

Gastrointestinal Sistem Kanseri Olan Hasta ve Bakımverenlerine Verilen Bireysel Danışmanlığın Yaşam Kalitesi ve Kaygı Düzeylerine Etkisi

The Effect of Individual Counseling Provided to Patients with Gastrointestinal System Cancer and Their Caregivers on Quality of Life and Anxiety Levels

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ÖZ

Amaç: Bu çalışmada pankreas, mide ve safra kesesi kanseri tanısı alan bireylere ve bakım verenlerine verilen bireysel eğitimin yaşam kalitesi ve kaygı düzeylerine etkisinin incelenmesi amaçlandı.

Yöntem: Araştırmada öntest-sontest deneysel tasarım kullanılmıştır. Örneklem, çalışmaya katılacak 30 hasta ve 30 bakım verenden oluşmuştur. Hastalar ve onların bakımverenleriyle iki eğitim oturumu ve son bir takip dahil olmak üzere toplam üç görüşme gerçekleştirildi.

Bulgular: Hastaların Yaşam Kalitesi ve HADS alt ölçek puanları arasındaki fark incelendiğinde, hastaların genel iyilik hali ölçümleri arasında istatistiksel olarak anlamlı bir fark olduğu görüldü ($p < 0,05$). Bakım verenlerin genel yaşam kalitesi ölçeği ve alt ölçeklerinden aldıkları puan ortalamaları arasındaki fark incelendiğinde, psikolojik ve manevi sağlık durumu puanlarının zaman içinde istatistiksel olarak farklılık gösterdiği ortaya çıktı ($p < 0,05$).

Sonuç: Planlanan eğitimin hem hastanın hem de bakım verenin yaşam kalitesini, anksiyete ve depresyon durumunu olumlu yönde etkilediği saptanmıştır. Bu çalışmanın bulguları, özellikle mide, pankreas ve safra kesesi kanserleri olmak üzere kanser yönetimine bakımverenlerinin de katılımını desteklemektedir. Aile odaklı psikoeğitim ve semptom yönetimi programı, bakım verenin yükünü iyileştirmede etkili olduğu bulunmuştur.

Anahtar Kelimeler: Mide, Pankreas ve Safra kesesi kanserleri, Yaşam kalitesi, Anksiyete seviyesi, Bireysel danışmanlık.

ABSTRACT

Objective: This study aimed to examine the effect of individual training given to individuals diagnosed with pancreatic, gastric, and gallbladder cancer and their caregivers on their quality of life and anxiety levels.

Method: The study used pretest-posttest experimental design. The sample consisted of 30 patients and 30 caregivers to participate in the study. Total 60 adults were newly diagnosed with pancreatic, gastric, or gallbladder cancer, completed curative surgery, came to receive preoperative treatment (neoadjuvant). A total of three interviews, including two training sessions and a final follow-up, were held with the patients and their caregivers.

Results: The examination of the difference between the patients Quality of Life and HADS subscale scores indicated that there was a statistically significant difference between the measurements of the general well-being score of patients ($p < 0.05$). The examination of the difference between the caregivers' mean scores from the overall quality of life scale and its subscales revealed that the psychological and spiritual health status scores varied statistically over time ($p < 0.05$).

Conclusion: It was planned training positively affected the quality of life, anxiety and depression status of both the patient, the caregivers. The findings of this study support family participation in cancer management, especially in Stomach, pancreatic,

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and gallbladder cancers. The family-focused dyadic psychoeducation and symptom management programme is effective to improve caregiver burden.

Key words: Stomach, Pancreatic and gallbladder cancer, Caregivers, Quality of life, Anxiety levels, Individual counseling.

1. INTRODUCTION

Cancer is one of the major health problems threatening the health across the world and our country, and it ranks second to cardiovascular diseases among diseases that lead to mortality in Turkey and many countries in the world (1,2). It is an important condition that is difficult to treat and in which patients potentially have to manage many symptoms (1,3). Stomach, pancreatic, and gallbladder cancers are biologically aggressive cancers. These diseases are among the types of cancer that require long-term hospitalization and care, have complex treatment protocols, and need a frequent follow-up of patients and their relatives at home (4). Generally, patients may experience severe pain due to affected retroperitoneal nerves, and fatigue, anorexia, nonspecific gastrointestinal symptoms (nausea, vomiting, steatorrhea, dyspepsia), unidentified weight loss, and mood changes (5,6).

The key point in the treatment of patients with pancreatic, stomach, and gallbladder cancer is to reduce pain and symptom distress and to improve their quality of life as much as possible. In this context, the patient and their family should be provided consultation regularly after the diagnosis, and they should be supported in the management of side effects throughout the treatment process. It is stated that patients who are not well informed about chemotherapy and its side effects fail to control symptoms and experience more severe side effects of the treatment they receive and that uncontrollable symptoms negatively affect the quality of life of the patient and their family (7). Informing patients about treatment and the management of its side effects improves self-care and self-efficacy behaviors, reduces the severity of symptoms, and helps them manage difficulties they encounter in daily life activities more easily (8,9). At the same time, some studies claim that individual training reduces anxiety and depression in patients with cancer and improves their quality of life (10). The information needs of patients with cancer should be structured according to the stage of the disease (pre-diagnosis, diagnostic process, treatment process, and post-treatment), the psychological adjustment process, and individual preferences (11).

Caregivers of patients with cancer take on many complex roles and responsibilities regarding the treatment and care of their relatives. Lack of education and inadequate readiness are among the most important problems of caregivers (12,13). This causes anxiety levels of caregivers to increase and their quality of life to be negatively affected (13,14).

Hypotheses

1-Patients who received individual counseling service had higher anxiety scores before and after chemotherapy and after completing treatments compared to before starting the training.

2-Patients who received individual counseling service had higher quality of life scores before and after chemotherapy and after completing treatments compared to before starting the training.

3-Cancer patient caregivers had higher quality of life scores before, during and after training compared to before starting the training.

4-Cancer patient caregivers had higher preparedness scores before, during and after training compared to before starting the training

Purpose of the research

We consider this study is significant and original in that it assesses the effect of training given to individuals diagnosed with stomach, pancreas, and gallbladder cancer and their caregivers and that there is not a similar study that has been conducted previously in Turkey. This study aimed to examine the effect of individual training given to individuals diagnosed with pancreatic, gastric, and gallbladder cancer and their caregivers on their quality of life and anxiety levels.

2. MATERIAL AND METHODS

Type of the Research

The study used a one-group, pretest-posttest experimental design.

Population and Sample of the Research

The study was conducted in Dokuz Eylul University (DEU) Hospital Chemotherapy Day Treatment Center, and the population consisted of patients with pancreatic, stomach, and gallbladder cancer. Since the number of patients treated in the unit due to pancreatic, gastric, and gallbladder cancer is not known clearly, the sample size of the study was estimated by performing a power analysis on the G-power statistics software package. The sample size was determined as 30 intervention cases based on a statistical power of 0.80 ($1 - \beta$) and an effect size of 0.74 calculated in previous studies at 0.05 significance level (α). The of the study consisted of 30 patients and 30 caregivers who agreed to participate in the study.

Inclusion criteria for the patients; patients who volunteered to participate in the study, were aged between 18 and 70, were newly diagnosed with pancreatic, gastric, or gallbladder cancer, completed curative surgery, came to receive preoperative treatment (neoadjuvant), were scheduled to start neoadjuvant/adjuvant treatment, were literate, with a life expectancy of more than one year, as determined by the physician, spoke Turkish, and had no hearing or sight problems were included in the sample. The exclusion criteria consisted of patients who had unresectable or distant metastases and did not want to participate in the study (6,11).

Inclusion criteria for caregivers; being a caregiver of the 30 caregivers included in the sample, Individuals who could communicate comfortably, had at least primary school education, and were primary caregivers of patients were included in the sample group. The exclusion criteria included individuals who did not want to participate in the study (4,15). The criteria for leaving the study for patients were determined as wanting to leave the study during the process and not being able to continue working due to developing complications. The criteria for leaving the study for caregivers were determined as wanting to leave the study and not being able to continue working due to the general condition of the patient.

The Research Plan

The training to be given in counseling service was developed by reviewing the current literature (4,6,11,15), and the patients and their caregivers were invited to the training sessions. A total of three interviews, including two training sessions and a final follow-up, were held with the patients and their caregivers. All trainings were held in the meeting room in the day treatment unit. Both patients and caregivers were taken to the trainings together. During the trainings, in addition to the trainings, the problems experienced by the patients and caregivers during the process and their problems, if any, were shared. Each training session lasted one hour on average. The training content was designed according to the plan specified below.

The treatment process and preliminary information (Session 1); this interview was held with the patients and their family members before starting treatment (1st follow-up). They were informed about the treatment method, content and process. The educational content of this interview included training on possible complications that may occur due to treatment, such as mucositis, nausea-vomiting, neutropenia, bleeding risk, constipation/diarrhea, and fatigue. Side effects and management of treatment (Session 2); this second interview with the patients and their caregivers was held one day before coming to receive the second chemotherapy treatment (2nd follow-up). During the interview, the participants were trained on pain and anorexia management, alopecia, diarrhea, constipation, susceptibility to infection, bleeding, and anemia. Final training (Session 3); the final interview with the patients and their caregivers was held one day before the last chemotherapy session at the end of the treatment (3rd follow-up). In this session, important points in the training content provided to the patients and their family members were reviewed, and the questions arising were answered face to face.

Data Collection Tools

The data collection tools for patients included an Information Form, the ECOG Performance Status Scale, the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), the Hospital Anxiety and Depression Scale (HADS), and the Satisfaction Scale. The tools for caregivers consisted of an Information Form, the Quality of Life Family Version (QOL-FV), the Preparedness for Caregiving Scale, and the Satisfaction Scale.

The Patient Information Form: The form was developed based on literature to collect socio- demographic data of the patients (4,15). The form includes items about the age, body mass index, educational status, employment status, marital status, disease stage, surgery status, and chemotherapy status of the patients.

The Caregiver Information Form: The form was developed based on literature to collect socio- demographic data of the caregivers (4,15,16,17). The form consists of items questioning caregivers' age, educational status, employment status, marital status, presence of any chronic diseases, number of children, and family history of cancer.

The Hospital Anxiety and Depression Scale (HADS): was developed by Zigmond and Snaith (1983) to diagnose anxiety and depression in individuals with physical disorders. HADS is also used to determine the risk of anxiety and depression in patients with cancer (18). The adaptation of the scale to the Turkey context was carried out by Aydemir (1997). Cronbach's alpha coefficients were 0.85 for the anxiety subscale and 0.77 for the depression

subscale. The item- total correlation coefficients ranged between 0.81 and 0.85 for the anxiety subscale and between 0.73 and 0.77 for the depression subscale (4). In our study, the Cronbach alpha value of the scale was found to be 0.82 for the anxiety sub-dimension and 0.87 for the depression sub- dimension.

The EORTC QLQ-C30 Quality of Life Questionnaire: The form was developed by the European Organization for the Research and Treatment of Cancer Quality of Life. Cronbach's alpha coefficient was found as 0.90. The EORTC-QLQ-C30 Quality of Life Questionnaire has 30 items and three subscales, namely, general well-being, functional difficulties, and symptom control. The first 28 of the 30 items on the scale have a four-point Likert-type rating structure, and the items are evaluated as not at all: 1, slightly: 2, somewhat: 3, and very much: 4. The 29th question of the scale asks the patient to evaluate their health from 1 to 7 (1: very bad and 7: excellent), and the 30th question asks them to assess the general quality of life. Questions 29 and 30 make up the area of general well-being. The content validity and reliability study of the questionnaire was conducted by Beşer and Öz, and Cronbach's alpha value was found as 0.87 (19). In our study, the Cronbach alpha value of the scale was found to be 0.85.

The Quality of Life Family Version (QOL-FV): 37-item questionnaire was developed by Ferrell and Grant to evaluate the quality of life of patients with cancer. The scale consists of four subscales, namely, physical health status, psychological health status, social anxiety, and spiritual well-being. The test-retest reliability result of the study is $r = .89$, and the internal consistency alpha value is $r = .69$ (20). In our country, the validity and reliability study of the scale was carried out by Okçin, and the test-retest reliability coefficient was found as 0.86, and Cronbach's alpha coefficient for the internal consistency was determined as 0.90. The questions on the scale are evaluated between 0 and 10 points, and 10 shows the best, and 0 the worst. Questions 1, 12-15, 17-28, 30, and 31 are inverted. The mean overall and subscale scores are calculated by summing up the scores of the responses to the items of the reletad subscale and dividing the score by the number of items/questions. High scores indicate a high quality of life (21). In our study, the Cronbach alpha value of the scale was found to be 0.87.

The Preparedness for Caregiving Scale: The scale was developed by Archbold & Steward in 1983 based on the viewpoint of the role theory and was revised in 1993 and 2000. Cronbach's alpha value of the scale varies between 0.67 and 0.92. The scale consists of 8 items, which aim to evaluate the physical, emotional, social, and general preparedness of the caregiver. A Likert-type scale was used to rate the items. Each item is scored using one of the 5 options (2). The validity and reliability study of the scale for Turkey context was conducted by Uğur et al. (2017) and Cronbach's coefficient was found as 0.88 and the standardized value α was 0.89 (22). In our study, the Cronbach alpha value of the scale was found to be 0.82.

Data Collection

The study data were collected from the patients using the face-to-face interview method. The frequency of administration of the data collection tools is given in Table 1.

Study Variables

Independent variables included the patient's age, cancer diagnosis, stage of cancer, medications used, presence of chronic disease and the caregiver's age, gender, monthly income, employment status, presence of a disease, and the number of children.

Dependent variables included the mean HADS scale scores of both the patient and the caregiver, the EORTC QLQ-C30 quality of life scale score, the caregiver quality of life scale score, the preparedness for caregiving scale score.

Table 1. The Frequency of Administration of The Data Collection Tools.

Sessions	Patient	Caregiver
1. Follow-up	- The Patient Information Form - The EORTC QLQ-C30 Quality of Life Questionnaire - HADS Scale	- The Caregiver Information Form - The Quality of Life Family Version (QOL-FV) - The Preparedness for Caregiving Scale
2. Follow-up	- The EORTC QLQ-C30 Quality of Life Questionnaire - HADS Scale	- The Quality of Life Family Version (QOL-FV) - The Preparedness for Caregiving Scale
3. Follow-up	- The EORTC QLQ-C30 Quality of Life Questionnaire - HADS Scale	- The Quality of Life Family Version (QOL-FV) - The Preparedness for Caregiving Scale

Data Analysis

The study data were analyzed using the SPSS (Statistical Package for Social Sciences) for Windows 25.0 software package. Frequency, percentage, minimum, maximum, median, rank averages, and mean and standard deviation values, which are among the descriptive statistics, were used in the analysis of the data. Data collected using questionnaires with Likert-type scales do not often have a normal distribution. The normality of the data was examined with the Q-Q Plot. The data from the three administration of the caregiver quality of life scale was observed to have a normal distribution. Parametric tests were used for scales that had a normal distribution, and nonparametric tests were used for those that did not.

The Wilcoxon test was used to determine whether the two dependent groups differed in terms of quantitative variables. To test whether more than two dependent groups had differences, the Friedman test, a nonparametric test, was employed, whereas the analysis of variance, which is a parametric test, was utilized in repeated measures. The multiple comparison test was employed to reveal the group that caused the difference. Reliability analysis was conducted to test the reliability of the scales. The reliability coefficients of the scales and their subscales varied between 0.652 and 0.895. Accordingly, the scales were found to be reliable. The level of significance was taken as $p < 0.05$.

Ethics of the Study

At the outset, written approvals were obtained from Dokuz Eylül University Non-Invasive Ethics Committee (Issue:2019/12-43), Dokuz Eylül University Hospital Chief Physician, and Medical Oncology Department to conduct the study. Since the study did not include an interventional design on the patient, the ethics committee of the study was taken from the non-interventional ethics committee. To collect the data, the patients and caregivers were informed about the purpose and method of the study, and their written and verbal consents were obtained by the researchers.

3. RESULTS

The distribution of the patients and caregivers in the study according to their general characteristics is given in Table 2 in detail. Although not shown in the table, according to the sociodemographic data of the caregivers in the study, the mean age was 55.83 ± 10.98 , 50.0% were male, 50.0% were married, 36.7% were primary school graduates, 36.7% had an undergraduate degree, 70.0% had children, 50.0% were unemployed, 70.0% had equal income and expenses, 83.3% had social insurance, 56.7% were looking after their spouse as the patient, 66.7% lived in the same house with the patient, cancer was diagnosed for 14 months or more among 33.3%, 93.3% knew the diagnosis, 50.0% received assistance, and 43.3% gave care to their patients for 0-3 months and 43.3% for 4-6 months. It was determined that 43.33% of the caregivers were between the ages of 62-82 and high school graduates, 55.2% were female, 93.13% were married and 60.67% were employed. In addition, it was determined that 60% of the caregivers had no family history of cancer and 73.33% had no chronic disease. It was determined that the majority of those with chronic diseases had hypertension.

The examination of the difference between the patients' Quality of Life and HADS subscale scores indicated that there was a statistically significant difference between the measurements of the general well-being score of patients ($p < 0.05$). Multiple comparison test was administered to find out the group that caused the difference, and it was found that there was a statistically significant difference between the mean ranks of the 2nd and 3rd follow-ups and that the mean general well-being score was higher in the 3rd follow-up than that of the 2nd follow-up ($p < 0.05$). In addition, a statistically significant difference was found between the dyspnea, diarrhea, and physical function scores ($p < 0.05$). Multiple comparison test was employed to find out the group that caused the difference. As a result, dyspnea was found to show a statistically significant difference in terms of the mean ranks of the 1st and the 3rd follow-ups ($p < 0.05$). Accordingly, it was found that the mean dyspnea score of the patients was higher in the 3rd follow-up compared to the 1st follow-up. The examination of mean overall HADS and subscale scores indicated that there was a statistically significant difference between the measurements of anxiety and depression (HADS) scores of the patients ($p < 0.05$). Multiple comparison test was employed to find out the group that caused the difference. As a result, a statistically significant difference was found between the mean anxiety and depression scores obtained in the 1st and 3rd follow-ups and those obtained in the 2nd and 3rd follow-ups ($p < 0.05$). Accordingly, the mean anxiety and depression scores of the patients were higher in the 1st follow-up than the 3rd follow-up and higher in the 2nd follow-up than the 3rd follow-up (Table 3).

Table 2. Distribution of Patients and Their Caregivers According to General Characteristics.

Specifications	General Specifications	Patients		Caregivers	
		n	%	n	%
Average age ($x \pm SS$)		(67.59±10.46)		(69.57±10.56)	
Age	20-40	3	10.3	5	16.67
	41-61	13	44.8	12	40.0
	62-82	13	44.8	13	43.33
Gender	Woman	13	44.8	16	55.2
	Male	16	55.2	13	44.8
Marital status	Married	27	93.1	27	93.13
	Single	2	6.9	2	6.67
BMI average ($x \pm SS$)	(23.87±3.83)				
BMI	<18.5	3	10.3		
	18.5-24.9	18	62.1		
	25-29.9	6	20.7		
	≥30	2	6.9		
Education status	Illiterate	2	6.9	4	13.33
	Primary school graduate	13	44.8	5	16.67
	Secondary Education	11	37.9	13	43.33
	High education	3	10.3	8	26.67
Working status	Yes	9	31.0	20	60.67
	No	20	69.0	10	39.33
Living with the person	There is	28	96.6		
	No	1	3.4		
Smoke	No	30	100.0		
	Yes	2	6.9		
Alcohol	No	28	89.7		
	Yes	2	6.9		
Genetic presence of cancer	Yes	13	44.8	12	40.0
	No	16	55.2	18	60.0
Cancer protocol	Cisplatin+Degramon	2	6.9		
	Ifosfamid+Adriamisin+Mesn	2	6.9		
	Oksaliplatin+Doksetaxel	5	17.2		
	Karboplatin+5FU+Leukovori	4	13.8		
	Elaxatine+5FU	4	13.8		
	Gemcitabin+Paklitaxel	3	10.3		
	Oxaliplatin+İrinotekan+Leuk	4	13.8		
	Oxaliplatin+5FU+Folinikasit	5	17.2		
Medication	Yes	15	51.7		
	No	14	48.3		
Presence of chronic disease	Yes	15	51.7	8	26.67
	No	14	48.3	22	73.33
Chronic disease type	DM	4	26.7	4	26.80
	Hypertension	5	33.3	2	36.66
	Asthma	4	26.7		
	Hypo-Hyperthyroidism	2	13.3	2	36.66
Tumor place	Gastric cancer	26	86.7		
	Pancreatic cancer	3	10.0		
	Gallbladder cancer	1	3.3		

Table 3. Comparison Of Patients' Quality Of Life And HADS Scale Sub-Dimension Scores

Life quality Scale Sub-Dimensions	Measurements			Test Value		
	1.Follow-up (Before chemotherapy) Median(min/max)/ Rank Avg.	2.Follow-up (During chemotherapy treatment) Median(min/max)/ Rank Avg.	3.Follow-up (After chemotherapy) Median(min/max)/ Rank Avg.	X ²	p	Multiple comparison
General well-being	66.67 (41.67-100.00) / 1.90	66.67 (8.33-91.67) / 1.63	83.33 (8.33-100.00) / 2.47	12.419	0.002	2<3
	SYMPTOM CONTROL					
Tiredness	22.22 (0.00-66.67) / 2.02	33.33 (0.00-100.00) / 2.02	22.22 (0.00-77.78) / 1.97	0.063	0.969	-
Nausea and vomiting	0.00 (0.00-83.33) / 1.88	16.67 (0.00-66.67) / 1.92	33.33 (0.00-66.67) / 2.20	2.477	0.290	-
Pain	16.67 (0.00-83.33) / 2.05	8.33 (0.00-83.33) / 1.73	33.33 (0.00-83.33) / 2.22	4.429	0.109	-
Dyspnoea	0.00 (0.00-33.33) / 1.72	0.00 (0.00-66.67) / 1.87	33.33 (0.00-100.00) / 2.42	14.382	0.001	1<3
Sleeping disorder	33.33 (0.00-66.67) / 1.92	33.33 (0.00-100.00) / 2.02	33.3 (0.00-133.33) / 2.07	0.560	0.756	-
Loss of appetite	33.33 (0.00-66.67) / 2.10	33.33 (0.00-66.67) / 1.93	33.33 (0.00-66.67) / 1.97	0.700	0.705	-
Constipation	0.00 (0.00-66.67) / 1.87	33.33 (0.00-66.67) / 2.05	33.33 (0.00-66.67) / 2.08	1.089	0.580	-
Diarrhea	0.00 (0.00-66.67) / 1.73	0.00 (0.00-66.67) / 1.88	33.33 (0.00-100.00) / 2.38	14.136	0.001	1<3
Financial problems	0.00 (0.00-100.00) / 1.82	33.33 (0.00-66.67) / 2.05	33.33 (0.00-66.67) / 2.13	2.771	0.250	-
	FUNCTIONAL STATUS					
Physical functions	79.17 (16.67-100.00) / 1.72	75.00 (8.33-100.00) / 1.98	75.00 (50.00-100.00) / 2.30	6.463	0.039	1<3
Role functions	83.33 (33.33-100.00) / 2.12	75.00 (16.67-100.00) / 2.10	66.67 (33.33-100.00) / 1.78	3.256	0.196	-
Emotional state	66.67 (16.67-100.00) / 1.77	75.00 (50.00-100.00) / 2.03	79.17 (16.67-100.00) / 2.20	3.510	0.173	-
Cognitive state	91.67 (33.33-100.00) / 2.12	83.33 (33.33-100.00) / 2.18	83.33 (16.67-100.00) / 1.70	5.429	0.066	-
Social situation	66.67 (0.00-100.00) / 2.03	83.33 (33.33-100.00) / 1.97	83.33 (16.67-100.00) / 2.00	0.077	0.962	-
HADS						
Scale Sub-Dimensions						
Anxiety	10.00 (5-15) / 2.30	10.50 (5-17) / 2.27	5.00 (3-14) / 1.43	15.927	0.000	3<1; 3<2
Depression	8.50 (3-12) / 2.10	10.50 (4-14) / 2.43	6.00 (3-14) / 1.47	15.363	0.000	3<1; 3<2
HADS	19.50 (10-25) / 2.28	20.50 (9-30) / 2.37	11.00 (7-27) / 1.35	20.482	0.000	3<1; 3<2

Table 4. Difference Between Caregivers Readiness Scores Before and After Training.

Variable	Groups	N	Average Rank	Z	p
Ready to care	Decreasing	5	8.10	-3.582	0.000
	Incremental	22	15.34		
	Equal	3			

A statistically significant difference was found between the preparedness for caregiving scale scores before and after the training ($p < 0.05$). Accordingly, the scores of the caregivers' preparedness for caregiving were found to increase after the training (Table 4).

Table 5. Comparison Of Caregivers' Quality Of Life Scale And Sub-Dimensions.

Scale Sub- Dimensions	Measurements			Test Value		
	1.Follow-up (Before chemotherapy)	2.Follow-up (During chemotherapy)	3.Follow-up (After chemotherapy)	F	p	Multiple comparison
	$\bar{X} \pm SS$	$\bar{X} \pm SS$	$\bar{X} \pm SS$			
Psychological and spiritual health status	75.60±15.13	66.70±10.49	72.97±9.19	5.374	0.018	2<1; 2<3
Physical health status	54.27±7.57	56.40±7.28	58.40±8.24	3.305	0.044	1<3
Diagnostic approach to state Support and economic impact	49.73±7.75	48.33±7.53	50.67±6.15	1.188	0.312	-
	26.00±5.09	27.63±4.05	24.40±4.92	5.681	0.009	3<2
Total quality of life	205.60±24.37	199.07±21.20	206.43±22.11	1.851	0.174	-

1.Follow-up: Before-chemotherapy 2. Follow-up: While-chemotherapy 3 .Follow-up: After-chemotherapy

The examination of the difference between the caregivers' mean scores from the overall quality of life scale (QOL-FV) and its subscales revealed that the psychological and spiritual health status scores varied statistically over time ($p < 0.05$). Multiple comparison test was employed to find out the group that caused the difference. As a result, a statistically significant difference was found between the mean psychological and spiritual health status scores obtained in the 1st and 2nd follow-ups and between scores obtained in the 2nd and 3rd follow-ups ($p < 0.05$). Accordingly, the mean psychological and spiritual health status scores of the caregivers were higher in the 1st follow-up than the 2nd follow-up and higher in the 3rd follow-up than the 2nd follow-up. It was determined that the mean physical health status score of the caregivers, which is one of the mean scores of the quality of life scale (QOL-FV), showed a statistically significant difference between the follow-ups ($p < 0.05$). Multiple comparison test was employed to find out the group that caused the difference. As a result, a statistically

significant difference was found between the mean physical health status scores obtained in the 1st and 3rd follow-ups ($p < 0.05$). Accordingly, it was found that the mean physical health status score of the caregivers was higher in the 3rd follow-up than the 1st follow-up.

While the mean approach to diagnosis score of the caregivers, which is one of the mean scores of the quality of life scale (QOL-FV), did not vary statistically over time ($p > 0.05$), it was found that the support and economic impact score varied statistically over time ($p < 0.05$). Multiple comparison test was employed to find out the group that caused the difference. As a result, it was found that the mean support and economic impact score obtained in the 2nd and 3rd follow-ups was higher. The quality of life score was determined to not change statistically over time ($p > 0.05$). The examination of the patient and caregiver satisfaction in the study indicated that mean patient and caregiver satisfaction scores were 7.10 ± 0.92 and 7.27 ± 0.74 , respectively (Table 5).

4. DISCUSSION

We consider this study is significant and original in that it assesses the effect of training given to individuals diagnosed with stomach, pancreas, and gallbladder cancer and their caregivers and that there is not a similar study that has been conducted previously in Turkey.

In this study, the post-training mean scores obtained from the physical functions, general well-being, dyspnea, and diarrhea subscales of the quality of life scale were higher in the last follow-up compared to those of the first follow-up. Some studies show that patients who are not informed about the cancer treatment process and its side effects cannot manage their symptoms successfully and experience severe side effects of the treatment they receive. When the symptoms cannot be controlled, the quality of life of the patient and their family is negatively affected (8, 10, 12). Similar to the results of our study, Belgacem et al. (2014) found that training given to cancer patients positively affected physical functions. Informing patients about treatment and management of side effects improves self-care behaviors, reduces the frequency and variety of symptoms, and facilitates the process of adjustment to treatment (5). This process should be evaluated dynamically, the adaptation styles of the patients to the process and the factors that negatively affect the process should be determined, and the necessary measures should be structured (9). The second hypothesis in our study was accepted.

Patients' response to cancer depends on their beliefs, value systems, and their response to stress. The individual diagnosed with cancer realizes that the coping mechanisms used to survive and solve their problems until that day are not sufficient. Therefore, they experience emotional, cognitive, and physical weakness and emotions, such as anxiety, helplessness, fear of death, and depression. In individuals who experience such an affective process are also very sensitive to external influences, and therefore the therapeutic approaches of physicians, nurses, psychologists, social workers, and other healthcare professionals to the patient gain importance (23,24). In a study conducted on patients with metastatic gastrointestinal cancer, it was reported that patients commonly experienced severe symptoms of dysphagia, vomiting, pain, and nausea, resulting in more anxiety and depression (25). In the present study, the mean post-training anxiety and depression scores of the patients were found to be lower. Our findings were consistent with the literature (10). Ugalde et al. (2017) found that many supportive/motivational interventions involving training significantly decreased anxiety and depression scores (24). In

the literature, it is stated that especially patients and their caregivers want to receive customized information as much as possible (26,27,28). The first hypothesis in our study was accepted.

One of the most important needs of caregivers is that they begin to care for their patients without being prepared to do so. Since the focus of the health care system is to treat and care for the patient, the caregiver's caregiving process may have been neglected in the process. In this study, the post-training preparedness for caregiving score of the caregivers was found to increase. Owoo et al. (2020) and Muliira et al. (2019) reported that lack of training and preparedness of caregivers was the most important problem in their study (16,26). In this process, caregivers' preparedness for caregiving and their ability and desire to manage the care available to their patients are not often evaluated, and they try to meet the needs of their patients without getting enough information and guidance from the healthcare system while giving care to their patients. This increases the anxiety and concern levels of caregivers (13,14, 25,29). Some studies show similarities with our results, emphasizing that informing caregivers about the process will reduce their stress, caregivers will perform their caregiving task more effectively, and that their preparedness for their situation will increase (25). Since the focus of the health care system is to treat and care for the patient, the caregiver's caregiving process may have been neglected in the process. This neglect has been studied by many researchers. Literature indicates that healthcare professionals do not spend enough time informing them about certain aspects of an illness, such as symptoms and side effects. This can lead to caregiver distress and less ability to cope with uncertainty and problem solve (30), thus having a negative impact on the patient. This highlights the importance of preparing caregivers for patient compliance. The third hypothesis in our study was accepted.

In this study, the post-training physical health status and psychological and spiritual health status scores of the caregivers were found to increase (Table 5). Giving care to patients with cancer causes changes in the daily lives of family members, conflicts related to their social roles, the tension in marital and family relations, limitations in their daily activities, deterioration of their health status, and economic losses and thus negatively affects their quality of life. Many studies have found that the quality of life of caregivers of patients with cancer is low (28,29). Therefore, individuals who give care to patients with cancer need support to improve their care skills. It has been determined that training to be given (nutritional support, nursing care, providing comfort, or improving symptom management skills) increases the quality of life of caregivers and reduces the burden of providing care (8,16). These studies support the results of our study. In the study, the mean post-training satisfaction scores of the patients with cancer and their caregivers were found to be above average. This result was consistent with that of Belgacem et al. (2014) (5). Caregivers reported feeling sad, 'helpless' and experiencing guilt when patients' symptoms persisted despite caregivers' efforts to control them. They also reported that this guilt arose when patients experienced side effects of treatment. Informal caregivers also highlighted that they felt anxious when patients were unwilling/unable to continue with a treatment plan (31). Studies have highlighted a correlation between levels of anxiety or depression between patients and their informal caregivers (32). Our study found that the reduction in anxiety levels due to counselling provided to patients also led to a reduction in the psychological distress subscales in the caregivers' follow-up (Tables 3,5). The findings are similar to the literature. The fourth hypothesis in our study was accepted.

5. CONCLUSION

In conclusion, it was determined that patients and caregivers needed training on areas, such as the management of symptoms, the disease, and the treatment process, the training to be given on management should be a planned training and that the planned training positively affected the quality of life and anxiety and depression status of both the patient and the caregiver and increased satisfaction with care. According to these results;

- ✓ structuring individual counseling services for cancer patients and their caregivers in this population and effective home follow-up are important.
- ✓ it may be suggested to work with a large patient group related to this population in the future in order to obtain more structured information

Limitations

Since the study is limited to the sample, it is not possible to generalize it.

Ethical Considerations

Ethical approval for the conduct of this study was obtained from the Dokuz Eylül University Non-Interventional Research Ethics Committee (Decision No: 2019/12-43).

Conflict of Interest Statement

No potential conflicts of interest relevant to this article exist.

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