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The Evaluation of the Burden and Burnout Levels of the Caregivers of the Inpatients in Palliative Care

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Research Article

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ABSTRACT

The study was conducted to evaluate the care burden and burnout levels of caregivers for patients hospitalized in palliative care. This descriptive study was conducted with 76 caregivers who were hospitalized in the palliative care services of a university and state hospital between 02.12.2019 and 02.06.2022 in Turkey. After obtaining the permissions of the ethics committee and the institution, the data were collected with the Descriptive Characteristics Form, Palliative Performance Scale, Caregivers Burden Inventory, and Maslach Burnout Inventory. The total score of the Caregivers Burden Inventory was 50.31±15.37, sub-dimensions of time-dependency burden, developmental burden, physical burden, social burden, and emotional burden scores were 18.30±3.23, 10.94±6.03, 13.54±5.99, 4.09±4.68, and 3.42±3.89, respectively. The Maslach Burnout Inventory sub-dimensions were emotional exhaustion, depersonalization, and personal accomplishment, with mean scores of 24.78±10.33, 11.59±4.20, and 28.64±5.67, respectively. The mean Palliative Performance Scale score of the patients was 32.76±16.86. As the care burden of caregivers increased, so did their exhaustion scores. Caregivers had moderate care burdens, high time dependency and physical burdens, high emotional exhaustion, and low personal accomplishment burnout. All patients who were cared for were bedridden. The presence of incontinence in the patient affected the time dependency care burden of the caregivers, and the presence of chronic disease in the caregiver and living with the patient also affected the caregivers' emotional exhaustion. These results show that studies must be conducted to develop multidisciplinary interventions to reduce caregivers’ care burden and burnout.

Keywords: Palliative care, caregiver, care burden, burnout

Palyatif Bakımda Yatan Hastalara Bakım Verenlerin Yük ve Tükenmişlik Düzeylerinin Değerlendirilmesi

Süreç

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ÖZ

Araştırma palyatif bakımda yatan hastalara bakım verenlerin bakım yükü ve tükenmişlik düzeylerini değerlendirmek amacıyla yapılmıştır. Tanımlayıcı tipte olan bu çalışma, Türkiye'de 02.12.2019 ile 02.06.2022 tarihleri arasında bir üniversite ve devlet hastanesinin palyatif bakım servislerinde yatan 76 bakım veren ile gerçekleştirildi. Etik kurul ve kurum izinleri alındıktan sonra Tanımlayıcı Özellikler Formu, Palyatif Performans Ölçeği, Bakım Veren Yük Envanteri ve Maslach Tükenmişlik Envanteri ile veriler toplandı. Bakım Verenlerin Yükü Envanterinin toplam puanı 50,31±15,37, zamana bağımlılık yükü, gelişimsel yük, fiziksel yük, sosyal yük ve duygusal yük alt boyutları puanları ise sırasıyla 18,30±3,23, 10,94±6,03, 13,54±5,99, 4,09±4,68 ve 3,42±3,89olarak belirlendi. Maslach Tükenmişlik Envanteri alt boyutları duygusal tükenme, duyarsızlaşma ve kişisel başarı olup ortalama puanları sırasıyla 24,78±10,33, 11,59±4,20 ve 28,64±5,67'dir. Hastaların Palyatif Performans Ölçeği puanı ortalaması 32,76±16,86 idi. Bakım verenlerin bakım yükü arttıkça tükenmişlik puanları da artmaktadır. Bakım verenlerin orta d91recede bakım yükü, yüksek zamana bağımlılık ve fiziksel yük, yüksek duygusal tükenme ve düşük kişisel başarı tükenmişliği vardı. Tedavi gören hastaların tamamı yatalak durumdaydı. Hastada inkontinans varlığı bakım verenlerin zamana bağlı bakım yükünü etkilediği gibi, bakım verende kronik hastalık varlığı ve hastayla birlikte yaşama da bakım verenlerin duygusal tükenmesini etkilemiştir. Bu sonuçlar bakım verenlerin bakım yükünü ve tükenmişliğini azaltmaya yönelik multidisipliner müdahalelerin geliştirilmesine yönelik çalışmaların yapılması gerektiğini göstermektedir.

Anahtar sözcükler: Palyatif bakım, bakım veren, bakım yükü, tükenmişlik

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Introduction

The palliative approach improves the quality of life of patients (children and adults) and their families facing problems associated with life-threatening diseases, prevents and alleviates pain through early detection, accurate assessment, and treatment of pain and other physical, psychosocial, or mental problems[1].

Palliative care is needed for a wide variety of diseases around the world. An estimated 56.8 million people require palliative care each year, of which 25.7 million are in the last year of life. Only approximately 14% of people currently in need of palliative care receive it worldwide [1-3]. Palliative care services were put into service in 2010 in Turkey, and today, they continue to be provided by 297 health facilities with 3,899 beds in 79 provinces [4].

Caregiving means the process of undertaking care delivery activities and responsibilities. A caregiver is defined as an individual (i.e., a spouse, partner, family member, friend, or neighbor) who provides unpaid care to others in their daily activities and/or illness-related processes [5]. The caregiver must learn how to deal with a patient. In this process, the caregiver usually begins to feel a significant caregiver burden and is at risk of caregiver burnout[6]. In a study conducted by Gerain (2019), it was found that there is a relationship between caregiver stress, burden, and burnout [7]. The burden is defined as negative subjective and objective consequences such as psychological distress, physical health problems, economic and social problems, deterioration of family relationships, and loss of control. The caregiver feels obliged to provide the patient’s treatment, personal care, and psychosocial support[1,6]. Perpiñá-Galvañ et al. (2019) reported that anxiety is a significant problem in primary family caregivers of palliative care patients and there are signs of an intense burden on caregivers [8]. Caregiver burden also causes negative impacts on the emotional, social, financial, physical, and spiritual functioning of the caregiver [9]. Also, in burnout, the caregiver's physical health or emotional well-being is negatively affected due to the stress associated with caring for someone with care needs. Typically, burnout occurs when the caregiver does not receive adequate support or when the caregiver is overworked with too many tasks and responsibilities [9]. Also, burnout is a three-dimensional syndrome occurring in response to chronic stress [10]. Caregiver burnout can manifest in 3 ways feeling tired, not having the strength to continue giving care, and/or starting to withdraw from regular caregiving [11,12]. When outcomes related to caregiving are evaluated, especially the jobs and potential burdens that are likely to result in burnout for caregivers, which will affect both the caregiver and the care recipient, must be taken into account [13,14]. The care and treatment of patients in palliative care is a very difficult process in which the burden and burnout levels of caregivers can be affected at various levels. In the literature review, no study was detected in which the burden of caregivers was evaluated with the Caregiver Burden Inventory [15]. By associating it with the palliative performance scale score of patients hospitalized in palliative care, and their burnout was examined. In this regard, the study was conducted to contribute to the development of interventions to meet the needs of patients in palliative care by evaluating the care burden and burnout levels of caregivers.

Material Method

All procedures performed in procedures involving human participants were in accordance with the ethical standards of the institutional and/or national study committee. Before starting the study, approval was obtained from the Non-Interventional Clinical Study Ethics Committee of a university (Sivas Cumhuriyet University, Decision No: 2019-11/19). Written permission was obtained from the university hospital administration (93596471-774.99-E.32863) and Sivas Provincial Health Directorate (76728045-799-2557), where the implementation was made.

After selecting the eligible participants who agreed to participate in the study, the researchers were introduced to them, and the objectives of the study were explained to the participants. The participants were ensured that their information would remain confidential, and they provided informed consent. The study was conducted following the principles of the Declaration of Helsinki.

Study design and sample

This descriptive study was conducted with 76 caregivers of patients who were hospitalized in palliative care services of a university (33) and state (43) hospital between 02.12.2019 and 02.06.2022 in Turkey. In the study, no sample selection was made in the population, and all caregivers who volunteered to participate in the study and met the research criteria were included in the sample. The fact that the study was conducted during the COVID-19 pandemic and the length of hospitalization in palliative care caused the sample size to be limited.

The caregivers who were primarily responsible for the care of the patient in the hospital and at home, 18 years of age and older, paid or unpaid care, and literate, non-communicative caregivers were included in the study. Interviews were conducted with those who cared for the patient for longer in patients with more than one caregiver. The researchers provided them with an explanation of the study. Written informed consent was obtained from all.

Measures

The data were collected with the Descriptive Characteristics Form, Palliative Performance Scale (PPS), Caregiver Burden Inventory (CBI), and Maslach Burnout Inventory (MBI).

1. Descriptive Characteristics Form

In this form, which was created by researchers in line with the relevant literature data [6, 8, 9, 13, 14], there are 21 questions to learn information about the individuals the caregivers cared for. The form included 14 questions to determine the introductory characteristics of caregivers. Also, there were 7 questions to determine the introductory characteristics of the caregivers that may affect the burden of caregivers and burnout.

2. Palliative Performance Scale

Anderson et al. reported the development and trial use of the Palliative Performance Scale (PPS) in 1996 as a new tool for measuring functional status in palliative care [16]. The Turkish validity and reliability of the PPS were conducted by Oğuz et al. (2021). The score is derived from the assessment of 5 domains ambulation, activity, and evidence of disease, self-care, intake, and level of consciousness. The PPS is divided into 11 levels, from PPS 0% to PPS 100%, in 10% increments, a patient at PPS 0% is dead and at 100% is ambulatory and healthy [17].

3. Caregiver Burden Inventory

This is an inventory developed by Novak and Guest (1989) to quantify the impact of caregiving on caregivers [15]. The Caregiver Burden Inventory (CBI) includes five dimensions, namely time-dependent (T/dep-B), developmental (Dev-B), physical (Phys-B), social (Soc-B), and emotional burdens (Emot-B). It is a 5-level Likert-type scale. The score is between 0 and 100 (0 to 20 in each dimension) [15]. A higher score indicates a higher burden. The form was adapted for Turkish society [18]. The CBI Cronbach alpha value was 0.94, 0.93 for T/dep-B, 0.94 for Dev-B, 0.94 for Phys-B, 0.82 for Soc-B, 0.94 for Emot-B18. In this study, Cronbach's alpha = 0.86 for these five dimensions (0.873, 0.862, 0.891, 0.767, 0.750, respectively).

4. Maslach Burnout Inventory

This 22-item tool was developed by Maslach10 and adapted for Turkish people with validity and reliability studies conducted by Ergin (1992) [19] and Çam (1996) [20]. This five-point Likert-type scale evaluates three dimensions of burnout. These are emotional exhaustion (EE), depersonalization (D), and personal accomplishment (PA). The inventory of the EE subscale contains 9 items, the D subscale contains 5 items and the PA subscale has 8 items. High scores on the EE and D subscales but low scores on the PA subscale are considered burnout19. Ergin (1992) found Cronbach's alpha reliability coefficients for three dimensions to be 0.83 for EE, 0.65 for D, and 0.72 for a sense of PA [19]. The Cronbach's alpha was found to be 0.916 for EE, 0.815 for D, and 0.727 for PA in this study.

Statistical analysis

The data collected in this study were analyzed by using SPSS version 22.0. Frequencies, percentages, and mean values were used in the descriptive analyses. The normality of the distributions of the data was assessed by using the Kolmogorov–Smirnov test. Since the data did not meet the parametric test conditions, the Mann–Whitney U test was used for two independent groups, and the Kruskal–Wallis test was used for more than two independent groups. We also analyzed the Spearman rank correlation coefficient test for continuous variables to identify factors that were significantly associated with caregiver burden burnout and the patients' Palliative Performance Scale. Simple regression investigated predictors of caregiver burden and burnout. The level of statistical significance was taken as 0.05.

Results

The mean age of the caregivers was 53.86±14.72 (Min:21, Max:82), and 72.4% of them were women. 81% of the participants were married, 82.9% had children, 75% did not work in any job, and 17.1% perceived their income as good. Also, 52.6% of caregivers had a chronic disease (Table 1).

A total of 26.3% of the caregivers lived with the spouse of the patient and 65.8% lived with their patients. When giving care to their patients, 71.1% of the participants received support from their siblings (64.8%). Of the patient 85.5% were elderly, 50% had behavioral problems and 84.2% had incontinence. In addition to these, the average PPS score of the patients was 32.76±16.86 (Table 2).

Table 1. The descriptive characteristics of the caregivers of the patients

	n (%)
The hospital where the patient is hospitalized	
University hospital	33 (43.4)
Public Hospital	43 (56.6)
Mean age $\bar{x}$: 53.86±14.72 (Min:21, Maks:82)	
40 years and under	14 (18.4)
41- 64 years	43 (56.6)
65 years and older	19 (25.0)
Gender	
Female	55 (72.4)
Male	21 (27.6)
Education level	
Illiterate	9 (11.8)
Literate with no formal degree	8 (10.5)
Primary-secondary school	38 (50.0)
High school	13 (17.1)
University	8 (10.5)
Marital status	
Married	62 (81.6)
Single	14 (18.4)
Having Children	
Yes	63 (82.9)
No	13 (17.1)
Employment status	
Working	19 (25.0)
Not working	57 (75.0)
Income level	
High income	13 (17.1)
Middle income	55 (72.4)
Low income	8 (10.5)
Chronic disease	
Yes	40 (52.6)
No	36 (47.4)

The CBI sub-dimensions of the caregivers were T/dep-B, Dev-B, Phys-B, Soc-B, and Emot-B. and their mean scores were 18.30±3.23, 10.94±6.03, 13.54±5.99, 4.09±4.68 and 3.42±3.89, respectively. The CBI total score was 50.31±15.37. The MBI sub-dimensions were EE, D and PA with mean scores of 24.78±10.33, 11.59±4.20, and 28.64±5.67, respectively (Table 3).

The difference between the Dev-B among the caregivers of illiterate ($p<0.05$) and chronic disease ($p<0.001$) and others was high and statistically significant. Elderly ($p<0.05$), unemployed ($p<0.05$), and caregivers with chronic disease ($p<0.001$) had statistically significantly higher Phys-B. The Soc-B of the male caregivers was high and the difference between them and the others was statistically significant ($p<0.05$). The EE of caregivers who were illiterate ($p<0.05$), unemployed ($p<0.05$), poor income status ($p<0.05$), and chronic disease ($p<0.001$) were statistically and significantly higher. The total score of the CBI of those with chronic diseases is also significantly higher than the others ($p<0.001$) (Table 4).

Table 2. The caring characteristics of the caregivers of the patients

	n (%)
Relationship with patient	
Spouse	20 (26.3)
Children	43 (56.6)
Non-familial caregivers (paid caregiver)	8 (10.5)
Others (Parent, sibling, grandchild, bride)	5 (6.6)
Caregiving Time	
1 year and below	61 (80.3)
Over 1 year	15 (19.7)
Living with the patient	
Yes	50 (65.8)
No	26 (34.2)
Status of the person supporting the care	
Yes	54 (71.1)
No	22 (28.9)
Relationship with patient of the individual who supports the care to the patient (n=54)	
Child	12 (22.2)
Brother/Sister	35 (64.8)
Other (parent, grandchild, bride, uncle)	7 (13.0)
The status of receiving education for care	
Yes	58 (76.3)
No	18 (23.7)
Patient age group $\bar{x}$: 75.28±10.76 (Min:40, Maks:93)	
40-64 years	11 (14.5)
65 years and above	65 (85.5)
Patient behavioral problems (verbal-physical attack, agitation, etc.)	
Yes	38 (50.0)
No	38 (50.0)
Patient incontinence (urine/ stool) status	
Yes	64 (84.2)
No	12 (15.8)
Patient pychiatric disease (dementia, depression) status	
Yes	28 (36.8)
No	48 (63.2)
Patient neurodegenerative disease (Alzheimer, Parkinson) status	
Yes	31 (40.8)
No	45 (59.2)
Palliative Performance Scale $\bar{x}$: 32.76±16.86 (Min:10, Maks:70)	

The differences between T/dep-B the caregivers of the patients who received training on care (p<0.05), who had behavioral problems (p<0.001) and who had incontinence (p<0.001) were found to be higher than the others, and the differences between them were statistically significant. The total burdens (p<0.05), Dev-B, and Phys-B (p<0.001) of the caregivers living with their patients were significantly higher. The Phys-B of the caregivers who were the spouses of the patients and the children who supported the care was higher than the others, and the difference between them was statistically significant (p<0.001). Soc-B was higher in caregivers of neurodegenerative patients compared to others (p<0.001). The caregivers of patients who had behavioral problems and neurodegenerative diseases had higher Emot-B and the difference between them was statistically significant (p<0.05). Among the caregivers, the EE of the patient's relatives (parent, sibling, grandchild, daughter-in-law) (p<0.001), children supporting the care (p<0.05), and caregivers living with the patient (p<0.001) were found to be statistically and significantly higher. The D levels of the caregivers who lived with their patients and were trained for care were high and the difference between them was found to be statistically significant (p<0.05). It was also found that the levels of burnout due to PA of caregivers who gave care to inpatients in palliative care were statistically significantly higher than the others (p<0.001) (Table 5).

In the present study, a negative, moderate, and highly significant relationship was detected between T/dep-B and PPS (r=-0.592, p≤0.001). Also, a high level and positive correlation was detected between caregivers' total CBI score and MBI sub-dimensions EE (r=0.758, p≤0.001) and D (r=0.868, p≤0.001), and a moderate, high, and significant negative relationship was detected with PA (r=-0.364, p≤0.001). A negative, moderate and highly significant relationship was detected between the incontinence of the patient being cared for and T/dep-B (r=-591, p≤0.001) in the study. It was also found that caregivers with chronic disease (r=-378, p≤0.001) and living with their patients (r=-347, p≤0.001) had a negative, moderately highly significant relationship with EE.

Table 3. The mean scores of the Caregivers Burden Inventory and the Maslach Burnout Inventory of caregivers of patients

Scales	**Scale sub-dimensions/ total score**	**$\bar{X}$±SD**	**Median**	**Min- Maks.**	**Point Range**
Caregiver Burden Inventory	Time-Dependent Burden	18.30±3.23	20.00	1-20	0-20
	Developmental Burden	10.94±6.03	12.00	0-20	0-20
	Physical Burden	13.54±5.99	13.75	0-20	0-20
	Social Burden	4.09±4.68	3.00	0-20	0-20
	Emotional Burden	3.42±3.89	2.00	0-20	0-20
	Caregiver Burden Inventory	**50.31±15.37**	**51.00**	**20-83**	**0-100**
Maslach Burnout Inventory	Emotional Exhaustion	24.78±10.33	23.00	9-43	9-45
	Depersonalization	11.59±4.20	11.50	3-21	1-25
	Personal Accomplishment	28.64±5.67	29.00	13-40	1-40

It was shown that the T/dep-B of the caregivers could explain 34.9% of the presence of incontinence in the patient being cared for. The presence of incontinence in the caregiver affected the T/dep-B of the caregivers significantly by 59.2%. It was also shown that the EE of the caregivers participating in the study can explain 22.9% of the caregiver's chronic disease and living with their patients. The presence of chronic disease and living with their patients significantly affected the EE of the caregivers by 47.9% (Table 6).

Table 4. The mean scores of the Caregivers Burden Inventory and Maslach Burnout Inventory according to the descriptive characteristics of caregivers of patients

Scale	Caregiver Burden Inventory					Maslach Burnout Inventory		
Descriptive Features	Time-Dependent Burden	Developmental Burden	Physical Burden	Social Burden	Emotional Burden	Emotional Exhaustion	Depersonalization	Personal Accomplishment
Age Groups								
40 years and below	17.64±2.76	11.35±5.81	10.26±5.61	4.78±4.13	4.50±5.30	23.35±9.86	11.64±4.92	28.85±7.50
41- 64 years	18.86±2.18	9.83±6.46	13.25±5.98	3.72±4.80	2.97±3.34	22.74±10.26	10.91±3.76	28.8±5.43
65 years and above	17.52±5.26	13.15±4.66	16.63±4.97	4.42±9.92	3.63±3.94	28.18±10.16	12.46±4.35	28.33±5.08
KW	5.165	0.543	**8.106**	1.237	1.400	4.428	1.985	0.706
p	0.577	0.761	**0.017***	0.538	0.496	0.109	0.370	0.702
Gender								
Female	18.38±2.65	11.05±5.86	13.93±5.86	3.41±4.43	3.29±3.26	24.80±10.30	11.31±4.09	28.58±5.62
Male	18.09±4.49	10.66±6.62	12.53±6.36	5.85±4.95	3.76±4.30	24.76±10.69	12.33±4.50	28.80±5.92
Z	-0.685	-0.239	-0.838	**-2.094**	-0.208	-0.110	-1.100	-0.547
p	0.745	0.811	0.402	**0.036***	0.835	0.912	0.272	0.584
Education level								
Illiterate	17.55±4.12	16.88±4.56	16.19±5.45	7.44±7.35	6.22±5.58	34.33±9.88	15.16±4.44	27.55±6.82
Literate with no formal degree	18.75±3.57	10.75±6.47	15.31±6.70	3.25±3.37	3.87±4.38	31.37±10.91	12.75±4.88	25.37±5.09
Primary-secondary school	18.15±3.57	9.68±5.92	13.59±5.85	3.60±4.30	2.97±3.34	22.76±9.22	10.90±3.56	28.94±5.13
High school	18.53±2.69	11±5.43	12.59±5.60	3.92±4.76	3.69±4.15	23.76±10.90	11.38±4.67	29.84±6.29
University	19±1.77	10.37±5.87	10.15±6.62	3.75±2.86	1.5±1.92	18.75±5.36	10.06±3.94	29.75±6.31
KW	0.702	**10.595**	5.837	2.139	4.788	**13.240**	7.759	3.884
p	0.951	**0.031***	0.211	0.710	0.309	**0.010***	0.100	0.421
Employment status								
Working	18.78±1.98	10.10±6.53	10.65±6.95	3.89±4.85	3.10±3.95	19.52±8.90	10.76±4.69	30.63±5.87
Not working	18.14±3.55	11.22±5.89	14.51±5.37	4.15±4.66	3.52±3.91	26.54±10.25	11.87±4.03	27.98±5.49
Z	-0.541	-0.607	**-2.126**	-0.431	-0.705	**-2.533**	-0.835	-1.575
p	0.588	0.543	**0.033***	0.666	0.481	**0.011***	0.404	0.115
Income level								
High income	18.76±3.13	11.46±5.66	11.63±6.68	3.61±4.07	2.53±2.93	21.46±10.38	11.15±3.92	30.61±4.97
Middle income	18.27±3.30	10.45±5.91	13.74±5.86	3.70±4.34	3.45±3.79	24.34±9.98	11.43±4.08	28.47±5.51
Low income	17.75±3.24	13.5±7.48	15.31±5.69	7.5±6.78	4.62±5.80	33.25±9.40	13.43±5.49	26.62±7.44
KW	1.188	1.790	1.838	2.720	0.744	**6.456**	1.942	1.471
p	0.552	0.408	0.398	0.256	0.689	**0.039***	0.378	0.479
Chronic disease								
Yes	18.17±2.99	13.27±4.70	15.77±4.71	4.3±4.99	3.95±4.05	28.47±10.14	12.78±4.05	27.3±5.48
No	18.44±3.52	8.36±6.35	11.07±6.35	3.86±4.36	2.83±3.68	20.69±9.03	10.27±4.02	30.13±5.57
Z	-0.680	**-3.229**	**-3.371**	-0.379	-1.617	**-3.258**	-2.584	**-2.315**
p	0.496	**0.001****	**0.001****	0.704	0.105	**0.001****	0.009	**0.020***

Abbreviations: Z, Mann Whitney U**;** KW, Kruskal Wallis *p<0.05, **p<0.001

Table 5. The mean scores of the Caregivers Burden Inventory and Maslach Burnout Inventory according to the caregiver characteristics of the caregivers of patients

Scale **Characteristics of the caregivers**	**Caregiver Burden Inventory**					**Maslach Burnout Inventory**		
	Time-Dependent Burden	**Developmental Burden**	**Physical Burden**	**Social Burden**	**Emotional Burden**	**Emotional Exhaustion**	**Deperson-alization**	**Personal Accomplish-ment**
Relationship with patient								
Spouse	17.35±4.95	14.05±5.12	16.98±4.74	4.3±6.00	3.45±3.74	31.5±8.34	12.7±4.27	28±4.41
Children	18.62±2.38	9.65±5.87	12.5±5.60	4.72±4.366	3.72±4.06	22.30±10.09	11.05±3.89	28.02±6.01
Non-familial caregivers	18.75±2.05	9.37±6.41	10±7.41	1.12±2.100	1±2.13	17.12±5.64	10±4.90	34.12±3.31
Others (Parent, sibling, grandchild, bride)	18.6±2.60	12.2±7.15	14.5±6.64	2.6±2.607	4.6±4.77	31.6±9.01	14.4±4.49	27.8±6.61
KW	0.381	7.682	**12.67**	6.620	5.366	**16.99**	4.894	**9.932**
p	0.944	0.053	**0.005****	0.085	0.146	**0.001****	0.179	**0.019***
Living with the patient								
Yes	17.92±3.72	12.22±6.12	14.87±5.43	4.18±4.88	3.84±3.97	27.36±10.70	12.44±4.19	28.66±5.70
No	19.03±1.84	8.5±5.14	11.00±6.31	3.92±4.34	2.61±3.69	19.84±7.59	9.98±3.81	28.61±5.70
Z	-1.064	**-2.608**	**-2.692**	-0.016	-1.494	**-2.931**	**-2.500**	-0.164
p	0.287	**0.009****	**0.007****	0.986	0.134	**0.003****	**0.012***	0.869
Relationship with patient of the individual who supports the care to the patient (n=54)								
Child	18.91±1.97	13.25±6.19	16.87±5.57	3.08±4.56	4±4.13	31.41±9.51	12.41±5.17	27.75±4.51
Brother/Sister	17.97±4.15	9.65±6.36	12.86±5.23	4.2±4.17	2.71±3.23	22.97±10.11	10.88±3.56	28.94±5.14
Other (parent, grandchild, bride, uncle)	18.28±2.21	9.42±5.50	8.39±5.57	3.85±2.79	2.71±3.45	19.42±9.28	9.78±3.92	27.14±7.79
KW	0.276	3.480	**10.497**	1.638	1.014	**7.235**	2.332	1.462
p	0.871	0.175	**0.005****	0.440	0.602	**0.026***	0.311	0.481
The status of receiving education for care								
Yes	18.55±3.34	11.29±6.36	14.21±5.97	3.91±4.75	3.5±3.91	25.43±10.69	12.19±4.12	28.60±4.94
No	17.5±2.79	9.83±4.82	11.38±5.70	4.66±4.52	3.16±3.94	22.72±9.07	9.66±3.98	28.77±7.72
Z	**-2.353**	-1.170	**-2.017**	-0.966	-0.287	-0.874	**-2.337**	-0.355
p=	**0.018***	0.241	**0.043***	0.333	0.774	0.381	**0.019***	0.722
Patient behavioral problems (verbal-physical attack, agitation, etc.)								
Yes	19.21±1.86	10.52±5.90	14.26±5.83	3.44±3.86	4.05±3.80	24.34±10.27	12.10±4.14	27.15±6.13
No	17.39±4.01	11.36±6.22	12.83±6.14	4.73±5.35	2.78±3.93	25.23±10.52	11.09±4.26	30.13±4.79
Z	**-2.578**	-0.479	-1.092	-0.805	**-1.991**	-0.337	-0.884	-1.895
p	**0.009****	0.631	0.274	0.420	**0.046***	0.735	0.376	0.058
Patient incontinence (urine/ stool) status								
Yes	19.125±1.64	10.54±6.06	13.89±6.10	3.90±4.94	3.64±3.75	24.23±10.10	11.65±4.29	28.59±5.46
No	13.91±5.56	13.08±5.66	11.68±5.23	5.08±2.90	2.25±4.61	27.75±11.52	11.29±3.89	28.91±6.94
Z	**-3.939**	-1.307	-1.440	-1.843	-1.828	-0.912	-0.413	-0.235
p	**0.001****	0.191	0.149	0.065	0.067	0.361	0.679	0.813
Patient neurodegenerative disease (Alzheimer, Parkinson) status								
Yes	18.61±2.48	11.25±5.25	13.00±6.19	5.96±5.37±	4.25±3.68	23.54±9.95	11.90±4.03	29.03±5.64
No	18.08±3.67	10.73±6.57	13.92±5.89	2.8±3.67	2.84±3.97	25.64±10.62	11.38±4.35	28.37±5.73
Z	-0.061	-0.084	-0.692	**-2.839**	**-2.080**	-0.835	-0.635	-0.556
p	0.951	0.932	-0.692	**0.004****	**0.037***	0.403	0.525	0.578

Abbreviations: Z, Mann Whitney U**;** KW, Kruskal Wallis
*p<0.05, **p<0.001

Table 6. The results of the Caregiver Burden Inventory and Maslach Burnout Inventory regression analysis

Depend Variable Time-Dependent Burden							
Independ Variable	**B**	**SE**	**Beta**	**t**	**p**	**95% CI for β**	
						Lower Limit	**Upper Limit**
Constant	24.33	1.004	-0.591	24.226	0.001*	22.332	26.335
Patient incontinence (urine/ stool) status	-5.208	0.827		-6.295	0.001*	-6.857	-3.560
R:0.591; R2:0.349; F:(39.626) ;p:0.001; Durbin Watson:1.777							
*p< 0.001							
Depend Variable Emotional Exhaustion							
Independ Variable	**B**	**SE**	**Beta**	**t**	**p**	**95% CI for β**	
						Lower Limit	**Lower Limit**
Constant	43.550	4.161		10.466	0.001*	35.256	51.843
Caregiver chronic disease status	-6436	2.250	-0.297	-2.861	0.006*	-10.919	-1.952
Living with the patient	-6.869	2.137	-0.334	-3.214	0.002*	-11.129	-2.609
R:0.479; R2:0.229; F:(10.868) ;p:0.001							
*p<0 .001							

Discussion

Problems that are associated with life-threatening diseases affect both patients and caregivers at various levels. Palliative care services provide services to patients and caregivers to minimize these impacts and prevent and alleviate pain and suffering. Caregiving can turn into a care burden and burnout in caregivers over time. Accordingly, the findings of the study and the care burden and burnout levels of caregivers are discussed in the following section within the current literature.

In the present study, caregivers were found to have a moderate burden of care, a high level of T/dep-B, EE, and low PA burnout. In previous studies conducted with patients hospitalized in palliative care, it was found that caregivers experience a care burden [8, 21-23]. Similarly, Saraçoglu et al. (2022) [24] and Egici et al. (2019) [25] reported in their study that as the burden of caregivers increased, so did their burnout scores, and their PA- related burnout was low. Personal achievement encompasses positive dimensions of the helping experience, emphasizing that the caregiver can gain a sense of satisfaction and find meaning in the care work [26]. In the context of burnout, the tendency to increase this positive sense of achievement is thought to be related to the caregivers' efforts to give the best care [8, 21-24]. During the study process, almost all of the participants used the expression "I do my best while giving care". In previous studies, the different levels of burden and burnout of caregivers were associated with the patient groups and caregivers' characteristics, cultural, social, and support resources [8, 21-23]. These results also show that as caregivers' burden of care increased, their burnout also increased.

A low PPS score causes bed dependence, meeting basic physiological needs in bed, and the patient's need for more care, which affects the caregiver's care intensity, time allocated for care, caregiver burden, and burnout. All patients who were cared for in this study were bedridden according to their PPS scores. The caregivers of the bedridden and incontinence patients had a high time dependency burden. According to Ahmad Zubaidi et al. (2020), in the Eastern Cooperative Oncology Group (ECOG) performance scale, 55.4% of patients were bedridden and caregivers experienced a burden of care [22]. Similarly, Guerriere et al. (2016) reported that the burden of caregivers of patients with low PPS scores was higher [27].

It was also found that the total burden of caregivers with chronic diseases was higher. For caregivers who were illiterate, unemployed, low-income, and with chronic diseases the emotional exhaustion was higher, too. In the literature review, it was reported that the burden of care was higher because those with higher education levels were more conscious [22, 25, 28, 29]. According to Egici et al. (2019), however, no relationship was detected between caregivers' gender, education, degree of closeness, and burden of care and burnout [25]. The high burden of care in individuals who had low educational status was associated with the feeling of uncertainty because of not knowing the progress of their patients in the care process and giving more weight to care. According to Saraçoglu et al. (2022), caregivers who had low- income levels had high burdens and burnout [24]. Although the cost of treatment and care for critically ill individuals is high, it can be considered that low-income levels may play roles in the caregivers' feeling of care burden and burnout. In previous studies, it was found that caregivers with health problems or chronic diseases had a high burden of care [8, 28, 29] and EE [25]. Finding similar results with the literature is considered to be an indication that individuals with chronic diseases affect the care burden and emotional exhaustion while struggling and managing their health problems, as well as taking care of the patients.

The total burden of caregivers living with their patients and EE, the Phys-B of the children who were the spouses of the patients and supported the care, the Emot-B of the caregivers of the patients who had behavioral problems, and the D of the caregivers were found to be high. Studies reported that the risk of developing a care burden was higher in caregivers who were the spouses or lovers of the patients [29, 30]. Alsirafy et al. (2021) on the other hand, found that the degree of closeness of the caregivers to the patient and living with the patient did not affect their care burden [21]. In studies conducted on burnout, it was found that caregivers experienced more emotional exhaustion, less depersonalization, and lower personal accomplishment than non-caregivers [31]. When additional duties are given to caregivers, their care burden, EE, and D were found to be higher than other caregivers [25]. In the study conducted by Hiyoshi-Taniguchi, Becker, and Kinoshita (2018), it was found that caregivers experienced higher burnout when faced with agitation/aggression, irritability, abnormal motor behavior, and hallucinations [32]. When evaluating caregiver care burden and burnout, both patient and caregiver characteristics that might affect caregivers must be investigated and measures must be taken to prevent or minimize negative impacts.

LIMITATIONS

The long-term hospitalization of patients in palliative care services and the coinciding of the data collection process with the COVID-19 pandemic caused a limitation in the number of samples. Research results are limited to the sample studied, cannot be generalized. In addition, the limitations of the research can be stated as the fact that the research was conducted only in Sivas province.

CONCLUSION

As the burden of caregivers increased, so did their exhaustion levels. Caregivers have a moderate care burden, high time dependency and physical burdens, high emotional exhaustion, and low personal accomplishment burnout. All patients who were cared for were bedridden. The presence of incontinence in the patient affected the time dependency burden of the caregivers, and the presence of chronic disease in the caregiver and living with the patient also affected the caregivers' emotional exhaustion. These results may indicate the need for studies to develop multidisciplinary approaches to reduce caregivers' care burden and burnout.

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