological problems in caregivers, including caregivers in planning nursing care, and providing the necessary psychosocial care in the early period could be beneficial for the caregiver and the patient, and would increase both the quality and satisfaction of care.

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