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Research Article

Caregiving burden and quality of life in individuals caring for palliative care patients

Palyatif bakım hastalarına bakım veren bireylerde bakim yükü ve yaşam kalitesi

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Abstract

Introduction: Palliative care is commonly defined as supportive care given to patients and their relatives in life-threatening situations where therapeutic approaches are insufficient. Diseases requiring palliative care are a process that affects the relatives as well as the patient. This can have economic, physical, psychological, and social impacts. Caregivers are directly affected by numerous factors of care burden. Therefore, the aim of this study was to evaluate the effect of socio-demographic characteristics of caregivers and care burden on quality of life.

Methods: The study was cross-sectional. The study population consisted of the relatives of patients hospitalised in palliative care services in three public hospitals in Samsun between 1 July 2023 and 30 November 2023. No sample calculation was made in the study, and all relatives of patients who agreed to participate in the study were included (n=317). The study data were collected using the "Patient and Caregiver Information Form," the "Caregiving Burden Scale", and the "Quality of Life Scale", which aim to reveal the socio-demographic characteristics of patients and caregivers. Percentage, frequency, correlation, and multiple regression analysis were used in the study.

Results: The mean age of the patients was $\bar{X}=65.48\pm11.81$, 54.6% were male and 63.7% were being treated for neurological diseases. The mean age of caregivers was $\bar{X}=39.8\pm9.16$, 55.2% were female. The mean care burden scale ($\bar{X}=51.78$) and mean quality of life ($\bar{X}=17.77$) were determined in the study. A moderate negative relationship was found between care burden and quality of life ($r=-0.611$, $p<0.001$). According to the results of multiple regression analysis, it was determined that quality of life was affected by age, degree of closeness and caregiving burden ($p<0.05$).

Conclusion: As a result of the study, it was determined that quality of life decreased as the caregiving burden increased.

Keywords: Palliative Care, Caregiving Burden, Quality of Life

Öz

Giriş: Palyatif bakım, yaygın olarak tedavi edici yaklaşımların yetersiz kaldığı yaşamı tehdit eden durumlarda hasta ve yakınlarına verilen destekleyici bakım olarak ifade edilmektedir. Palyatif bakım gerektiren hastalıklar, hasta kadar hasta yakınlarını da etkileyen bir süreçtir. Bu durum, ekonomik, fiziksel, ruhsal ve sosyal boyutlarda etkiler yaratabilir. Bakım verenler, bakım yükünün çeşitli faktörlerinden doğrudan etkilenirler. Bu nedenle bu çalışmanın amacı, bakım verenlerin sosyo-demografik özelliklerinin ve bakım yükünün yaşam kalitesine etkisini değerlendirmektir.

Yöntem: Çalışma kesitsel tiptedir. Çalışmanın evrenini Samsun'da üç kamu hastanesinde 1 Temmuz 2023- 30 Kasım 2023 tarihleri arasında palyatif bakım servislerinde yatan hasta yakınları oluşturmaktadır. Çalışmada örneklem hesaplamasına gidilmeyip çalışmaya katılmayı kabul eden tüm hasta yakınları çalışmaya alındı (n=317). Çalışma verileri hastaların ve bakım verenlerin sosyo-demografik özelliklerini ortaya çıkarmayı amaçlayan "Hasta ve Bakım Veren Bilgi Formu", Bakım Yükü Verme Ölçeği" ve "Yaşam Kalitesi Ölçeği" kullanılarak toplandı. Çalışmada yüzde, frekans, korelasyon ve çoklu regresyon analizi kullanıldı.

Bulgular: Hastaların yaş ortalaması $\bar{X}=65.48\pm11.81$, %54.6'sı erkek ve %63.7'si nörolojik hastalıklar nedeniyle tedavi olmaktadır. Bakım verenlerin yaş ortalaması $\bar{X}=39.8\pm9.16$, %55,2'si kadındır. Çalışmada bakım yükü ölçeği ortalaması ($\bar{X}=51.78$) ve yaşam kalitesi ortalaması ($\bar{X}=17.77$) tespit edildi. Bakım yükü ile yaşam kalitesi arasında negatif yönlü orta düzeyde bir ilişki tespit edildi ($r=-0.611$, $p<0.001$). Çoklu regresyon analizi sonuçlarına göre de yaşam kalitesinin yaş, yakınlık derecesi ve bakım yükünden etkilendiği belirlendi ($p<0.05$).

Sonuç: Çalışma sonucunda bakım yükü arttıkça yaşam kalitesinin düştüğü belirlendi.

Anahtar Kelimeler: Palyatif Bakım, Bakım Yükü, Yaşam Kalitesi

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Key Points

1. Quality of life decreases as caregiving burden increases.
2. The majority of caregivers are in families.

Introduction

Palliative care is commonly defined as supportive care given to patients and their relatives in life-threatening situations where therapeutic approaches are insufficient [1]. World Health Organisation (WHO) defines palliative care services as “an approach that includes practices aimed at preventing and alleviating pain and other problems, pain and other problems in patients and families who face problems arising from life-threatening illnesses, through early diagnosis and perfect evaluation, meeting physical, psychosocial and spiritual needs, and aiming to improve quality of life” [2]. Palliative care services, whose aim is to reduce the symptoms caused by the disease and improve the quality of life by adhering to the cultural values and beliefs of individuals in need of palliative care, are currently offered by many public and private organisations [3-6].

It is estimated that 56.8 million people globally require palliative care, with the majority residing in low- and middle-income countries. Among children, 98% of those in need of palliative care are in low- and middle-income countries. Many adults requiring palliative care suffers from chronic conditions, including cardiovascular diseases (38.5%), cancer (34%), respiratory diseases (10.3%), AIDS (5.7%), and diabetes (4.6%). Apart from these, patients with diseases such as neurological diseases, renal failure, and liver failure need palliative care [2-7,8]. For this reason, with the support of the World Health Organisation (WHO), many countries have allocated some of the beds in their health services to palliative care centres. One of these countries is Türkiye. In 2014, Türkiye put the Directive on the Implementation Procedures and Principles of Palliative Care Services into force. According to the Directive, Palliative Care Services with 6 beds were opened in State Hospitals with 25 beds, especially for the older adult population. In other hospitals, palliative care services/centres can be opened to 25% of the total number of beds according to the number of hospital beds [9].

The disease process requiring palliative caregiving affects the patient as well as the patient’s relatives, especially within the scope of the caregiving burden [10,11]. These effects may be economic, physical, psychological, and social. Caregivers are affected by varied factors of the caregiving burden [12]. These can be listed as economic, physical, psychological, and social factors. Caregivers, especially those who encounter mental fear, anxiety, and loss, are sleep-deprived due to long-term caregiving. As a result of this situation, their stress levels increase, and they are faced with depression. Socially, their close relationships with their own environment may deteriorate due to their limited time. As a result, their quality of life is negatively affected [13-18]. Health perception levels of caregivers are essential for both themselves and the quality of life of the individuals they care for. This study evaluated the effects of socio-demographic characteristics and the caregiving burden of caregivers on quality of life.

Methods

Population and Sample of the Study

The population of the cross-sectional study consisted of relatives of patients treated in palliative care services between July and November 2023 in three public hospitals in Samsun. A face-to-face questionnaire was applied to 359 relatives of patients who agreed to participate in the study between 01.07.2023-30.11.2023. As a result of the study, 317 completed questionnaire forms were analyzed.

Data Collection Tools

The research data were collected by using the “Patient and Caregiver Information Form”, “Caregiving Burden Scale”, and “Quality of Life Scale” to determine the personal characteristics of both patients and caregivers.

Personal Information Form*:* It comprises 13 statements formulated by the researchers regarding the socio-demographic attributes of the caregivers and patients.

Caregiving burden scale*:* The Zarit Burden Interview was developed by Zarit et al. in 1990 to evaluate the caregiving burdens experienced by caregivers of individuals requiring care. This instrument is a 5-point Likert-type scale with 22 items, where the responses range from “0-Never” to “4-Almost Always”. The Turkish validity and reliability of the scale were established by İnci and Erdem in 2006. Scores on the scale can range from 0 to 88, with higher scores indicating greater levels of distress [19,20].

Quality of Life Scale*:* The validity and reliability of the scale developed by the WHO for Turkish populations were assessed by Eser et al. This scale utilizes a 5-point Likert scale for responses, with the endpoints labeled as “1-never ...” and “5-very ...”. The minimum score possible on the scale is 8, while the maximum score is 40. The scale does not contain any reverse-scored items and is unidimensional. It is anticipated that higher scores on the scale correspond to a higher quality of life [21].

Analysing the data

In the study, data analysis was performed with SPSS 26.0 package program. In the evaluation of the data, numbers, frequencies and percentages were used to describe demographic characteristics. Correlation was used to determine the relationship between the scales and multiple regression analysis was used to determine the effect. Statistical significance level was taken as ($p<0.05$).

Ethical approval

Ethical approval for the study was obtained from Alanya Alaaddin Keykubat University Non-Interventional Clinical Research Ethics Committee with the date 06.06.2023 and number 10. Informed consent signed by all participants prior to the survey.

Results

Of the caregivers, 55.2% were female, 74.4% were primary school graduates and 69.4% were spouses/children/grandchildren of the patient. The mean age of caregivers was $\bar{X}$=39.8±9.16 years, patients had needed care for an average of $\bar{X}$=15.9±3.46 years, and caregivers had an average of $\bar{X}$=4.44±1.01 individuals living in their homes (Table 1).

Table 1. Socio-demographic characteristics of caregivers (n=317)

Features	**n**	**%**
Gender		
Female	175	55.2
Male	142	44.8
Age		
20-29	37	11.7
30-39	189	59.6
40-49	44	13.9
50 and above	47	14.8
Education Level		
Primary School	236	74.4
High School	70	22.1
Associate degree	6	1.9
Undergraduate Degree	5	1..6
Income Perception		
Income more than expenditure	25	7.9
Income less than expenditure	292	92.1
Your Degree of Proximity to the Patient		
Spouses	61	19..2
Child	187	58.9
Grandchild	33	10.4
Caregiver	36	11.5
How many years of care (Min- Max-1-25) 15.9±13.46		
How many people do you have at home? (Min- Max-2-8) 4.44±1.01		

The mean age of the patients (min.24-max.90) was $\bar{X}$=65.48±11.81. 54.6% of the patients were male, 94.6% were married, 95.3% were primary school graduates, 63.7% were being treated for neurological diseases. The average number of children of the patients was $\bar{X}$=3.2±1.59 (Table 2).

Table 2. Socio-Demographic Characteristics of the Patients (n=317)

Features	**n**	**%**
Gender		
Female	144	45.4
Male	173	54.6
Age		
20-29	8	2.5
30-39	5	1.6
40-49	18	5.7
50-59	27	8.5
60-69	154	48.6
70-79	79	24.9
80 and above	26	8.2
Marital Status		
Married	300	94.6
Single	17	5.4
Education Level		
Primary School	302	95.3
High School	6	1.9
Associate degree	3	0.9
Undergraduate Degree	6	1.9
Diseases		
Oncological Diseases	48	15.1
Neurological Diseases	202	63.7
Endocrinologic Diseases	67	21.2
How many children do you have? (Min- Max-1-10) 3.2±1.59		

When the scale averages were analysed, it was found that the mean of care burden scale was ($\bar{X}$ =51.78±11.55) and the mean of quality of life was ($\bar{X}$ =17.77±5.54). According to these results, it can be stated that the caregivers had moderate caregiving burdens and low quality of life (Table 3).

According to the results of the correlation analysis, there is a negative, moderate, statistically significant relationship between care burden and quality of life (r=-0.611, p<0.001) (Table 3).

Table 3. Scale Averages, Correlation Analysis Results

Scales	Min	Max	$\bar{x}$	*S*	1	2
1. Caregiving Burden	0	88	51.78	21.55	1	-0.611*
2. Quality of Life	8	40	17.77	5.54		1

*. Correlation is significant at the 0.001 level (2-tailed)

In Table 4, quality of life and factors affecting quality of life were analysed with a multiple regression model. As a result of the analysis, the regression model was statistically significant (F (10,306) =1.921 p<0.05), and the independent variables explained 23.4% of the change in quality of life (R^2 =0.234). According to the results of this analysis, quality of life is affected by care burden, age and degree of closeness (Table 4).

Table 4. Quality of Life and Affecting Factors, Multiple Regression Analysis

Variables	B	SE	β	t	p	Tolerance	VIF
Constant	18.724	1.200		15.602	0.000		
Gender	0.829	0.033	0.074	1.120	0.263	0.700	1.429
Age	1.163	0.740	0.103	1.800	0.040*	0.942	1.062
Education Level	-0.136	0.646	-0.011	-0.178	0.859	0.847	1.180
Income Status	-1.331	0.767	-0.065	-1.076	0.283	0.851	1.174
Degree of Proximity	0.455	1.238	0.037	0.552	0.035*	0.675	1.482
Patient Age	0.057	0.037	0.095	1.544	0.124	0.912	1.674
Patient Gender	-0.110	0.750	-0.009	-0.146	0.455	0.673	1.236
Patient Education Level	0.693	0.771	0.057	0.900	0.369	0.968	1.518
Patient Marital Status	-2.425	1.828	-0.099	-1.327	0.185	0.180	1.611
Caregiving Burden	-0.381	0.014	-0.148	-2.633	0.009*	0.980	1.020
Adjusted R^2 = 0.234 F=1.921 *p< 0.05							
Dependent Variable: Quality of Life							

Variables included in the model: Gender (Female, 30-39 years old, income less than expenses, degree of closeness (son), Patient gender (male), Patient age (60-69), Patient educational status (primary education), Patient marital status (married)

Discussion

Turkish society has a patriarchal structure in terms of its culture, traditions, and customs. For this reason, as in many similar societies, the burden of care usually falls on women. In accordance with this data, 55.2% of the caregivers in the study were women. This rate was 71.3% in the study conducted by Taşkın Eğici et al. (2019), 68.8% in the study conducted by Kaplan and Beydağ (2023) and 65.9% in the study conducted by Şener et al [3-22,23]. The lower rate of female caregivers in this study compared to other studies may be explained by the fact that 54.6% of the patients were male. As in most societies, when men take on the burden of caregiving, which is perceived as women's responsibility in Turkish society, masculinity norms cause more discomfort due to social pressure. It is thought that men have difficulty in meeting both the burden of caregiving and their own needs due to environmental pressure [24]. Therefore, it may be thought that women should do this task in accordance with traditional gender roles.

Spouses, children or grandchildren provide care for 89.6% of patients. The study conducted by Taşkın Eğici et al. (2019) determined that 42.6% of caregivers were children of the caregiver [3]. In the study conducted by Kol and Yılmaz Karabulutlu (2021), it was determined that 70% of the caregivers were the daughters of the patients [25]. In the study conducted by Özmen and Yurttaş (2018), it was determined that 23% of the caregivers were the children of the patient [26]. These results are like the results of the study. It can be said that this result is expected in Turkish society with a traditional family structure.

When the diseases of the caregivers were analyzed, it was determined that 63.7% had neurological diseases, 21.2% had endocrinological diseases and 15.1% had oncological diseases. In the study conducted by Göksel et al. in Türkiye, 35% of the patients were cancer patients, and according to the World Health Organisation data, 38.5% of the patients treated in palliative care centres had cardiovascular disease [8-27]. It can be said that the result of the study is different from these data due to the difference in the region and hospital structure.

Caring for patients in need brings some difficulties for the caregiver. The long duration of care negatively affects the caregiver mentally and socially. The quality of life of the caregiver who is mentally and emotionally exhausted decreases significantly [3-28].

As a result of the study, the mean of the caregiving burden scale was 51.78±11.55, and the mean of quality of life was 17.77±5.54. At the same time, a moderate negative relationship was found between the burden of care and quality of life (p<0.001) (r= -.611). In the study conducted by Cengiz et al. (2021) in Türkiye, the mean caregiving burden was 52.12 ± 16.19, the mean quality of life was 24.23 ± 7.01, and a negative relationship between care burden and quality of life, and in the study conducted by Şener et al. (2022), the mean of caregiving burden was 30.73 ± 9.44, the mean of life satisfaction was 21.25 ± 8.49, and a negative relationship between care burden and life satisfaction was determined [22-29]. In a study conducted by Perpiñá-Galvañ et al. (2019) in a palliative care centre in Spain, the mean burden of caregiving was 52.2±16.1. The same study determined that the participants' mental and physical quality of life scores were also low [17]. The study conducted by Caro et al. (2018) in Brazil found that caregivers had a moderate level of care burden and a moderate level of quality of life [30]. Based on these results, the mean burden of care and quality of life varies according to the characteristics of the centre and the participant profile. In this study, although the burden of care was moderate (41-60 points), quality of life scores was low.

As another result of the study, it was determined that quality of life was affected by caregiving burden, age, and degree of closeness. The study conducted by Barros et al. (2019) determined that quality of life was affected by caregiving burden, age, and educational level [31]. In the study conducted by Abbasi et al. (2020), it was determined that quality of life decreased as the burden of care increased, and quality of life was affected by care burden, marital status, and income status [32]. Comparable results were obtained in many studies conducted in Türkiye [33-36].

Palliative care is a health service that focuses on improving the quality of life and alleviating symptoms, especially for individuals with severe and advanced diseases. This type of care covers the physical, psychological, social, and even spiritual needs of patients and their relatives. However, this process is quite challenging for caregivers of palliative care patients. Caregivers are usually family members or relatives of the patients, and they are under an intense emotional, physical, and financial burden. As this burden increases, caregivers’ own quality of life may significantly decrease. Decreased quality of life may lead to conditions such as depression, anxiety, and burnout. Therefore, during palliative care services, it is of immense importance to support and meet the needs of caregivers as well as the patient. Understanding the difficulties experienced by caregivers and creating support systems for them can increase the effectiveness of palliative care and improve the quality of life of both patients and caregivers.

Limitations

The limitation of the study is that the study was conducted only in three public hospitals in Samsun province within a certain time interval.

Conclusion

As a result, it was determined that quality of life decreased as the caregiving burden increased. This situation affects both the caregiver and the environment negatively. For this reason, to reduce the burden of care, it may be recommended that caregivers share their caregiving burden with other family members, increase social support for caregivers, provide training by health professionals specialised in patient care, and develop social projects to improve the quality of life of caregivers.

Conflict of interest: No conflict of interest was declared by the authors.

Author Contributions	**Author Initials**
SCD Study Conception and Design	YD, ED, SÖ
AD Acquisition of Data	YD, ED, SÖ
AID Analysis and Interpretation of Data	YD, ED
DM Drafting of Manuscript	YD, ED, SÖ
CR Critical Revision	YD, ED, SÖ

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