

Research Article

The burden of care among caregivers: a comparison between home care and palliative care

Bakım verenlerin sorumluluk yükü: Evde bakım ve palyatif bakımın karşılaştırılması

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Abstract

Introduction: We aimed to determine whether there is a difference in care burden, anxiety, and depression between caregivers of patients living at home and those in the palliative care unit.

Methods: The study was cross-sectional in the palliative care and home health units. The study population consisted of 1,879 patients. Different from home care, caregivers in the palliative unit were educated by the nurses on patient care during their stay in the hospital. A total of 186 caregivers were enrolled in the study. Unlike those receiving home care, caregivers of the patients in the palliative care unit received training on patient care while they were in the hospital. The care burden, anxiety, and depression levels of the caregivers in both groups were measured using the Zarit Caregiver Burden and Hospital Anxiety and Depression scales.

Results: The mean age of the participants was 51.44±12.11 years. The caregivers' mean burden and anxiety scores were higher in palliative care compared to the homecare group. Both burden and anxiety scores were significantly higher in the palliative care group ($p < 0.001$ and $p = 0.031$, respectively).

Conclusion: One of the distinguishing features of patients in the palliative care unit is the opportunity to provide ongoing medical support, social support, and education to the caregivers. However, the interventions at the palliative unit were not enough to compensate for the difference in the burden of care between the two groups.

Keywords: Caregivers, Caregiver Burden, Palliative Care, Home Care Services

Öz

Giriş: Çalışmamızda, evde hastalara bakım verenler ile palyatif bakım ünitesindeki bakım verenler arasında bakım yükü, anksiyete ve depresyon düzeyleri arasındaki ilişkinin değerlendirilmesi amaçlanmıştır.

Yöntemler: Kesitsel bir çalışmadır. Çalışmanın evrenini 1,879 hasta oluşturmaktadır. Evde bakımdan farklı olarak palyatif ünite de bakım verenler, hastanede kaldıkları süre boyunca hemşireler tarafından hasta bakımı konusunda eğitildiler. Çalışmaya dahil edilme kriterlerine uyan 186 hasta bakıcı dahil edildi. Palyatif bakım ünitesindeki hastaların bakım verenleri, evde bakım alanlardan farklı olarak hasta bakımı konusunda hasta hastanede eğitim almıştır. Her iki gruptaki bakım verenlerin bakım yükü, anksiyete ve depresyon düzeyleri Zarit Bakıcı Yükü ve Hastane Anksiyete ve Depresyon ölçekleri kullanılarak ölçüldü.

Bulgular: Katılımcıların yaş ortalaması 51.44±12.11 idi. Palyatif bakımda bakım verenlerin ortalama yük ve anksiyete puanları evde bakım grubuna göre daha yüksekti. Palyatif bakım grubunda hem yük hem de anksiyete skorları anlamlı olarak yüksekti (sırasıyla $p < 0,001$ ve $p = 0,031$).

Sonuç: Palyatif bakım ünitesindeki hastaların ayırt edici özelliklerinden biri, bakım verenlere sürekli tıbbi destek, sosyal destek ve eğitim sağlama fırsatıdır. Ancak çalışmamızda palyatif ünitesinde yapılan müdahaleler iki grup arasındaki bakım yükü farkını telafi etmeye yetmediği görülmüştür.

Anahtar Kelimeler: Bakıcılar, Bakıcı Yükü, Palyatif Bakım, Evde Bakım Hizmetleri

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Key Points

- Home care caregivers exhibited significantly lower mean anxiety and caregiver burden scores than their counterparts in the palliative care group.
- Caregiver burden scores were significantly higher among palliative care patients, highlighting the special challenges faced by caregivers working in this setting.
- Anxiety, depression, and receiving palliative care are independent predictors of caregiver burden.

Introduction

Prolongation of the lifespan together with an increase in chronic diseases increased the need for caregivers all over the world. Most caregivers do this service because of either economic or emotional reasons [1]. During patient care, the caregiver has already a high burden. If the workplace, social environment, and other family responsibilities are added to this, the increase in burden becomes inevitable. The burden of care is defined as psychological distress ensuing from physical, economic, and social problems, deterioration of family relations, and a feeling of having no self-control. A caregiver experiencing a burden may have difficulty in performing many functions including caring for the patient [2]. It was demonstrated that some factors including gender, educational level, and the degree of consanguinity increase the burden of care [2]. Caregivers are a vital component of palliative care and home care. Therefore, the large load of the caregiver endangers the caregiving process.

Home care aims to provide follow-up of a chronic disease and health services in the home environment after the diagnosis and initial treatment [1]. This service is required for patients who prefer to stay at home and continue treatment and care, who can be taken care of by their family and friends at home. These caregivers usually do not receive patient care training at home.

The primary goal in palliative care is to manage the patient's and family's suffering and care process in the best way. Pieces of training on behalf of the right management of this process are important for both the patient and the caregiver. It has been shown that professional support to the family and caregivers is effective in prolonging the patients' survival and reducing the anxiety of caregivers [3].

There are some differences between palliative care and home care, concerning caregiver education. Training of patients and/or caregiver(s) can be provided by certificated nurses in the palliative care unit. The competencies of the caregivers in oral care, wound care, patient positioning, and other relevant topics can be directly observed and corrected by the health workers. Hence, the care burden is expected to decrease in the hospital setting. The effectiveness of home care and palliative care services regarding care burden was not studied before [1-3]. Therefore, we think it is necessary to discuss the effectiveness of the palliative care units in reducing the care burden of patients and their relatives.

In this study, we aimed to compare care burden, anxiety, and depression among caregivers who served for at least three months in palliative care or at home.

Methods

Design and Setting

A cross-sectional study was conducted. Study reporting was done according to the STROBE criteria [4]. Ethical approval of the study was obtained from the Dumlupinar University Medical Faculty (IRB number: 2018/7-08). All participants were informed about the aims and scope of the research. Written informed consent was obtained from each participant.

The study was executed at the Kütahya Evliya Çelebi Hospital, palliative care and home care unit. At the beginning of the study, a total of 1879 patients were registered to the unit. The palliative service operates with eight nurses, of whom one is certified in wound care. Caregivers have to stay with the patients for 24 hours. During the hospital stay, the caregivers are offered free training on patient care. The staff nurses conduct training sessions on topics such as nutrition, positioning, and oral care. Home care units; these are patients who do not want to receive inpatient treatment. Patients in this group are not eligible to be hospitalized or who do not wish to be hospitalized. Certificated health professionals go to their homes for treatment and training of patients, on certain days. The average visit time is about 1-2 times per week. The duration of the visit is an average of half an hour. Training is provided within this period.

Participants

The study was conducted among caregivers of bedridden patients registered to the Kütahya Evliya Çelebi Hospital. The study population consisted of persons responsible for the care of patients registered at home health and palliative units. The inclusion criteria were age ≥ 20 years, literacy sufficient to understand and answer questions, and caregiving during the last three months. Participants with a diagnosis of psychiatric disease and salaried caregivers were excluded. Participants in the palliative care group had to spend three or more days in the palliative care unit.

Of these 95 patients, 93 (97.8%) caregivers accepted to participate in the study. From the remaining patients receiving home care, a random sample of 95 caregivers were invited to join the study as controls, of which 93 (97.8%) responded positively (Figure 1).

Data collection

Data were collected by the same person using the data collection forms by face-to-face application. The data collection tools consisted of the socio-demographic characteristics questionnaire prepared by the researchers, the Zarit caregiver scale, and the Hospital anxiety scale (HAD) [5,6].

Bias

To prevent bias, data collection was done by the same person. Error checking and debugging were made after the data was entered into the computer.

Study size

Using the formula for a finite population of 1879 people, the expected prevalence as 50%, the confidence level as 90%, and the margin of error as 0.6, the minimum required sample size was calculated as 171 people [9]. A total of 186 caregivers were included in the study.

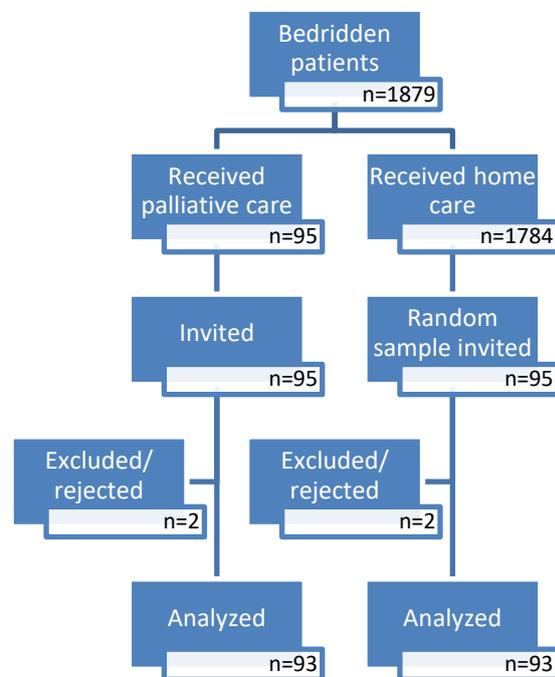


Figure 1: Study flow chart.

Data collection tools

- Socio-demographic scale;** consisted of 12 questions querying socio-demographic characteristics, the presence of comorbidities, medication usage, consanguinity with the caregiver, and the difficulties encountered in care provision. Socio-demographic scale was designed for this study by the researcher according to the literature.
- Zarit caregiver load scale;** Developed by Zarit et al. in 1980 and validated in Turkey by Inci in 2006, the scale consists of 22 questions assessing the effects of caregiving on the life of the individual [5,7]. The items in the scale are generally oriented towards the social and emotional areas. A high score shows high levels of difficulties experienced. The highest score that can be obtained from the five-point Likert-type (0-never, 1-rarely, 2-sometimes, 3-often, 4-almost always) scale is 88. Scores on the scale are interpreted as, 0-20: low load/no load, 21-40: moderate load, 41-60: high load, and 61-88: overload.
- Hospital anxiety and depression scale;** Developed by Zigmond et al. in 1983, and validated in Turkey by Aydemir et al. in 1997, the scale can be easily used in the community and hospital settings. To distinguish psychiatric symptoms from physical disorders, attention was focused on the subjective destruction of mood [6,8].

Statistical methods

Data were presented as mean \pm standard deviation (SD) or median (min-max). The numerical variables were checked for normal distribution using the Kolmogorov-Smirnov analysis. Variables with normal distribution were analyzed with the Independent Samples t-test whereas the Mann-Whitney U test was used for skewed data. The Chi-Square test was used for the comparisons between categorical variables. Linear regression analysis was done to check for independent variables affecting the caregiver burden scores. All statistical analyses were done with the statistical package program SPSS (version 20.0). A *p*-value less than 0.05 was accepted as statistically significant.

Results

Participants

A total of 186 participants (93 home care patient relatives and 93 palliative care patient relatives) were included in the study. From the home care patients, 28 (30.1%) were males, and 65 (69.9%) were females, while from the palliative care patients, 21 (22.6%) were males and 72 (77.4%) were females (Chi-Square = 1.358, *P* = 0.244) (Figure 1).

Descriptive data

The mean age of the participants was 51.44 ± 12.11 years in the home care group and 51.52 ± 13.48 years in the palliative care group ($t=-0.040$, $p=0.968$). There was no significant difference between the two groups concerning the demographic characteristics except for the principal diagnosis and sex of the patients (Table 1).

Table 1. Baseline characteristics of home care and palliative care.

	Home Care mean±SD/n (%)	Palliative Care mean±SD/n (%)	<i>p</i>
Caregiver			
Age	51.44 ± 12.11	51.52 ± 13.48	0.968*
Sex			
Female	65 (69.9)	72 (77.4%)	0.244
Relationship to patient			
Child/spouse	50 (53.8)	59 (63.4)	0.181
Grandson/niece	19 (20.4)	21 (22.6)	
Cousin/other	13 (14.0)	5 (5.4)	
Professional Attendant	11 (11.8)	8 (8.6)	
Marital status			
Married	71 (76.3)	71 (76.3)	0.127
Single	13 (14.0)	19 (20.4)	
Divorced/widow	9 (9.7)	3 (3.2)	
Education			
Primary school	38 (40.9)	35 (37.6)	0.307
Secondary school	38 (40.9)	47 (50.5)	
University	17 (18.2)	11 (11.8)	
Duration of care			
<5 years	70 (75.3)	67 (72.0)	0.618
5 years or more	23 (24.7)	26 (28.0)	
Patient			
Age	71.34±17.96	71.73±12.56	0.865
Sex			
Female	59 (63.4)	44 (47.3)	0.027
Main diagnosis			
Senility	31 (33.3)	30 (32.3)	<0.001
CVA	22 (23.7)	19 (20.4)	
COPD	4 (4.3)	22 (23.7)	
Cancer	6 (6.5)	22 (23.7)	
Other	30 (32.2)	0 (0)	

SD: Standard deviation, CVA: Cerebrovascular accident, COPD: Chronic obstructive lung disease. *Student's t-test.

Outcome data

Mean anxiety and caregiver burden scores were significantly lower among homecare patient caregivers. However, there were no significant differences between the two groups concerning the depression scores (Table 2).

Subgroup analyses were performed by splitting the file according to the sex of the caregivers. Mean caregiver burden scores of the palliative care patients were significantly higher for both genders ($p < 0.001$, Table 2).

Table 2. Comparison of outcome data between the home care and palliative care patient caregivers.

	Home Care		Palliative Care		<i>t/Z</i>	<i>P</i>
	Mean	SD	Mean	SD		
Anxiety	9.02	5.08	10.15	3.79	-2.155*	0.031
Depression	9.62	5.38	9.33	3.43	-0.238*	0.812
Caregiver Burden	29.42	18.84	47.76	16.42	-7.077	<0.001
Men						
Anxiety	9.21	5.42	10.14	3.62	-0.678	0.501
Depression	10.21	5.00	8.62	2.51	-1.440*	0.150
Caregiver burden	26.46	17.57	48.67	19.92	-4.132	<0.001
Women						
Anxiety	8.94	4.93	10.15	3.86	-1.611	0.109
Depression	9.37	5.56	9.54	3.64	-0.525*	0.599
Caregiver burden	30.69	19.35	47.50	15.40	-5.648	<0.001

SD: standard deviation, *Mann-Whitney U test.

Mean anxiety, depression, and caregiver burden scores were not significantly different between the caregivers with less than five years (mean±SD, 9.71±14.64, 9.58±4.73, and 39.11±20.71, respectively) and those with five years or more (mean±SD, 9.24±4.08, 9.18±3.83, and 37.14±17.48, respectively) care (p values 0.537, 0.595, and 0.554, respectively).

The mean anxiety, depression, and caregiver burden scores were not statistically different between caregivers with different educational levels (Table 3). Also, there is no relationship between the mean outcome variables and the marital status of the caregiver (Table 3).

Table 3. The distribution of the mean anxiety, depression, and caregiver burden scores according to the educational levels and marital status of the caregivers.

Education of the caregiver	Anxiety score		Depression score		Caregiver burden	
	Mean	SD	Mean	SD	Mean	SD
Primary school	10.01	4.68	9.89	4.70	37.40	19.91
Secondary school	8.87	4.11	8.86	4.15	39.02	19.56
University	10.64	4.89	10.29	4.90	40.39	21.27
F	2.210		1.567		0.265	
p	0.113		0.212		0.768	
Marital status of the caregiver						
Married	10.01	4.68	9.89	4.70	37.40	19.91
Single	8.87	4.11	8.86	4.15	39.02	19.56
Divorced/widow	10.64	4.89	10.29	4.90	40.39	21.27
F	2.210		1.567		0.265	
p	0.113		0.212		0.768	

SD: standard deviation

A two-way ANOVA analysis with caregiver burden score as dependent and care group and sex of the caregiver as fixed factors revealed the mean caregiver scores were significantly higher among the palliative care patients ($F = 43.059, P < 0.001$). Still, there were no significant differences concerning the sex of the caregivers ($F = 0.265, P = 0.607$), neither was there an interaction between care groups and sex ($F = 0.823, P = 0.365$) (Figure 2).

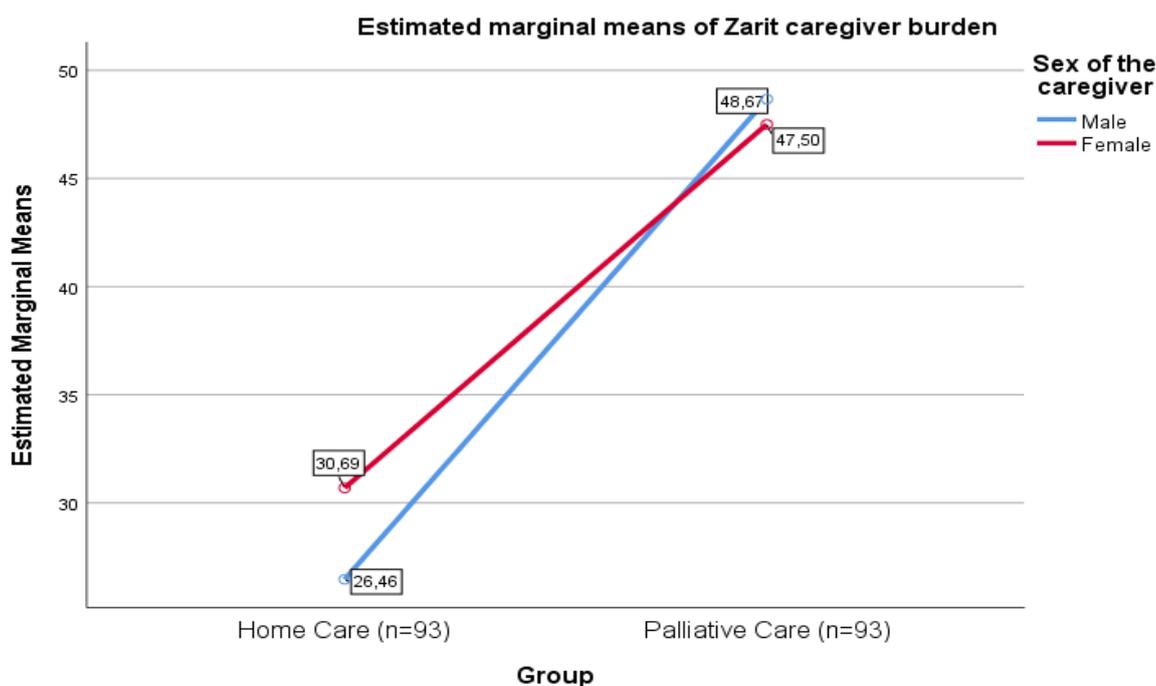


Figure 2. Mean caregiver burden scores compared to the care group and sex of the caregiver.

A linear regression with the caregiver burden scores as dependent and anxiety scores, depression scores, patient age, caregivers' age, and receiving palliative care (dummy variable) as independent variables (R Square=47.2%) demonstrated that the anxiety (Beta=1.442; 95% CI: 0.758-2.125; $p < 0.001$) and depression (Beta=1.113; 95% CI: 0.459-1.767; $p = 0.001$) scores as well as receiving palliative care (Beta=16.015; 95% CI: 11.406-20.623; $p < 0.001$) were independent predictors of the caregiver burden. Caregiver age ($p = 0.800$) and patient age (0.401) were not significant predictors of caregiver burden.

Discussion

Consequently, this study demonstrated significant differences between patients receiving home care and palliative care concerning the burden of the caregivers.

The mean age of the caregivers was 55.35 years, which is similar to other studies in the literature [10,11]. Although there was no difference between the groups regarding patient age, the proportion of women was significantly higher in both home care and palliative care groups. Other studies showed that the caregivers were more likely to be females [10-12]. The reason for higher female gender proportions may be due to women considering giving care as a requirement of their social responsibilities, while men may be unfamiliar with caregiving [10].

In only one out of 93 articles examined in a meta-analysis, it was stated that the care burden of the male caregivers were heavier, and in four articles the gender did not differ concerning care burden, while in the remaining articles, the women perceived higher burden of care [13]. In our

study, the burden of care was significantly higher among men, which was more significant in the palliative care group. In many cultures, caregiving is a task of women. One reason for the high caregiver burden in females is probably that this task is regarded as a simple job of the women [10]. Our study demonstrated the opposite of the literature, which might be related to the sample size [14,15]. However, the level of education did show have any effect on the caregiver burden in our study. The reason for this may be that patient care is a special condition, and anxiety and caregiver burden cannot be reduced if the caregiver is not fully conscious of the patient and his/her health condition.

In a study performed by Ay et al., the age of the caregiver, the degree of consanguinity to the patient, and the duration of care did not show any effect on the caregiver burden [10]. In addition, these variables were independent of anxiety and depression. According to the results, rather than the sociodemographic characteristics of the patient, the different features of the caregivers are related to the burden of care, anxiety, and depression. According to the study of Ay et al., anxiety and depression levels were remarkably high among caregivers. Also in our study, the anxiety levels of caregivers were higher in the palliative care group [10].

In the study of Orak et al., it was determined that the caregiver's duration of care affected the caregiver burden scores [16]. In our study, it was observed that the duration of caregiving increased parallel to the burden of care, anxiety, and depression, but there was no significant difference between the groups.

According to the literature, the stresses of daily life, as well as the difficulties and negative events in life can affect the burden of caregivers. Ivarsson, Sidenvall, and Carlsson stated that the factors causing the burden in family caregivers are complex, including many areas such as daily life activities, occupations, and feelings of social repression [17]. In our study, significant indicators of the caregiver burden were; staying in the palliative care unit, depression, and anxiety.

In our study, while the caregiver burden and anxiety levels of caregivers in the palliative unit were significantly higher than those in-home care group, the difference between depression levels was not significant. There is no study comparing both groups in the literature.

We expected that due to the training received in the palliative care unit, these caregivers would have less burden. However, this anticipation proved invalid. There may be many reasons potentially explaining this outcome. First, in the palliative care unit, patients do not have separate rooms; the patient beds are separated by a curtain. Staying in common rooms may be a factor in increasing the stress of the caregivers. Patients and caregivers may have felt uncomfortable, and the caregivers may be affected by each other during the day. It should not be overlooked that hospital conditions will create extra anxiety for people. Home caregivers are probably more comfortable in terms of their freedom. In addition, patients hospitalized in palliative care may have more serious health conditions and medical support requirements compared to home care patients. Besides, not all nurses who provided training to the caregivers had palliative care certificates; special training for palliative care nurses may be required.

Family caregivers may experience physical, psychological, social, and economic difficulties during the caregiving process [18]. A chronic patient who requires assistance during daily living disturbs the functioning of the family and brings a burden to the family members [2,19]. As a result, the caregiver with unmet needs or burdens may experience difficulties in accomplishing his/her functions including the caregiving role. Determination of the care burden and the search for solutions will contribute to meeting the needs of both the caregivers and patients, and thus, increase the quality of life of both parties [20]. Hence, one aim of palliative care beyond managing the health problems of the sick is, to decrease the burden of the caregiver and strengthen the person by administering training and awareness programs [21].

Limitations

This study has several limitations. First, the study was conducted in a single center with a limited study duration and number of participants. Second, the general limitations of questionnaire studies apply to this work. Additionally, the sex differences between home care and palliative groups require caution when interpreting the results. The burden of care and anxiety of caregivers in our study was quite high. In the palliative care center, it was predicted that receiving inpatient training would reduce the burden of care and anxiety of the caregivers; however, this was not observed.

Conclusion

As a result, we concluded that the caregivers of the patients receiving home health care may be more comfortable. The results of this study emphasize the need for palliative care units to be organized considering patient privacy, to provide psychological and social support to the caregivers, to support and develop specific training activities, and to enable patients and caregivers to feel in an atmosphere more or less resembling their homes. The absence of a study comparing homecare and palliative care makes this research valuable. In future research, measures to be taken to alleviate the burden of care should be determined by examining the burden of care and the affecting factors in larger samples consisting of participants from different socio-cultural and economic backgrounds. A further step of this study should be conducting the same data collection after additional measures to reduce the anxiety and care burden. Our results can be used for developing new strategies to solve prospective problems pertaining to palliative care patients.

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