Evaluation of caregiver burden and depression in caregivers of palliative care patients in the emergency department

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Abstract

Introduction: Palliative care (PC) is comprehensive care that includes not only patients but also families. In Turkish culture most caregivers consist of families. Caregiver burden (CB) is a serious problem which can lead to worsening of the quality of care. The aim of the study is evaluation of CB, depression and possible causes of these conditions.

Material and methods: Demographic information, follow-up in PC units, diagnosis and duration of disease of their patients and the outcome of follow-up in the emergency department (ED) (discharge, clinical or intensive care unit hospitalization, death) were collected in forms from all caregivers who have PC patients in the ED. Additionally, the Karnofsky Performance Scale (KPS) and Edmonton Symptom Assessment System (ESAS) were applied to the patients. The Zarit Caregiver Burden Inventory (ZCBI) was used to evaluate the burden levels of caregivers. The Beck Depression Inventory (BDI) was used to determine depressive symptoms.

Results: Fourty four (57.1%) females and 33 (42.9%) males were included in the study. The mean BDI score was 21.68 ±12.6 points, while the mean ZCBI score was 45.70 ±16.5. A moderately statistically significant relationship was found between the BDI and ZCBI score (r – 0.337, p – 0.001). There was no statistically significant difference between BDI and ZCBI scores of caregivers according to KPS scores of patients (p – 0.243 and p – 0.304).

Conclusions: The palliative care team should be aware of CB for caregivers of PC patients. Early detection of factors can be vital for preventing CB and possible development of depression.

Key words: caregiver burden, depression, ZCBI, ESAS, KPS, BDI.

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INTRODUCTION

Palliative care (PC) was defined by the World Health Organization in 2006 as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" [1]. Palliative care patients may need assistance during their diseases. It is well known that the caregivers of PC patients have a very important role in this kind of care. In Turkish culture, most caregivers consist of family members. Palliative care comprises patients and families in this time-consuming process and it aims to improve their quality of life [2]. Caregivers can face emotional, psychological and physical difficulties during this care [3]. Caregiver burden (CB) is defined as stress or load which is felt by caregivers who attend to chronically ill, disabled or elderly patients [4]. There are many studies about CB in different diseases. It can increase the risk of cardiovascular diseases, cancer and somatic morbidity [5]. In addition, it is well known that CB can also affect patients. It may cause depression in patients and it may even worsen the prognosis of diseases. The underlying cause can be feeling unprepared for this care not only psychologically but also socially, physically and economically. The psychological factors are grief, guilt, anxiety and depression. Patient related factors such as presenting multiple symptoms, onset of terminal stage and reduction of functional status can aggravate these psychological factors [6]. In a previous study it was stated that female gender, spousal relationship to the recipient of care, high perceived

caregiver burden, financial problems, familial conflict, poor patient performance status, duration of illness, lung cancer diagnosis and palliative treatment intent act as factors increasing CB [7].

One of the important components of supplying PC effectively is early detection of CB. Hereby, solutions can be found to prevent CB. In Turkey, there is no hospice care; therefore home care represents a large portion of PC. If CB proceeds to depression, it will also decrease the quality of care given to patients. Palliative care is patient centered care and even financial problems of patients must be determined by the PC team in order to correct all errors in the system. In the present study, the Zarit Caregiver Burden Inventory (ZCBI) was used to evaluate CB. Caregiver's depression status was evaluated by the Beck Depression Inventory (BDI). Due to the fact that multiple factors can cause CB, in addition to demographic information, economical and educational status, etc., current symptoms and performance status of patients were also assessed by the Karnofsky Performance Scale (KPS) and Edmonton Symptom Assessment System (ESAS). The aim of this study was to evaluate the variables that affect CB and to detect a possible relation between CB and depression. Consequently, early prevention of CB can be achieved only by determining the causes of CB.

MATERIAL AND METHODS

This prospective study included caregivers of patients needing PC who were admitted to the emergency department (ED) of a university hospital. Patients were chosen according to the first step of the 3-step screening model belonging to a study titled "Content validation of a novel screening tool to identify emergency department patients with significant palliative care needs" [8]. There are two inpatient PC units, 1 outpatient PC unit and also home health care services in the province where the present study was conducted. Demographic information (age, gender, marital status), relation to patient, financial status and whether they receive financial support from the government or follow-up in PC units, diagnosis and duration of disease of their patients and the outcome of follow-up in the ED (discharge, clinical or intensive care unit hospitalization, death) were collected in forms from all caregivers. Additionally, KPS and ESAS were applied to the patients for detailed evaluation of their current state. The Zarit Caregiver Burden Inventory was used to evaluate the burden levels of caregivers. The Zarit Caregiver Burden Inventory consists of 19 self-reported items which have responses from 1 (never) to 5 (nearly always). The items are generally social and emotional and high scores indicate a heavy burden. Özlü *et al*. conducted the Turkish validity and reliability study of ZCBI [9].

The Beck Depression Inventory is a touchstone for presenting depression by evaluating cognitive, emotional, physical and motivational symptoms. Its validity and reliability study was conducted by Hisli in 1989 [10]. Scores in the range 10–16 are assessed as mild depressive symptoms, 17–29 moderate depressive symptoms, and 30–63 severe depressive symptoms in this inventory. The possible relation between CB and depression was evaluated in this study. Additionally, the related factors that affect CB were also assessed.

Statistical analyses

The data were analyzed using the software IBM SPSS Statistics Version 22. Frequency (f) and percentage (%) values of all variables were calculated. Descriptive analyses were used to provide general information about the sample. The mean and standard deviation were used for the quantitative variables fitting a normal distribution, while median and interquartile range (25–75%) were used for the variables that did not fulfil this requirement, along with counts and percentages. The independent sample t-test and one-way analysis of variance were used to compare the normally distributed group means. The Kruskal-Wallis H test was used for inter-group comparisons of quantitative parameters that did not show normal distribution. Spearman's correlation coefficient was performed to evaluate the relationship between parameters. In the analyses, $p < 0.05$ was considered significant.

RESULTS

Fourty four (57.1%) female and 33 (42.9%) male relatives were included in the study. 74% of them were married and 26% were single. 21.1% had only one child, while 52.6% had 2 or more children. 26.3% had no children. The income level of the majority was between 2000 and 3000 TL (39.5%). 13% of those participating in the study received government support while 87% did not. 67.5% of the patients who received PC services were cancer patients and the rest of their illnesses are presented in Table 1 displaying their ratios accordingly. 40.8% of the patients who received care had been diagnosed less than 6 months ago, 39.5% between 6 months and 5 years, and 19.7% more than 5 years ago. Only 18.6% of the patients were followed up in PC services while the majority (81.4%) were not. 44.3% of those who did not receive any follow-up in PC services stated the reason as having no information about these facilities. 78.7% of the caregivers were first degree relatives. During the study, 52.1% of the patients were hospitalized and 5.5% of them died. It was observed that 32% of the caregivers had moderate depression according to the BDI (Table 1).

The age distribution of the study group was 17–81 years (mean ±SD: 40.24 ±14.13). The mean

Table 1. Distribution of qualitative values

Variables		n	%
Gender	Female	44	57.1
	Male	33	42.9
Marital status	Married	57	74.0
	Single	20	26.0
Whether he/she has children	None	20	26.3
	Only child	16	21.1
	2 or more than 2	40	52.6
Caregiving on his/her own	Yes	27	35.5
	No	49	64.5
Income	0–1000 TL	13	17.1
	1000–2000 TL	19	25.0
	2000–3000 TL	30	39.5
	3000 TL and over	14	18.4
Financial government support	Yes	10	13.0
	No	67	87.0
Diagnosis	Advanced dementia or central nervous system diseases	5	6.5
	Cancer	52	67.5
	End stage renal failure	7	9.1
	Advanced chronic obstructive pulmonary disease	3	3.9
	Advanced heart failure	4	5.2
	End stage liver failure	3	3.9
	Septic shock, multiple organ dysfunction syndrome	1	1.3
	Others	2	2.6
Time of diagnosis	Less than 6 months	31	40.8
	6 months – 5 years	30	39.5
	More than 5 years	15	19.7
PC follow-up	Yes	13	18.6
	No	57	81.4
If answer is no; reason	Being unaware of this type of care	27	44.3
	Other	34	55.7
Degree of relationship	Family	59	78.7
	Other	16	21.3
ED follow-up	Discharge	22	30.1
	Hospitalization	38	52.1
	Hospitalization to ICU	9	12.3
	Dead	4	5.5
Beck Depression Inventory	Normal 0–9	13	17.3
	Mild depressive symptoms 10–16	16	21.3
	Moderate depressive symptoms 17–29	24	32.0
	Severe depressive symptoms 30–63	22	29.3

BDI – Beck Depression Inventory, ICU – intensive care unit, PC – palliative care

BDI score was 21.68 ±12.64 points, while the mean ZCBI score was 45.70 ±16.49 points (Table 2).

In Table 3, the BDI and ZCBI scores of the caregivers are compared according to whether the patients they were responsible for showed the symptoms stated on the ESAS; although not statistically significant, the caregivers tending to patients with pain have higher BDI and ZCBI scores. Additionally, a statistically significant difference was found between caregivers of patients with symptoms of fatigue, drowsiness, insomnia, skin/nail changes and caregivers of patients without these symptoms according to BDI scores (*p*-values economical – 0.013, 0.030, 0.001, respectively). The difference between ZCBI scores of caregivers tending to patients with skin/nail changes (mean ±SD: 54.05 ±13) and caregivers of patients without this symptom (mean ±SD: 44.61 ±14.21) was found to be statistically significant (*p* – 0.013) (Table 3).

Table 2. Distribution of quantitative values

Variables	Mean	Median	Standard deviation	Minimum	Maximum	25%	75%
Age	40.24	38.00	14.13	17.00	81.00	30.00	49.00
BDI score	21.68	20.00	12.64	0	63.00	12.00	32.00
ZCBI total score	45.70	51.00	16.49	0	81.00	38.00	55.00

BDI – Beck Depression Inventory, ZCBI – Zarit Caregiver Burden Inventory

Table 3. Distribution of Edmonton Symptom Assessment System with Zarit Caregiver Burden Inventory and Beck Depression Inventory scores

ESAS		BDI		ZCBI	
		n	**Mean ±SD**	*n*	**Mean ±SD**
Pain	Yes	50	23.59 ±10.62	50	49.04 ±14.14
	No	24	18.5 ±15.9	24	42.33 ±15.92
Test; *p*			1.421; 0.165		1.833; 0.109
Tiredness	Yes	62	20.54 ±11.6	62	47.58 ±15.22
	No	11	30.73 ±15.7	11	45 ±12.59
Test; *p*			2.535; 0.013*		0.530; 0.598
Nausea	Yes	27	23.65 ±12.11	27	48.67 ±15.21
	No	40	20.93 ±13.73	40	45.7 ±15.88
Test; *p*			0.826; 0.412		0.763; 0.448
Feeling depressed	Yes	58	20.93 ±11.66	58	47.69 ±14.96
	No	13	27.46 ±16.99	13	44.23 ±15.39
Test; *p*			1.665; 0.100		0.749; 0.456
Anxiety	Yes	58	21.88 ±11.98	58	48.26 ±13.38
	No	13	23.85 ±16.62	13	45.62 ±16.39
Test; *p*			0.496; 0.622		0.618; 0.539
Drowsiness	Yes	44	18.47 ±10.16	44	48.2 ±15.12
	No	21	26.95 ±15.5	21	45.38 ±14.05
Test; *p*			2.281; 0.030*		0.739; 0.464
Lack of appetite	Yes	39	21.13 ±10.66	39	48.97 ±12.76
	No	26	22.28 ±16.13	26	44.19 ±17.23
Test; *p*			0.316; 0.754		1.211; 0.232
Shortness of breath	Yes	15	21.5 ±10.19	15	51.53 ±14.46
	No	50	22.14 ±13.81	50	45.6 ±14.67
Test; *p*			0.161; 0.872		1.378; 0.173
Skin/nail changes	Yes	21	29.65 ±10.06	21	54.05 ±13
	No	44	18.64 ±12.99	44	44.61 ±14.21
Test; *p*			3.356; 0.001*		2.571; 0.013*
Mouth sore	Yes	15	23.33 ±8.62	15	47.4 ±11.23
	No	50	21.8 ±14.25	50	47.48 ±15.39
Test; *p*			0.510; 0.613		0.019; 0.985
Numbness in hands	Yes	18	26.78 ±11.58	18	51.17 ±15.82
	No	48	20.19 ±13.23	48	45.56 ±14.07
Test; *p*			1.856; 0.068		1.393; 0.168

DI – Beck Depression Inventory, ESAS – Edmonton Symptom Assessment System, SD – standard deviation, ZCBI – Zarit Caregiver Burden Inventory

Table 4. Distribution of Karnofsky Performance Scale with Zarit Caregiver Burden Inventory and Beck Depression Inventory scores

Variables		BDI		ZCBI	
		n	Mean ±SD	*n*	Mean ±SD
KPS	Very ill, urgently requiring admission, requires supportive measures or treatment	3	37 (8–42)	3	25 (2–37)
	Severely disabled, hospital admission indicated but no risk of death	3	9 (1–13)	3	42 (23–57)
	Requires help often, requires frequent medical care	2	15 (10–20)	2	48 (37–59)
	Requiring some help, can take care of most personal requirements	3	18 (15–35)	3	55 (43–55)
	Caring for self, not capable of normal activity or work	2	12 (11–13)	2	46.5 (33–60)
	Normal activity with some difficulty, some symptoms or signs	5	32 (18–33)	5	57 (55–58)
	Capable of normal activity, few symptoms	7	11 (7–19)	7	44 (36–57)
	Healthy, no symptoms or signs of disease	4	10.5 (3.5–19)	4	28.5 (22.5-35.5)
Test; *p*			10.324; 0.243		9.478; 0.304

BDI – Beck Depression Inventory, KPS – Karnofsky Performance Scale, SD – standard deviation, ZCBI – Zarit Caregiver Burden Inventory

There was no statistically significant difference between BDI and ZCBI scores of caregivers according to KPS scores of patients (*p*-values – 0.243, 0.304, respectively) (Table 4).

In Table 5, the socio-demographic characteristics of caregivers and their BDI and ZCBI scores are compared; it was observed that female caregivers had higher BDI (mean ±SD: 23.26 ±12.46) and ZCBI scores (mean ±SD: 48.59 ±15.39) compared to male caregivers, but the difference was not statistically significant (*p*-values, respectively: *p* – 0.213, *p* – 0.076). Depending on the marital status, the BDI score and ZCBI score do not differ statistically (*p*-values – 0.772, 0.453, respectively). Furthermore, the BDI and ZCBI scores of the caregivers did not show a statistically significant difference according to whether the patient was followed up in PC services or not (*p*-values – 0.633, 0.786, respectively). Beck Depression Inventory score differs statistically according to the time of diagnosis (*p* < 0.001). Caregivers of patients with time of diagnosis more than 5 years had the highest BDI scores (*p* < 0.001). In addition, statistically significant differences were found between the BDI scores of caregivers according to the status of their patients after ED evaluation (discharge, hospitalization to services or intensive care unit and death). Caregivers of dying patients had higher BDI and ZCBI scores compared to other caregivers (*p* – 0.001) (Table 5).

A moderately statistically significant relationship was found between the caregiver's BDI and ZCBI score (r – 0.337, *p* – 0.001) (Table 6).

DISCUSSION

It was found that caregivers of PC patients have moderate to severe CB and moderate depression in

this study. Additionally, there is a significant relation between ZCBI and BDI scores, indicating that CB increases depression of caregivers.

Ustaalioglu *et al*. evaluated CB in caregivers of cancer patients and they found that most of the caregivers had mild CB in their study. They evaluated patients who receive chemotherapy with a low performance status; therefore duration of care might be shorter than that in our patients [11]. Similarly, there are some studies that evaluated CB via ZCBI in the Turkish population. Their scores were lower than the results obtained in the present study [12–14]. It is presumed that the scores in the present study were observed to be higher because the questionnaires were done in the ED. It is known that ED visits can increase CB [15] with or without the presence of an emergency problem. Caregivers of dying patients had higher CB than others. It may be related to the duration of care, low performance status or being aware of poor prognosis.

When the risk factors of CB were evaluated in the present study, it was found that age, gender, marital status, financial status and PC follow-up had no significant effect on CB. In contrast, Karabekiroılu *et al*. reported that male caregivers have higher CB than female caregivers [7]. Additionally, Hsu *et al*. detected a correlation between financial status and CB. It is found that duration of care is an important factor determining the degree of CB [16]. Similarly, Orak *et al*. and Yuksel *et al*. described a possible relation between CB and duration of care. It is suggested that CB increases along with the duration of care [13, 17]. There is need for more than one caregiver, especially concerning PC patients.

According to patient related factors, there was no statistically significant difference between low performance status detected via KPS and CB. Although

Table 5. Distribution of demographic data with Zarit Caregiver Burden Inventory and Beck Depression Inventory scores

Variables		BDI		ZCBI	
		n	Mean ±SD	*n*	Mean ±SD
Gender	Female	43	23.26 ±12.46	44	48,.9 ±15.39
	Male	32	19.56 ±12.77	33	41.85 ±17.34
Test; *p*			1.257; 0.213		1.802; 0.076
Marital status	Married	56	21.93 ±12.8	57	44.86 ±17.46
	Single	19	20.95 ±12.45	20	48.1 ±13.47
Test; *p*			0.291; 0.772		0.754; 0.453
Whether he/she has children	None	19	21.84 ±13.16	20	47.5 ±13.96
	Single	16	23 ±10.55	16	48 ±8.53
	2/more than 2	39	21.23 ±13.52	40	43.65 ±19.91
Test; *p*			0.108; 0.898		0.570; 0.568
Caregiving on his/her own	Yes	25	20.48 ±13.71	27	40.44 ±19.06
	No	49	22.43 ±12.24	49	48.41 ±14.45
Test; *p*			0.622; 0.536		1.892; 0.065
Income	0–1000 TL	12	30.33 ±14.32	13	47.31 ±17.83
	1000–2000 TL	18	18.33 ±11.88	19	47.05 ±16.59
	2000–3000 TL	30	21.1 ±11.72	30	46.1 ±16.64
	Over 3000 TL	14	20.07 ±12.47	14	41.71 ±16.55
Test; *p*			2.509; 0.066		0.348; 0.791
Financial government support	Yes	8	25.13 ±12.15	10	43.2 ±20.36
	No	67	21.27 ±12.72	67	46.07 ±15.98
Test; *p*			0.814; 0.418		0.512; 0.610
Time of diagnosis	< 6 months	31	15.74 ±11.06(a)	31	41.1 ±18.56
	6 months – 5 year	29	23.17 ±10.51(b)	30	50.4 ±12.61
	> 5 years	15	31.07 ±13.57(c)	15	48.87 ±12,41
Test; *p*			9.557; < 0.001*		3.078; 0.052
PC follow-up	Yes	12	20.42 ±13.04	13	45.54 ±19.53
	No	57	22.4 ±13.06	57	47.12 ±14.06
Test; *p*			0.479; 0.633		0.277; 0.786
If answer is no, reason	Being unaware of this type of care	26	20.81 ±12.72	27	48.59 ±14.92
	Other	34	24.12 ±12.95	34	46.29 ±13.33
Test; *p*			0.988; 0.327		0.634; 0.528
Degree of relationship	Family	59	20.46 ±12.58	59	45.27 ±16.74
	Other	15	26.73 ±12.39	16	50.31 ±11.46
Test; *p*			1.730; 0.088		1.132; 0.261
ED follow-up	Discharge	22	23.27 ±12.47(ab)	22	45.5 ±13.34
	Hospitalization	38	17.5 ±11.66(a)	38	44.74 ±18.74
	ICU hospitalization	8	29.63 ±8.28(b)	9	51.44 ±5.79
	Dead	4	38.0 ±8.68(b)	4	57 ±6.48
Test; *p*			5.766; 0.001*		1.076; 0.365

BDI – Beck Depression Inventory, ICU – intensive care unit, PC – palliative care, ZCBI – Zarit Caregiver Burden Inventory

Table 6. Correlation of Zarit Caregiver Burden Inventory and Beck Depression Inventory scores

Median scores of inventories	Median (25%–75%)	r	p
BDI	20 (12–32)	0.373	0.001*
ZCBI	51 (38–55)		

BDI – Beck Depression Inventory, ZCBI – Zarit Caregiver Burden Inventory

there was no significant correlation between performance status and CB in the present study, it was found that pain and skin/nail changes were factors increasing CB in PC patients. Kim *et al.* also stated that there was no statistically significant relation between CB and patient's performance status [6]. By contrast, it was found in two separate studies [13, 16] that there was a possible relation between low performance status and CB. These differing results may be due to diversity among patient groups in terms of diagnosis, stages, etc. It is known that KPS can be used to determine the performance status of PC patients. It may aid in revealing the risk factors of CB.

There are many studies with similar results to those of the present study, which indicate a positive correlation between CB and depression [11, 16, 18]. In Perpiñá-Galvañ *et al.*'s study, they presented a possible relation between CB and depression. They suggested that depression is the most predicted burden factor in caregivers of PC patients [19]. Additionally, Ullrich *et al.* reported a rate of 41% moderate or severe depression in caregivers of cancer patients [20]. Karabekiroılu *et al.* evaluated the possible relation between CB and depression and they found that burden level could be a force determining the depression variance of caregivers (41%) [7]. Palliative care has a multidisciplinary approach and psychologists are an important member of the PC team, not only for patients but also for caregivers. Possible CB should be identified early for measures to be taken to prevent or decrease CB. Multiple factors can induce CB; therefore the PC team should reveal the source of the present obstacle such as personal (financial problems, unmet needs, etc.) and patient related situations. For example, social status was a determined factor for CB in a previous study [16]. After revealing problems and their sources, the PC team should try to solve them quickly, with the support of those who can be of help in the current situation such as a social worker, psychologist, chaplain, home care team, etc.

The present study obtained an expected result about dying patients. It was a burden factor and increased depression levels in caregivers. It is known that the PC process is not concluded with the death of the patient. Along with the primary purposes, it also aims to support families and caregivers in their stages of grief. Therefore, the PC team can work in coordination with the ED team [15]. When combined, they can support caregivers and families at the end of life in the ED.

Impact paragraph

Caregiver burden and depression are very important subjects for caregivers of PC patients.

The caregivers of PC patients have a very important role in this kind of care. The determination of their burden and depression and evaluation of possible factors about them are very important. In this study, we tried to do all of them in our emergency department. We believe it is valuable research for early prevention of CB and depression.

CONCLUSIONS

According to our results, there was moderate to severe CB and moderate depression in caregivers of PC patients. In addition, a strong relation between CB and depression was observed. It is known that CB is an important matter among caregivers of PC patients. It can lead to depression, which is an undesired outcome for both patients and caregivers. Palliative care includes not only patients but also caregivers. Therefore, the role of the PC team in this process is the early detection of CB in order to prevent depression along with the detailed evaluation of possible factors leading to CB.

The authors declare no conflict of interest.

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