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ARAŞTIRMA / RESEARCH

Effects of psychoeducation on palliative caregivers' quality of life and skills to cope with stress

Psikoeğitimin palyatif bakım vericilerin stresle baş etme ve yaşam kalitesi üzerine etkisi

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Abstract

Purpose: The aim of this study was to evaluate the effect of psychoeducation on caregivers' coping with stress and quality of life in patients receiving palliative care treatment. **Materials and Methods:** This study was conducted as a quasi-experimental study with a pre- and post-test design. The population of the study comprised the relatives of the patients (N = 40) monitored in the Palliative Care Unit of the Manisa State Hospital during a period of 6 months. All the people in the study population were included in the sample. The data were collected through face-to-face interviews by the researcher using a structured questionnaire. The questionnaire consisted of three parts: "Caregiver Information Form", "Quality of Life Form (SF-36)", "Ways of Coping Questionnaire (WCQ)". **Results:** Psychoeducation given to caregivers participating in the study significantly increased their physical and mental health status and quality of life. The analysis of the mean scores revealed that the participants' physical health improved by 12.2%, mental health status by 20.6% and quality of life by 15.9%. In addition, the difference between their mean pre- and post-test scores was significant. The mean pre-test score (58.83) increased by 15.7% to 69.76 at the posttest. **Conclusion:** In the present study, psychoeducation given to the caregivers improved the quality of life and skills for coping with stress.

Keywords:. Palliative care, caregiver, psychoeducation, psychiatric nursing

Öz

Amaç: Bu araştırmada psikoeğitimin palyatif bakım tedavisi alan hastalara bakım vericilerin stres ile baş etme ve yaşam kalitesi üzerine etkisini değerlendirmek amaçlanmıştır. **Gereç ve Yöntem:** Bu çalışma, ön test - son test deseninde yarı deneysel bir araştırma olarak yapılmıştır. Araştırmanın evrenini, Manisa Devlet Hastanesi Palyatif Bakım Ünitesinde 6 aylık süre içerisinde takip edilen hasta yakınları (N=40) oluşturmuştur. Araştırma, örneklem seçimine gidilmeden evrenin tümü üzerinde gerçekleştirilmiştir. Veriler, yapılandırılmış özellikteki anket aracılığıyla araştırmacı tarafından yüz yüze yöntemle toplanmıştır. Anket, üç bölümden oluşmuştur: "Bakım verici Tanıtım Formu, "Yaşam Kalitesi Formu (SF-36)", "Stresle Baş Etme Ölçeği". **Bulgular:** Araştırmaya katılan bakım vericilere verilen psikoeğitim, palyatif bakım vericilerin fiziksel ve zihinsel sağlık durumları ile yaşam kalitelerini istatistiksel olarak anlamlı ölçüde arttırmıştır. Ortalamalar incelendiğinde; fiziksel sağlık durumunun %12,2; zihinsel sağlık durumunun %20,6 ve yaşam kalitesinin genel olarak %15,9 arttığı görülmektedir. Ayrıca, genel olarak stresle baş etme ön test ve son test ortalamaları arasında anlamlı bir fark olduğu görülmektedir 58,83 olan ön test ortalaması %15,7 artış ile 69,76'ya çıkmıştır. Yani, bakım vericilere verilen psikoeğitim palyatif bakım vericilerin stresle baş etme becerilerini anlamlı olarak arttırmıştır. **Sonuç:** Araştırmada bakım vericilere uygulanan psikoeğitimin yaşam kalitesini ve stresle baş etme gücünü yükselttiği görülmüştür.

Anahtar kelimeler: Palyatif bakım, bakım verici, psikoeğitim, psikiyatri hemşireliği

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INTRODUCTION

Given today's conditions, families of palliative patients face challenges while providing and maintaining the care the patients need in this chronic progressive period due to changes in the social structure of the society, increase in the aging population, chronic nature of the diseases because of the advances in medicine, decrease in the household population and increase in the rate of women who work outside the home, and thus seek professional help[1,2,3]. Palliative care is a kind of philosophy and approach that has emerged to meet the needs of the patients who face a life-threatening disease and their relatives[3].

As defined by The World Health Organization (WHO) in 2002, palliative care is an approach that reduces / prevents suffering from pain and thus improves the quality of life by means of early identification, assessment and treatment of the problems associated with life-threatening diseases[4]. In this statement of the WHO, it is argued that the provision of palliative care in the early stages of the disease is of great importance. Palliative care handles, assesses and tries to solve all the problems of patients and their relatives by considering all the aspects of the problems[4]. Therefore, it includes provision of not only medical services, but also psychosocial and social support[5].

Both the prolongation of average human life expectancy and the increased survival rate have led to an increase in the number of individuals who need healthcare. Along with all the aforementioned issues, the concept of care and caregiver has gained importance to a great extent.[3] The increase in the aging population of societies has brought about an increase in the need for caregivers all over the world[6]. Even though family members assume significant responsibilities to give care to the patient in the family, along with the changes in economic and cultural conditions, caregivers' responsibility and role have become rather difficult[7]. Being a caregiver is a process which cannot be planned or cannot be selected in advance. Therefore, adaptation to this situation occurs after the need for healthcare arises[8].

Because the primary caregiver in the family is at the center of the care receiver's daily life, he/she is the one who often interacts with the care receiver's social environment regarding the disease-related issues. As caregivers' responsibilities and burden due to the provision of care increase, the relationship between caregiving and care receiving can become a one-sided, dependent, intensive and long-term obligation that complicates the caregiver's life[9-12].

In conclusion, caregivers are increasingly recognized as a group at risk within the health care system, and they need professional support such as educational interventions and counseling aimed at improving their quality of life.

The present study was aimed at investigating the effects of psychoeducation on the quality of life of caregivers of patients receiving palliative care and on strategies they used for coping with stress.

MATERIALS AND METHODS

Study Population

This quasi-experimental study with a pre- and post-test design was conducted in the Palliative Care Unit of Manisa State Hospital, located in western Turkey, between February 2017 and September 2018. The relatives of the patients (N = 40) monitored in the Palliative Care Unit of the Manisa State Hospital during a period of 6 months comprised the study population. No sampling method was implemented in the present study. All the people in the study population were included in the sample.

Manisa Celal Bayar University Faculty of Medicine Health Sciences Ethics Committee approval was obtained for this study (date: 26.04.2017, number: 20.478.486), written permission from the Administration of Manisa State Hospital where the study was to be conducted, and written informed consent from the caregivers were obtained.

For the scales used in the research, permission was obtained from the researchers who developed the scale by e-mail. Financial support to carry out the project was received from the Manisa Celal Bayar University Scientific Research Projects Coordination Unit (2018-008).

Instruments

The study data were collected through face-to-face interviews by the researcher using a structured questionnaire. The questionnaire consisted of three parts: Caregiver Information Form, Quality of Life Form (SF-36) and Ways of Coping Questionnaire (WCQ)

Caregiver Information Form

The form developed by the researcher has 16 items questioning caregivers' sociodemographic characteristics, issues related to the patient receiving care and the support caregivers receive while they provide care.

Quality of Life Form (SF-36)

The Quality of Life Form (SF-36) developed by Sullivan et al. to obtain information about the quality of life of individuals was adapted to Turkish in 1999 by Koçyiğit et al. [13,14]. The responses given to the items of the scale are rated on a 2-, 3-, 5- and 6-point Likert-type scale. This multidimensional scale consists of 36 items in eight sub-dimensions (physical functioning, role physical, energy/fatigue, bodily pain, general health perceptions, social functioning, role emotional and mental health) and 2 main dimensions (physical and mental).The higher the score obtained from the scale and its subscales is, the higher the quality of life is.

Koçyiğit et al. conducted a comprehensive study on the reliability of the Turkish version of the Quality of Life Form (SF-36)[14]. In their study, the Cronbach's alpha coefficients calculated separately for all the sub-dimensions ranged between 0.73 and 0.76. On the other hand, in the present study, Cronbach's alpha analysis performed to determine the reliability of the Quality of Life Form (SF-36) demonstrated that the reliability coefficient was 0.955. Therefore, because the coefficient determined was greater than 0.70, the scale was considered reliable.

Ways of Coping Questionnaire (WCQ)

The 66-item WCQ developed by Folkman and Lazarus is the revised form of the original 68-item Ways of Coping Checklist (WCC) developed by the same authors in 1980 to determine the respondents' level of coping with stress. It was adapted into Turkish by Şahin and Durak [15,16]. The Turkish version of the WCQ consists of 30 items in 5 sub-dimensions. However, in the present study 27 items were used in the present study because 3 items (11, 15 and 27) did not meet the validity and reliability criteria, they were excluded from the scale. Responses given to the items are rated on a 4-point Likert-type scale. The higher the score obtained from the overall scale and its subscales is, the higher the level of coping is. The items 1 and 9 (1 → 4, 4 → 1) reverse scored.

In the present study, analyses were performed to determine the validity and reliability of the Ways of Coping Questionnaire (WCQ). The results of the factor analysis performed to determine the validity demonstrated that the Quality of Life Form (SF-36) accounted for 60.62% of the total variance and had a 5-factor structure. Therefore, because the Ways of Coping Questionnaire (WCQ) accounted for more than 50% of the total variance, the scale was considered valid. On the other hand, in the present study, Cronbach's alpha analysis performed to determine the reliability of the Quality of Life Form (SF-36) demonstrated that the reliability coefficient was 0.712.

Data collection

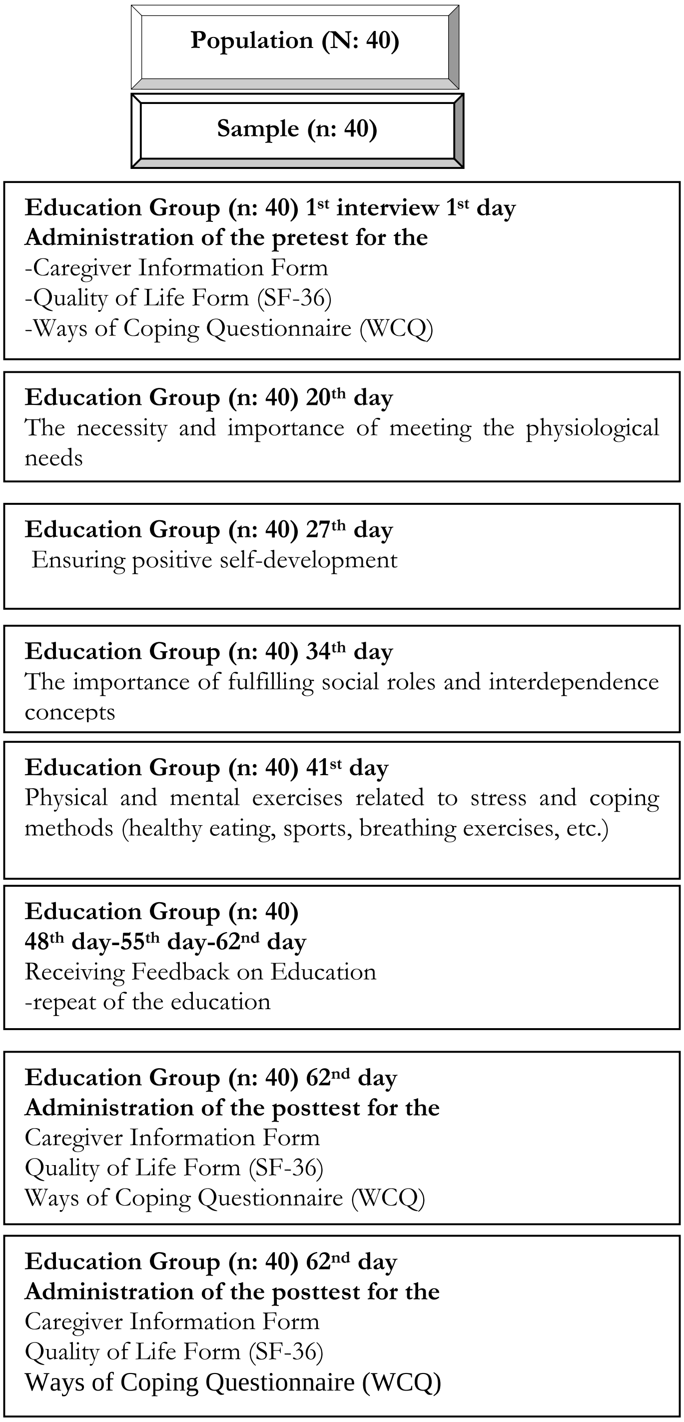
After the psychoeducation group was formed, the first session was held as a meeting session in the multi-purpose hall of the Palliative Care Unit.

The psychoeducation program was started after its aim and general structure were presented to the participating caregivers. Each caregiver was given a psychoeducation booklet after an expert approval was obtained. From the second session on, each caregiver was provided with private education. The caregivers were informed about the features and aim of the palliative care and the disease of the patients to whom they gave care.

During the remaining 5 weeks, all the caregivers were given education on the necessity and importance of the meeting of the physiological needs, development of positive self, importance of fulfilling social roles, concepts of interdependence, physical and mental exercises related to stress and coping methods (healthy eating, sports, breathing exercises, etc.). The psychoeducation program consisted of 40- to 60-minute sessions held once per week for seven weeks. In the last session, the verbal evaluation of the effects of the psychoeducation given on coping with stress and quality of life was performed, and after the posttest was given, the session was closed (Figure 1).

Statistical analysis

While the results obtained in the study were analyzed descriptive statistical methods (arithmetic mean, median, mode, standard deviation, etc.), Nonparametric Mann Whitney U and Paired Sample t-test were used. Statistical significance level was set as $p<0.05$ and 95% confidence interval. The analysis was performed using the SPSS 24.



Population (N: 40)

Sample (n: 40)

Education Group (n: 40) 1st interview 1st day
Administration of the pretest for the
-Caregiver Information Form
-Quality of Life Form (SF-36)
-Ways of Coping Questionnaire (WCQ)

Education Group (n: 40) 20th day
The necessity and importance of meeting the physiological needs

Education Group (n: 40) 27th day
Ensuring positive self-development

Education Group (n: 40) 34th day
The importance of fulfilling social roles and interdependence concepts

Education Group (n: 40) 41st day
Physical and mental exercises related to stress and coping methods (healthy eating, sports, breathing exercises, etc.)

Education Group (n: 40)
48th day-55th day-62nd day
Receiving Feedback on Education
-repeat of the education

Education Group (n: 40) 62nd day
Administration of the posttest for the
Caregiver Information Form
Quality of Life Form (SF-36)
Ways of Coping Questionnaire (WCQ)

Education Group (n: 40) 62nd day
Administration of the posttest for the
Caregiver Information Form
Quality of Life Form (SF-36)
Ways of Coping Questionnaire (WCQ)

Figure 1. Flow chart

RESULTS

The present study conducted to determine the effects of psychoeducation on the quality of life of palliative caregivers and on strategies they used for coping with stress included 40 palliative caregivers. Of the participants, 21 (52.5%) were female and 19 (47.5%) were male. As is seen in Table 1, of the participants, 37.5% were in the ≥40 age group, 35% had upper secondary education, 35% had tertiary education, 57.5% had income equal to expenses, 52.5% were currently working, and 65% were living with their spouses.

As is shown in Table 2, of the caregivers, 80% provided care to first-degree relatives, 10% to close relatives and 10% to distant relatives. While 97.5% of the caregivers received support from family members, 75% received support from relatives, 5% from neighbors, 2.5% from others and 2.5% from nobody. While 97.5% of the caregivers received healthcare support, 95% received psychological / emotional support, 85% received informational support and 37.5% received financial support.

While 60% of the caregivers perceived the support they received as adequate, 37.5% perceived it partly adequate and 2.5% perceived it inadequate (Table 2). Table 3 shows that the participants had difficulties in the following areas: bathing (32.5%), communicating (30%), dressing (25%), mobilization (10%), feeding (5%) and changing position (5%).

According to Table 4, differences between the mean pre-test and post-test scores in terms of physical health status, mental health status and quality of life were significant (p = 0.000 <0.05). In other words, psychoeducation given to the participating palliative caregivers significantly improved their physical and mental health status, and quality of life.

The analysis of the mean scores shows that their physical health improved by 12.2%, mental health by 20.6% and quality of life by 15.9%. According to Table 5, there were increases in all the sub-dimensions after psychoeducation.

The increases in the physical function and role emotional sub-dimensions were not significant (p = 0.058> 0.05 and p = 0.133> 0.05 respectively). In other words, psychoeducation given to the participating palliative caregivers did not have a significant effect on their physical functions and emotional roles.

However, the differences between the mean pre- and post-test scores for the physical role, energy, mental health, social functioning, pain and general health perception sub-dimensions were significant (p <0.05). In other words, psychoeducation given to the participating palliative caregivers led to significant improvements in their physical role, energy, mental health, social functioning, pain and general health perceptions. The increase rates ranged between 11.5% and 27.9%.

Table 1. Sociodemographic characteristics of the participating caregivers

Variable		**n (%)**
Sex	Female	21(52.5)
	Male	19 (47.5)
Age	26-32 years	11 (27.5)
	33-39 years	14 (35.0)
	≥40 years	15 (37.5)
Level of education	Primary	7 (17.5)
	Lower secondary	5 (12.5)
	Upper secondary	14 (35.0)
	Tertiary	14 (35.0)
Monthly income	Income equal to expenses	23 (57.5)
	Income less than expenses	14 (35.0)
	Income more than expenses	3 (7.5)
Current employment status	Employed	21 (52.5)
	Not employed	19 (47.5)
The person(s) lived together	Spouse	26 (65.0)
	Alone	8 (20.0)
	Children	1 (2.5)
	Others	5 (12.5)
Total		40

Table 2. Kinship relationship between the caregiver and the patient, the sources from which the caregiver receives support, type of help the caregiver receives and how adequate the level of the support

Variable		n (%)
How are you related to the person you give care?	1st degree relatives	32 (80.0)
	Close relatives	4 (10.0)
	Distant relatives	4 (10.0)
From whom do you receive help while providing care?	Family members	39 (97.5)
	Relatives	30 (75.0)
	Neighbors	2 (5.0)
	None	1 (2.5)
	Others	1 (2.5)
If you receive support, what type is it?	Healthcare support	39 (97.5)
	Psychological / emotional support	38 (95.0)
	Information support	34 (85.0)
	Financial support	15 (37.5)
How adequate is the level of the support you receive?	Adequate	24 (60.0)
	Partly adequate	15 (37.5)
	Inadequate	1 (2.5)

Table 3. Difficulties encountered by the caregivers while they provided care and the lengths of treatment and care the patients received

Variable		n (%)
In what area(s) did you have difficulty while providing care to your patient?	Bathing	13 (32.5)
	Communication	12 (30.0)
	Dressing up	10 (25.0)
	Mobilization	4 (10.0)
	Feeding	2 (5.0)
	Changing the position of the patient	2 (5.0)

Table 4. General findings regarding the effects of psychoeducation on the quality of life of palliative caregivers

Quality of life Status	$\bar{x}$	Difference %**	t	SD	p*
Physical Health Status (pretest)	67.90	12.2▲	-4.509	39	0.000
Physical Health Status (posttest)	77.30				
Mental Health Status (pretest)	48.70	20.6▲	-4.514	39	0.000
Mental Health Status (posttest)	61.33				
Quality of Life (pretest)	58.30	15.9▲	-4.798	39	0.000
Quality of Life (posttest)	69.32				

* p <0.05 level of significance and 95% confidence interval, Paired Sample t-test; ** The difference between the pretest and posttest scores (▲: increase; ▼: decrease)

Table 6 shows that there was a significant difference between the mean pre- and post-test scores obtained from the Ways of Coping Questionnaire ($t = -11.695$; $p = 0.000 < 0.005$). The mean pre-test score (58.83) increased by 15.7% to 69.76 at the posttest. In other words, psychoeducation given to the palliative caregivers significantly improved their coping skills

The analysis of the sub-dimension scores demonstrated that the mean scores for the self-confident approach, optimistic approach and seeking social support subscales increased significantly ($p < 0.05$). In other words, psychoeducation given to the palliative caregivers significantly improved their self-confident, optimistic and seeking social support approaches.

On the other hand, the mean scores for the helpless approach and submissive approach sub-dimensions decreased significantly ($p < 0.05$). In other words, psychoeducation given to the palliative caregivers significantly reduced their helpless and submissive approaches.

Table 5. Sub-dimension-related findings on the effects of psychoeducation on the quality of life of the participants

Variable	$\bar{x}$	Difference %**	t	SD	p*
Physical Functioning (Pretest)	84.25	2.2▲	-1.955	39	0.058
Physical Functioning (Posttest)	86.13				
Role Physical (Pretest)	53.75	21.1▲	-2.251	39	0.030
Role Physical (Posttest)	68.13				
Role Emotional (Pretest)	43.33	21.2▲	-1.535	39	0.133
Role Emotional (Posttest)	55.00				
Energy (Vitality) (Pretest)	38.75	27.9▲	-9.253	39	0.000
Energy (Vitality) (Posttest)	53.75				
Mental Health (Pretest)	53.50	14.4▲	-5.604	39	0.000
Mental Health (Posttest)	62.50				
Social Functioning (Pretest)	59.23	20.0▲	-4.813	39	0.000
Social Functioning (Posttest)	74.06				
Pain (Pretest)	81.10	11.5▲	-4.826	39	0.000
Pain (Posttest)	91.69				
General Health Perceptions (Pretest)	52.48	17.1▲	-7.149	39	0.000
General Health Perceptions (Posttest)	63.28				

* p <0.05 level of significance and 95% confidence interval; ** The difference between the pretest and posttest scores (▲: increase; ▼: decrease)

Table 6. Effects of psychoeducation on the participating palliative caregivers' strategies to cope with stress

Variable	$\bar{x}$	Difference %**	t	SD	p*
Self-Confident Approach (Pretest)	60.82	25.1▲	-14.391	39	0.000
Self-Confident Approach (Posttest)	81.25				
Helpless Approach (Pretest)	59.71	22.0▼	6.508	39	0.000
Helpless Approach (Posttest)	48.96				
Submissive Approach (Pretest)	57.92	11.1▼	3.262	39	0.002
Submissive Approach (Posttest)	52.13				
Optimistic Approach (Pretest)	55.70	27.8▲	-9.838	39	0.000
Optimistic Approach (Posttest)	77.15				
Seeking Social Support (Pretest)	60.00	32.8▲	-9701	39	0.000
Seeking Social Support (Posttest)	89.31				
Coping With Stress (Pretest)	58.83	15.7▲	-11.695	39	0.000
Coping With Stress (Posttest)	69.76				

* p <0.05 level of significance and 95% confidence interval; ** The difference between the pretest and posttest scores (▲: increase; ▼: decrease)

DISCUSSION

The number of people who experience abnormal declines in physical and cognitive functioning due to aging is increasing day by day. The urgent need to consider the health of caregivers is increasingly recognized as a public health issue.[1,2] Caregivers often experience health-related problems due to discomforts such as stress, physical and psychological fatigue, feelings of overwhelmed caused by their responsibilities to care for their aging relatives[17-20]. Therefore, performing timely interventions is important for caregivers. Caregivers should be aware of both what challenges they are to face after their relatives' diagnosis, and especially of the services that will support them. Then, within the framework of their own routine lives, they will have to develop strategies to better manage stressful situations related to daily care of their patients receiving palliative care and to seek the necessary assistance from social support networks. Finally, caregivers should also know how to communicate with the health personnel when their interventions are needed and to better understand and learn the new environment palliative care patients have to live in. Therefore, the present study has drawn attention to the need for interventions adapted to the needs of caregivers which focus on the development, testing and experimental evaluation of psychoeducation programs aimed at supporting caregivers.

The present study provides data on the impacts of the psychoeducational support program on the quality of life of caregivers. In the present study, the palliative caregivers' coping with stress level was higher than moderate. Our search for studies investigating palliative caregivers' coping with stress levels demonstrated a gap in the literature. However, in Gün's study, coping with stress levels of caregivers of stroke patients were moderate [21] On the other hand, in her study conducted with the caregivers of patients receiving palliative care, Arkın investigated not the caregivers' coping with stress levels but their anxiety and depression levels and found that while their anxiety levels were low, their depression levels were moderate[22]. Wharton's et al. in art interventions study, caregiver burden and depressive symptoms were measured pre- and post program. For participants with pre- and postprogram data, caregiver burden decreased significantly. This intervention helped caregivers creatively communicate their experience and demonstrated efficacy in the improvement of caregivers' psychological well-being[23].

In Özdemir's study conducted to determine the psychosocial problems of the relatives of the patients receiving palliative care, the relatives' anxiety and depression levels were reported to be moderate and higher than moderate respectively[24]. Therefore, the comparison of the results of the present study with those of the aforementioned studies showed that while the stress levels of the caregivers in the present study were not higher than those of the caregivers in other studies, their levels of coping with stress were relatively higher. The results of the present study indicated that the methods caregivers used to cope with stress most were seeking social support approach, self-confident approach and optimistic approach respectively, whereas the methods they used least were the submissive approach and helpless approach. From this aspect, the results of the present study were different from those of the studies performed by Gün and Kopuz [21,25]. In Gün's study conducted to investigate stress coping skills of caregivers of patients with stroke, the methods used most by the caregivers were self-confident, helpless and optimistic approaches respectively[21]. Similarly, in Kopuz's study conducted with nurses, the methods used most were self-confident approach, optimistic approach and helpless approach respectively[24]. While the self-confident approach ranked first in these two studies, it took the second place in the present study after the seeking social support approach. Another striking result was that the helpless approach which was among the first three methods used in the studies by Gün[21] and Kopuz[25] was one of the least used methods in the present study[21,25].

Caregivers of palliative patients do not feel as helpless as do caregivers of stroke patients or nurses. In addition, the quality of life of palliative caregivers in the present study was higher than average. Our search for studies investigating palliative caregivers' quality of life demonstrated a gap in the literature. However, in studies conducted by Erdoğan and Toptaş, the quality of life of the family caregivers of cancer patients was determined very high and moderate respectively[26,27]. These results suggest that the findings in the literature spread in a wide range and that the results of the present study are in the middle of this range.

Another important finding of the present study was that psychoeducation significantly improved the quality of life and the coping skills of the palliative caregivers. Akgün conducted a similar study to investigate the effects of symptom control education given to the caregivers of chemotherapy patients on their anger and stress management levels[28]. In the literature, there are studies indicating that educational interventions have positive effects on patients and their relatives[1,2,29-35].

Psychoeducation given in this study had a positive effect on the caregivers, which indicated that our results were consistent with those of other studies in the literature. The analysis of the sub-dimension scores demonstrated that while the mean scores for the self-confident approach, optimistic approach and seeking social support subscales increased significantly, the mean scores for the helpless approach and submissive approach sub-dimensions decreased significantly. These results are consistent with the findings of the study by Akgün, who stated that after the education given, the self-confident approach and optimistic approach increased whereas the helpless approach decreased[28]. Our study has some limitations. The study was carried out only in a palliative care unit of a hospital. In addition, the data of the research are limited to the characteristics measured by SF-36 and Stress Coping scale. The strength of the study is that no similar study has been found in the literature that demonstrates the quality of life and levels of coping with stress in palliative caregivers of psychoeducation.

In conclusion, psychoeducation given to palliative caregivers improves their coping with stress skills and quality of life. The process of palliative care is a challenging and weary process not only for the care receiver but also for the caregiver. In addition, palliative care is a process which involves services provided not only for patients, but also for the families of patients, namely caregivers. Therefore, palliative care should also include psychosocial and social support services. In the present study, it was determined that psychoeducation, which may be considered as a kind of psychosocial and social support, significantly contributed to the improvement of the quality of life and coping skills of the palliative caregivers. Therefore, psychoeducation activities given to palliative care providers should be expanded and should be more comprehensive. In psychoeducation, emphasis should be placed on gaining caregivers knowledge and skills that will especially increase their role emotional and energy (vitality).

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