

Symptoms, performance status and quality of life in cancer patients receiving palliative care

Palyatif bakım alan kanser hastalarında semptomlar, performans durumu ve yaşam kalitesi

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ABSTRACT

Aim: The aim of the study was to describe the symptoms experienced by cancer patients receiving palliative care, patients' performance and the effects on their quality of life.

Materials and Methods: This is a descriptive study and was conducted with 106 patients admitted to palliative care unit at a university hospital in Izmir, located in the west of Turkey, between December 2019 and April 2020. For data collection, Patient Information Form, "Eastern Cooperative Oncology Group (ECOG) Performance Status Scale", "Edmonton Symptom Assessment Scale (ESAS)" and "Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) Scale" were applied. For data analysis, descriptive statistics, Chi-square test, Kruskal Wallis Analysis and linear regression analysis were used.

Results: Patients reported that the most common symptoms experienced were fatigue, sense of being unwell, anxiety, sadness (depression) and pain. According to the regression analysis, there was a statistically significant difference between the total quality of life scores of the patients and pain, fatigue and nausea from the patients' ESAS symptoms. The quality of life scores were significantly lower in the patients who were hospitalized, had an advanced disease stage, did not have metastases or did not know their metastases status and had a low performance status ECOG. There was a statistically significant difference between patients' ECOG performance status and quality of life.

Conclusion: Patients have multiple symptoms and poor quality of life. Our findings support the importance of symptom assessment and management to improve quality of life.

Keywords: Cancer, quality of life, palliative care, symptoms.

ÖZ

Amaç: Çalışmanın amacı, palyatif bakım alan kanser hastalarının yaşadıkları semptomları, hastaların performanslarını ve yaşam kalitelerine olan etkilerini tanımlamaktır.

Gereç ve Yöntem: Tanımlayıcı bir çalışma olup, Türkiye'nin batısında yer alan İzmir'de bir üniversite hastanesinin palyatif bakım ünitesine başvuran 106 hasta ile Aralık 2019-Nisan 2020 tarihleri arasında yapılmıştır. Veri toplama için Hasta Bilgi Formu, "Doğu Kooperatif Onkoloji Grubu (ECOG) Performans Durum Ölçeği", "Edmonton Semptom Değerlendirme Ölçeği (ESAS)" ve "Kronik Hastalık Tedavisinin Fonksiyonel Değerlendirmesi-Palyatif Bakım (FACIT-Pal) Ölçeği" uygulandı. Verilerin analizinde betimsel istatistikler, Ki-kare testi, Kruskal Wallis Analizi ve lineer regresyon analizi kullanılmıştır.

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Bulgular: Hastalar en sık yaşadıkları semptomların yorgunluk, kendini iyi hissetmeme, kaygı, üzüntü (depresyon) ve ağrı olduğunu bildirmiştir. Regresyon analizine göre hastaların toplam yaşam kalitesi puanları ile hastaların ESAS semptomlarından ağrı, yorgunluk ve bulantı arasında istatistiksel olarak anlamlı fark vardı. Hastanede yatan, hastalığı ileri evrede olan, metastazı olmayan veya metastaz durumunu bilmeyen ve performans durumu ECOG düşük olan hastalarda yaşam kalitesi puanları anlamlı olarak daha düşüktü. Hastaların ECOG performans durumu ile yaşam kalitesi arasında istatistiksel olarak anlamlı bir fark vardı.

Sonuç: Hastaların birden fazla semptomu ve düşük yaşam kalitesi vardır. Bulgularımız, yaşam kalitesini iyileştirmek için semptom değerlendirilmesi ve yönetiminin önemini desteklemektedir.

Anahtar Sözcükler: Kanser, yaşam kalitesi, palyatif bakım, semptomlar.

INTRODUCTION

Cancer remains a major international public health problem. In 2040, it is expected that 30.2 million people will live with cancer, most of them from low and middle-income countries (1). Patients with cancer can receive palliative care from the time they are diagnosed, during treatment, and at any time after. Palliative care is an integral component of comprehensive care for oncology patients and focuses on the philosophy of improving the quality of life of patients living with a serious illness. It provides this process by helping patients cope with their illness and treatment side effects, supporting them in the process of realisation and helping to alleviate symptoms (2, 3). Effectively coping with symptoms is very important in the palliative care of cancer patients. While studies conducted around the world report that cancer patients frequently use meditation, relaxation, hypnotherapy, various vitamins and herbal medicines, it is reported that various complementary and integrative approaches are used in Turkey, especially herbal medicine and prayer/religious practices (4-7).

Holistic care in palliative care patients is possible by considering not only the current chronic disease state, but also the activity levels and symptoms of the patients. Systematic reviews and guidelines indicate that the holistic care approach is important in palliative care, and this care is changed to be possible with effective symptom management. However, knowing which symptoms affect quality of life and how it affects it, is the first step in planning holistic care. A person-centered approach to identify holistic care priorities begins with addressing patients' quality of life including unaddressed or suboptimally treated symptoms. In the literature, it is stated that symptom frequency has a significant effect on health-related quality of life and patient satisfaction (8, 9). Inadequate management of

symptoms seen in all cancer patients, especially those with advanced stage cancer, adversely affects the daily activity performance and quality of life of every patient (9, 10).

Symptoms and quality of life were assessed among patients with cancer and we hypothesized that cancer patients would experience a lot of symptom burden and low quality of life. In addition, we considered that variables such as age, performance status, presence of additional chronic disease and disease stage would also affect the quality of life. The aim of the research was to describe the symptoms experienced by cancer patients receiving palliative care, patients' performance and the effects on their quality of life.

MATERIALS and METHODS

Study Design and Participants

This descriptive study was conducted with adult cancer patients admitted to a palliative care unit in a university hospital in Izmir, in west Turkey, between December 2019 and April 2020. There are 24 patient beds in the palliative care unit and oncology service. There is also a separate 72-bed department where oncology and palliative care patients receive outpatient care service.

Patients with cancer who agreed to participate, and those who were receiving inpatient or outpatient treatment in the palliative care unit were included in the study. Patients who had not been diagnosed with cancer, under the age of 18, patients were not willing to participate in the study or those who with a communication disability were excluded. During the data collection period, 155 patients were reached. Those who did not want to participate in the study (n=45) and could not fully answer the research questions (n=4) were also excluded from the study. Thus, 106 patients composed the final sample. The overall response rate for adults were 68.4% (106/155).

Data Collection and Instruments

Data were collected via face-to-face interviews with the patients using the Patient Information Form, Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, Edmonton Symptom Assessment Scale (ESAS) and Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) Scale.

Instruments

Patient Information Form

There were 23 questions in this form, which was created by the researchers based on a literature review (8, 11, and 12). The form included questions about sociodemographic (age, gender, marital status, educational status, etc.) and medical characteristics (diagnosis, disease duration, cancer stage, metastasis condition, applied treatments, presence of additional chronic disease, etc.).

Eastern Cooperative Oncology Group (ECOG) Performance Status Scale

This is widely used in clinical oncology to determine functional status and is a performance evaluation scale accepted by WHO. In the scale, the activity levels of individuals are grouped between 0 and 5. While low scores indicate well-being, high scores indicate poor prognosis (13-15).

Edmonton Symptom Assessment Scale (ESAS)

ESAS was firstly developed by Bruera and colleagues as a clinical instrument to document the symptom burden in patients with advanced cancer received to a palliative care unit (16). The ESAS is a self-reported measure of symptom intensity in cancer patients. In the scale, there are 10 symptom related questions such as pain, loss of appetite, nausea, shortness of breath, feeling unwell, fatigue, anxiety, sadness, insomnia, and other similar problems. The severity of each symptom is evaluated between 0 and 10 thus 0 point indicates no symptom, while 10 points indicate very severe symptom. For the country where the study was conducted, the validity and reliability analyses of the scale was carried out by Sadırlı and Ünsar with cancer patients (17). Afterwards, this scale was increased to 12 items by adding mouth sores, skin and nail changes, and numbness in the hands (18). In this study, the Cronbach's alpha value of the scale was found to be 0.85.

Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) Scale

We assessed symptom severity during the disease and treatment period with the FACIT-Pal.

The scale consists of 46-items measure of self-reported health-related quality of life. The FACIT-Pal contains 27-items FACT-G that measures four domains of quality of life: physical well-being (seven items), social/family well-being (seven items), emotional well-being (six items), and functional well-being (seven items). The Turkish validity and reliability of the scale was performed in 2018 (19). The Chronbach's alpha coefficient is 0.93. In the Turkish adaptation, 1-item was removed, and the scale was reduced to 45-items. The total score of this scale, which is 5-point Likert (0 to 4) type, is between 0-184. The items left blank are taken into account in the score calculation of the FACIT-Pal scale. The total score of the scale is obtained by the sum of the scores of all sub-dimensions. Higher scores indicate greater quality of life. In this study, the Cronbach's alpha value of the scale was found to be 0.73.

Statistical Analysis

Data were analyzed with the Statistical Package for Social Sciences 22.0 (SPSS, IBM Corp., Armonk, NY, USA). Frequencies and percentages were calculated on all surveys, patient characteristics, patients' most irritating symptoms, and their perception of symptom assessment and management. Chi-square test was used to compare categorical data and Kruskal Wallis Analysis was used for further analysis. Finally, the relationship between ESAS symptoms and total quality of life scores was evaluated using linear regression analysis. All tests were two-tailed, and a p-value of <0.05 was considered significant.

Ethical Considerations

This research was conducted in accordance with the Helsinki Declaration Principles. The study protocol was approved by the Medical Research Ethics Committee of Ege University (19-12T/33; 11.12.2019-E.389111). Moreover, permission was acquired from the institute where the research was conducted, and permission to use the scale was obtained from the owner of the scale via e-mail. The patients participating in the study were informed and their verbal consent was obtained.

RESULTS

General characteristics of sample

The final research sample was composed of 106 patients out of the total 155 patients who were initially invited to participate in the study. The overall response rate for patients was 68.4%. In Table-1, the socio-demographic and medical characteristics of the patients are summarized.

Table-1. Mean score of the quality of life scale by some of the patients' features.

Characteristics (n = 106)	$\bar{X} \pm SD$ (Min - Max)		
Age	54.04 ± 15.89 (18 - 87)		
Hemoglobin level	10.45 ± 2.03 (7.20 - 15.20)		
Hematocrit level	31.73 ± 5.79 (21.70 - 43.60)		
Size	166.79 ± 8.99 (150 - 187)		
Weight	71.21 ± 17.70 (34.5 - 128)		
	n (%)	FACIT-Pal	p
		$\bar{X} \pm SDT$	
Age group			
< 64	74 (69.8)	106.60±15.54	0.659*
≥ 65	32 (30.2)	108.06±16.49	
Gender			
Female	55 (51.9)	106.20±16.29	0.557*
Male	51 (48.1)	107.96±15.29	
Marital status			
Married	82 (77.4)	107.57±15.82	0.480*
Single	24 (22.6)	105.25±15.81	
Living style			
Alone	16 (15.1)	104.06±17.73	
With partner	29 (27.4)	105.24±17.04	0.491**
With children	10 (9.4)	104.60±13.49	
With partner and children	51 (48.1)	109.04±15.77	
Educational status			
Primary school and below	61 (57.6)	108.88±16.47	
High school	24 (22.6)	108.08±15.64	0.104**
University	21 (19.8)	108.52±16.26	
Income status			
Expenditure > income	7 (6.6)	114.14±18.79	
Expenditure = income	91 (85.8)	106.82±15.06	0.264**
Expenditure < income	8 (7.5)	103.37±21.10	
Working status			
Not working	45 (42.5)	109.20±17.42	
Working	8 (7.5)	103.75±12.17	0.167**
Retired	53 (50.0)	108.54±14.20	
Smoking			
Yes	10 (9.4)	108.90±13.90	0.723*
No	96 (90.6)	106.85±16.01	
Alcohol use			
Yes	2 (1.9)	118.00±4.24	0.287*
No	104 (98.1)	106.83±15.84	
Treatment style			
Hospitalized	44 (41.5)	99.04±15.98	0.000*
Not hospitalized	62 (58.5)	112.72±13.01	
Medical treatment			
Chemotherapy	34 (32.1)	112.70±12.80	
Radiotherapy	10 (9.4)	101.30±22.13	0.051**
Mixed type	62 (58.5)	104.87±15.46	
Disease stage			
Not know	39 (36.8)	111.76±13.43	
Stage 1	21 (19.8)	110.52±14.09	
Stage 2	13 (12.3)	109.92±13.07	0.011**
Stage 3	7 (6.6)	102.14±18.22	
Stage 4	26 (24.5)	97.03±17.02	
Metastasis			
Not know	9 (8.5)	105.00±22.43	
Yes	48 (45.3)	101.04±15.96	0.001**
No	49 (46.2)	113.30±11.57	
Comorbidity status			
Yes	60 (56.6)	107.38±14.67	0.877*
No	46 (43.4)	106.80±17.40	
ECOG performance status			
Stage 0	34 (32.1)	117.53±13.89	
Stage 1	28 (26.4)	109.93±11.53	
Stage 2	13 (12.3)	101.92±14.52	0.000**
Stage 3	15 (14.2)	100.29±12.20	
Stage 4	16 (15.1)	89.81±11.57	

*Mann Whitney-U test, **Kruskal Wallis test Statistical significance values (p<0.05) are given in bold.

Table-2. Patients' facit-pal scale total and subscales mean scores (n = 106).

Scale	$\bar{X} \pm SD$	Min - Max
Physical well-being	16.78±7.78	0 - 28
Social/family well-being	21.36±3.59	7 - 24
Emotional well-being	10.25±5.35	0 - 24
Functional well-being	17.19±7.56	2 - 28
Palliative subscale	41.44±3.73	30 - 49
FACIT-Pal Total	107.05±15.85	63 - 133

Table-3. Linear Regression of Quality of Life According to ESAS.

Edmonton Symptom Assessment Scale (ESAS)	$\bar{X} \pm SD$	Min-Max	B*	p
Pain	3.57 ± 3.55	0 - 10	-1.536	.000
Fatigue	4.81 ± 3.28	0 - 10	-1.316	.004
Nausea	1.99 ± 2.88	0 - 10	-1.139	.010
Depression	3.60 ± 3.68	0 - 10	-.716	.131
Anxiety	4.00 ± 3.79	0 - 10	-.116	.797
Drowsiness	3.33 ± 3.55	0 - 10	-.558	.121
Appetite	2.98 ± 3.31	0 - 10	-.782	.050
Being unwell	4.33 ± 3.21	0 - 10	-.763	.126
Shortness of breath	2.95 ± 8.84	0 - 8	-.064	.618
Skin and nails changes	2.08 ± 3.12	0 - 10	-.149	.722
Stomatite or sore mouth	1.76 ± 2.54	0 - 10	-.589	.191
Numbness at hands	2.02 ± 3.03	0 - 10	-.438	.437

*B- Regression coefficient, Statistical significance values (p<0.05) are given in bold.

Table-4. FACIT-Pal Scale Mean Scores According to ECOG Groups (n = 106).

Group	n	Physical		Social/famil y		Emotional		Functional		Palliative subscale		FACIT-Pal Total	
		\bar{X}	SD	\bar{X}	SD	\bar{X}	SD	\bar{X}	SD	\bar{X}	SD	\bar{X}	SD
ECOG 0	34	23.59	4.67	22.14	3.15	6.61	2.88	23.41	5.21	41.76	3.09	117.53	13.89
ECOG 1	28	18.00	4.83	21.64	3.39	10.07	5.29	17.85	6.66	42.35	2.58	109.93	11.53
ECOG 2	13	14.38	5.00	20.84	5.44	11.76	5.03	14.00	5.44	40.92	4.75	101.92	14.52
ECOG 3	15	11.53	6.38	20.46	2.87	14.66	4.09	13.20	5.59	40.64	4.78	100.29	12.20
ECOG 4	16	7.06	5.85	20.43	3.53	12.87	6.07	9.12	4.48	40.31	4.61	89.81	11.57
Test X²		60.21		7.874		30.925		49.153		3,304		44.170	
p		0.000*		0.096		0.000*		0.000*		0.508		0.000*	
Bonferroni Test		0>1>3, 0>2>4, 1>4				0>1>3, 0>2, 0>4		0>1>4, 0>2, 0>3				0>2, 0>3, 0>4, 1>4	

X²: Kruskal Wallis test, *p<0.001, Statistical significance values (p<0.05) are given in bold.

The mean age of the patients enrolled into the study was 54.04±15.89 years (range 18–87). More than half of the patients were female (51.9%) and most of them were married. More

than half of the participants (58.5%) were receiving outpatient treatment, 46.2% stated that they had metastasis. In addition, 56.6% of the participants had an additional disease other than

cancer (Table-1). Considering the primary diagnoses of the patients, 20.7% had GIS cancer, 16.9% lung cancer, 16% breast-ovarian cancer, 8.5% pancreas cancer, 7.6% leukemia, 5.7% lymphoma, 3.8% liposarcoma, and the primary diagnosis of 20.8% is unclear.

Quality of life scale score characteristics

The mean quality of life score was 107.05 ± 15.85 . In Table-2, distributions of subscale of the quality of life score are presented.

Relationship between Characteristics and quality of life

Patients with outpatient care, low disease stage (stage 1 + not knowing), no metastasis, and good EGOG performance (stage 0 + 1) were found to have significantly higher mean scores on the quality of life scale compared to other patients ($p < 0.05$). No significant differences were observed relating to age, gender, educational level, marital status, employment status, income level, alcohol use and smoking, current treatment or comorbidity ($p > 0.05$) (Table-1).

Relationship between symptoms and quality of life

The symptoms and symptom severity experienced by the patients participating in the study are listed in Table-3. The highest scores obtained by patients related to ESAS were as followed: fatigue (mean 4.81), sense of unwell-being (mean 4.33), anxiety (mean 4.0), depression (mean 3.60) and pain (mean 3.57). There was a statistically significant difference between the total quality of life scores of the patients and pain, fatigue and nausea from the patients' ESAS symptoms in the regression analysis ($p < 0.05$) (Table-3).

FACIT-Pal scale score averages according to ECOG groups

Table-4 shows the relationship between patients' performance levels and quality of life scores. There was a statistically significant difference between patients' ECOG performance level and quality of life ($p < 0.001$). It was found that as the performance levels of the patients improved, quality of life total score also improved (Table-4).

DISCUSSION

This study provides an explanation of how the severity of symptoms and performance levels experienced by palliative care patients affect their quality of life. As it is known, cancer is a disease of the modern world and it is necessary for

holistic care to start the palliative care process from the moment the patients are diagnosed.

Patients must cope with multiple symptoms during cancer and palliative care process. The symptoms experienced by these patients affect them negatively in many ways. Symptom is expressed as "stressors perceived by a patient and the meaning of the stressor for that particular person" (20). Symptom management is a care process focused on identifying and alleviating symptom distress to reduce pain and maximize the function and quality of life. The first step of the process is to define the presence of symptoms and their impact on the person's life process and quality of life (21). In our study, the most common symptoms experienced by cancer patients receiving palliative care were fatigue, sense of unwell-being, anxiety, sadness (depression) and pain. In a previous study, the most common symptoms experienced by cancer patients receiving palliative care were fatigue, sense of being unwell, loss of appetite, anxiety, sadness (depression) and pain (22). Although the most distressing symptoms were similar in our study and in that previous study, the symptom severity was generally lower in our study (22). This difference is thought to be due to the low disease stage of most of the participants in our study and the high performance status of 58.5% of the participants. However, interestingly, the regression analysis revealed that the most important symptoms affecting the quality of life of the patients were pain, fatigue and nausea. Cancer patients need supportive care at every stage of their illness. Although, 20-50% of cancer patients suffer symptoms such as pain, fatigue and nutritional problems, this should be systematically evaluated and addressed (23-25). Additionally, in our study, the absence of metastasis in most of the patients supports the low disease stage, it also supports the results of low symptom severity.

There are studies that reinforce this result. It has been found that many simultaneous symptoms (symptom cluster), especially seen in advanced cancer patients, adversely affect the physical, mental and social well-being of patients and reduce their quality of life (20, 21). It is also known that cancer patients generally have the worst quality of life compared to the general population (26, 27). On the other hand, in this study, the total mean score of the FACIT-Pal scale that evaluated quality of life of patients is 107.05 ± 15.85 . The highest score that can be

obtained from the scale is 184 and taking under consideration the fact that the high score indicates a high quality of life, therefore we can easily state patients included in the sample had good quality of life. This result is a supportive data in parallel with the low symptom severity findings obtained in our study. However, it does not match most studies in the literature. In a different study, it is stated that only 17.56% of the participants had a good or average quality of life (28). In another study, 39.1% of the participants' quality of life was stated as very low while 43.72% of them were stated as low (12). It is possible that this situation depends on sampling characteristics such as disease stage and treatment options. As a matter of fact, in studies where the quality of life was found to be low, the characteristics of the patient population might be worse than our study population.

Another finding in our study is performance level of patients. As shown in Table-1, most of the patients included in the sample had high performance level. This can be explained by the fact that their disease had not progressed to an advanced stage. It is possible to say that there is a linear relationship between patients' ECOG performance level and quality of life. Because, in our study, there is a statistically significant difference between patients' ECOG activity level and quality of life. It was determined that the total quality of life score of the patients with good performance level was higher than the quality of life score of the patients with poor performance level. In another study, a positive relationship was found between the performance status of the patients and their quality of life. In a study conducted with cancer patients (28), it was stated that there was a statistically significant relationship between participants' performance status and quality of life. Similarly, in another recent study, breast cancer patients were included in a sample, and it was found that there was a significant relationship between the performance status and quality of life of the patients, and the quality of life of fully active patients was in better state (29). As expected, these results of our study support the current literature information.

As shown by this study, cancer patients experience a low severity level of symptoms, and there is a significant negative correlation between their symptom severity and disease level, and quality of life scores. Furthermore, there is a significant positive correlation between the

patients' performance and quality of life. It was seen that patients with cancer experiencing severe symptoms had a poor quality of life. Moreover, we found that the performance status of patients was closely related to the quality of life. It is thought that alleviating the severity of symptoms experienced by cancer patients and ensuring that patients have a good performance level may result in higher quality of life. Based on these findings, some strategies can be developed to increase the patients' performance level and to decrease their symptom severity. As health care professionals, nurses should spend greater effort to improve symptom severity and performance level of their patients. They should also provide comprehensive symptom management in order to prevent patients' severe symptoms resulted due to cancer and cancer treatments.

Limitations

Although the results reveal the patients' symptom experiences, performance status and quality of life, this study had some limitations. First, the study was carried out within a developing country and palliative care services are not sufficiently developed yet. However, the institution where the study was conducted is one of the best palliative care service provider in the country. This is thought to be an important factor that influenced the research results. Secondly, the patients who participated in this study were only part of a small group from the palliative care patients. Thus, the study findings may not be generalized to all palliative care patients. In addition, the global pandemic had a negative impact on the sample size during data collection. Considering the limited number of palliative care units in the country, we believe the sample size is still not very low. For this reason, we recommend multi-center studies with larger sample size to be conducted. Detailed data obtained from a large sample group may help to increase the standard of care by improving the quality of life for palliative care patients.

CONCLUSION

In conclusion, this research aimed to find out how symptoms and performance status affect quality of life in palliative care patients. Study findings included some implications for symptoms, performance status, and quality of life for palliative care patients. Nursing intervention should utilize a holistic approach to provide effective and individualized symptom management in palliative care. For this reason,

the first step should be dedicated to defining the presence of symptoms and performance status of patients. The study results provide a valuable reference to determine the content of care to be provided for palliative care patients. Furthermore, the study may keep light for nursing studies by providing a base for future palliative care

researches. Although this study is restricted to one palliative care unit in the country, the researchers recommend for more researches to be conducted in-depth on this topic in heterogeneous and large groups.

Conflict of interest: We declare that we have no conflict of interest.

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