

Determination of Symptom Frequency and Symptom Clusters in Cancer Patients in Palliative Care

Palyatif Bakımdaki Kanser Hastalarında Semptom Sıklığı ve Semptom Kümelerinin Belirlenmesi

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Abstract

Objective: To determine the frequency of symptoms and symptom clusters experienced by patients with cancer receiving palliative care services.

Methods: This cross-sectional study included 187 patients with cancer who were hospitalized in the palliative care service between March 10, 2017 and October 30, 2018. The data were collected by the researcher face-to-face using the patient identification form, memorial symptom rating scale, and Karnofsky performance scale. The research data were analyzed using SPSS software.

Results: Cluster analysis identified 2 symptom clusters. The first symptom cluster included physical symptoms and psychogenic symptoms related to cancer diagnosis and treatment, while the second symptom cluster mainly included nutritional (gastrointestinal system related) and genitourinary system-related problems.

Conclusion: Further studies are recommended for effective symptom management according to the type of cancer and for developing detailed symptom clusters.

Keywords: Palliative care, symptom cluster, cancer

Öz

Amaç: Palyatif bakım hizmeti alan kanser hastalarının yaşadıkları semptomların sıklığını ve semptom kümelerini belirlemektir.

Yöntem: Araştırma kesitsel tipte olup 10 Mart 2017-30 Ekim 2018 tarihleri arasında palyatif bakım servisi'nde yatan 187 kanser hastası ile yapılmıştır. Veriler araştırmacı tarafından hasta tanımlama formu, memorial semptom değerlendirme skalası ve Karnofsky performans skalası kullanılarak yüz yüze anket yönetimi ile toplanmıştır. Araştırma verileri SPSS programında analiz edilmiştir.

Bulgular: Kümeleme analizinde 2 semptom kümesi belirlenmiştir. Birinci semptom kümesinde kanser tanı ve tedavisiyle ilişkili fiziksel semptomların ve psikojenik semptomlar, ikinci semptom kümesinde ağırlıklı olarak beslenme (gastrointestinal sistem ilişkili), genitoüriner sistemle ilgili sorunların yer aldığı belirlenmiştir.



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Öz

Sonuç: Kanserin türüne göre etkin semptom yönetimi yapılabilmesi ve ayrıntılı semptom kümeleri çıkarılması için daha fazla çalışma yapılması önerilmektedir.

Anahtar Kelimeler: Palyatif bakım, semptom kümelenmesi, kanser

Introduction

Patients with cancer, who constitute a significant proportion of palliative care patients, may experience many symptoms, such as pain, fatigue, nausea, vomiting, loss of appetite, constipation, anxiety, sleep disturbance, pruritus, and depression caused by the disease itself, the stage of cancer, or cancer treatment⁽¹⁾. In symptom management, when only one symptom is evaluated or focused on, other symptoms may be overlooked, treatment may be incomplete, and the patient's quality of life may deteriorate^(1,2). At the same time, concurrent symptoms observed in patients with cancer can increase the severity of symptoms by increasing the effects of each other and causing the emergence of new symptoms⁽³⁾.

Distressing symptoms theory is an intermediate-level theory developed by Lenz et al.⁽⁴⁾ in 1995 and revised in 1997. The theory of distressing symptoms is based on the integration of findings from symptom research. The model plays a key role in the creation of symptom clusters in terms of the synchronicity and interrelatedness of symptoms. This theory comprises three dimensions. The first dimension is defined as the factors affecting the symptoms (physical, psychological and situational), the second dimension is defined as the duration, intensity, quality, and distress of the symptoms, and the third dimension is considered the effect of these symptoms on the achievements of individuals, including cognitive and functional activities caused by these symptoms⁽⁵⁾.

The coexistence of three or more symptoms in patients with cancer was initially defined as a "symptom cluster", but today it is defined as the coexistence of two or more symptoms that are interrelated and continuously present in the patient continuously⁽⁶⁾. Although there is not yet a complete consensus on the definition of symptom clusters, symptom clusters have been created based on both definitions in studies⁽⁷⁾. It is necessary to increase evidence-based knowledge in the clinical management of symptom research, and more data on the symptoms experienced by patients with cancer are needed to generate evidence in this field. Symptom clustering is a concept that started to be used in the nursing literature about 15 years ago, and there are not enough studies in this field. It is emphasized that by

identifying symptom clusters, nurses will be better able to define symptoms more accurately and target interventions that will facilitate symptom management. Effective symptom identification is reflected in patient care and quality of life of patients undergoing effective symptom management⁽⁸⁾.

The aim of this study was to help caregivers improve the quality of care by reducing the symptom burden of patients with cancer, to determine patient care needs, and to assess the frequency of physical and psychological symptoms related to cancer diagnosis and treatment.

Materials and Methods

The type of study is cross-sectional. The study sample consisted of 187 patients with cancer who were hospitalized in the palliative care service of a hospital between March 10, 2017, and October 30, 2018, and who agreed to participate in the study.

Statistical Analysis

The data were entered into the statistical software program SPSS 25.0 (SPSS Inc., Chicago, IL, USA) and analyzed. The findings are presented as numbers, percentages, means, and standard deviations. The Kruskal-Wallis test was used to evaluate the significance of the difference between the means of the groups, and correlation analysis was used to compare the relationship between the groups. Cluster and factor analysis were used to determine the clusters. Statistical significance level $p < 0.05$ was accepted. The patient introduction form, Karnovsky performance scale, and memorial symptom rating scale will be used as data collection tools in the study.

I. Patient identification form: This form consists of 10 questions regarding socio-demographic characteristics, such as age, gender, education and income status, and the duration of the individual's hospitalization in the clinic and current status⁽⁹⁾.

II. Memorial symptom rating scale: The memorial symptom rating scale (MSRS) is a comprehensive multidimensional cancer-related symptom assessment tool. The material safety data sheet (MSDS) format developed by Portenoy not only reveals the prevalence of symptoms but also the frequency

and distress analysis of 32 physical and psychological symptoms. In the scale, 24 symptoms were evaluated in terms of frequency, severity and distress; 8 symptoms are evaluated in terms of frequency and distress. The scale consists of the global distress index (GDI), physical symptom subscale score (MSDS-Physical), and psychological symptom subscale score (MSDS-Psychological). This validated multidimensional scale measures the prevalence, characteristics, and distress of common symptoms in serious illnesses. The Total MSDS 41 (TMSDS) score is the mean symptom score of the 32 symptoms in the MSDS scale⁽¹⁰⁾ Turkish reliability analysis of the scale was conducted by Yildirim et al.⁽¹¹⁾. In the validity and reliability analysis conducted by Yildirim et al.⁽¹¹⁾, the item total score correlation was 0.03–0.64. The Cronbach's alpha values of the total MSDI and MSDI sub-dimensions were between 0.71 and 0.84.

III. The Karnofsky performance scale (KPS): is a scale developed for patients with cancer and was introduced into the literature by Karnofsky et al.⁽¹²⁾ in 1948. The Karnofsky performance scale was evaluated numerically on a scale of 0–100 with a 10-point incremental number. The scale provides information about the patient's functional capacity, such as the ability to perform normal activities and work, the need for caregivers, and the level of dependency on medical care.

Patients who agreed to participate were informed about the study and provided written informed consent. Participants were also informed that they could withdraw from the study at any time. Ethical approval for the current study was obtained from the Scientific Research Ethics Committee of University of Health Sciences Turkey, İzmir Tepecik Education and Research Hospital, (approval number: 2018/8-9, date: 11.07.2018).

Results

A total of 187 patients receiving palliative care participated in the study. Of the study group, 73.3% (n=137) were male, and the mean age was 63.7±12.124 (min: 19; max: 109). 71.1% of the patients were not married and 51.3% (n=96) were not actively working. The percentage of those with high school education and above was 25.7% (n=48). It was found that 54% (n=101) of the patients had normal body weight and 76.5% (n=143) were anemic. It was learned that 61% (n=114) of the patients were diagnosed with lung cancer, 62% received the diagnosis 1 month ago, and 43.3% (n=81) had metastasis. The mean duration of hospitalization was

22.9±21.390 min: 1; max: 210) days, and the mean serum vitamin B12 level was 313.8±89.126 min: 129; max: 834) mg/dL. The socio-demographic characteristics of the study group are presented in Table 1.

The 3 most common symptoms according to the MSDS were fatigue [88.8% (n=166)], pain [81.3% (n=152)], feeling sad, and worrying [71.7% (n=134)], respectively. The frequency of symptoms according to MSDI is presented in Table 2.

Table 1. Socio-demographic characteristics of palliative care patients socio-demographic

Socio-demographic characteristics		n	%
Gender	Woman	50	26.7
	Male	137	73.3
Age group	≤64	92	49.2
	65≥	95	50.8
Marital status	Married	54	28.9
	Not married	133	71.1
Level of study	Illiterate	22	11.8
	Primary	117	62.6
	High school and above	48	25.7
Employment status	Actively working	91	48.7
	Not actively working	96	51.3
Body mass index	Slim	32	17.1
	Normal	101	54.0
	Overweight/obese	54	28.9
Anemia	There is	143	76.5
	There isn't	44	23.5
Diagnosis of the disease	Lung cancer	114	61.0
	Breast cancer	18	9.6
	Bowel cancer	20	10.7
	Prostate cancer	8	4.3
	Stomach cancer	16	8.6
	Central nervous system malignancy	4	2.1
	Other	7	3.7
Time of diagnosis	1 month ago	116	62.0
	3 months ago	26	13.9
	6 month ago	16	8.6
	More than 1 year	21	11.2
	More than 3 years	8	4.3
Metastasis status	Yes	81	43.3
	No	106	56.7
Total		187	100.0

As a result of the clustering analysis, 2 symptom clusters emerged in the palliative care patient sample. In the first symptom cluster, physical symptoms related to cancer diagnosis and treatment (shortness of breath, numbness and tingling in the hands and feet, changes in the skin, feeling irritable), pain, weakness/loss of energy, feeling sad, and worrying, which are included in the main cluster as a sub-cluster, are concentrated. The second cluster of symptoms

is often characterized by gastrointestinal problems. These symptoms include changes in the taste of food, nausea, vomiting, bloating, itching, difficulty swallowing, and difficulty urinating. The second set of symptoms also includes psychosocial symptoms. The leading symptoms were self-dissatisfaction, sexual desire, and activity. The Dendrogram obtained from the clustering analysis according to the frequency of symptoms is shown in Graph 1.

Table 2. Symptom frequencies of the study group according to the MSDS

MSDS substances	n	%
Difficulty concentrating	63	33.7
Pain	152	81.3
Fatigue-loss of energy	166	88.8
Cough	104	55.6
Feel frustrated	118	63.1
Dry mouth	120	64.2
Nausea	75	40.1
Feeling sleepy or light-headed	118	63.1
Numbness/tingling in the hands and feet	92	49.2
Difficulty sleeping	91	48.7
Feeling bloated	53	28.3
Difficulty urinating	52	27.8
Vomiting	46	24.6
Dyspnea	102	54.5
Diarrhea	25	13.4
Feel sad	134	71.7
Perspiration	98	52.4
Be worry	134	71.7
Problems with sexual desire and activity	78	41.7
Itch	48	25.7
Loss of appetite	104	55.6
Dizziness	99	52.9
Dysphagia	59	31.6
Feeling sensitive	98	52.4
Mouth sores	30	16.0
Change in the taste of food	71	38.0
Weight loss	62	33.2
Hair loss	103	55.1
Constipation	115	61.5
Swelling in the arms or legs	35	18.7
Self-dissatisfaction	68	36.4
Change in the skin	93	49.7
MSDS: Material safety data sheet		

In the comparison of the symptom clusters and socio-demographic data, males experienced more symptom clusters; single, anemic patients, patients diagnosed with lung cancer, patients diagnosed within one month, and patients without metastasis experienced more symptom clusters (Table 3).

In this study, a significant difference was found between the two symptom clusters of MSDS total score, physical and

psychological subgroups, and scale global distress index ($p<0.001$). In addition, although a significant difference was identified between symptom clusters in terms of KPS scores ($p=0.007$), no significant relationship was found between length of hospitalization and B12 levels (Table 4).

Table 3. Comparison of symptom clusters in terms of socio-demographic and diagnosis-related characteristics

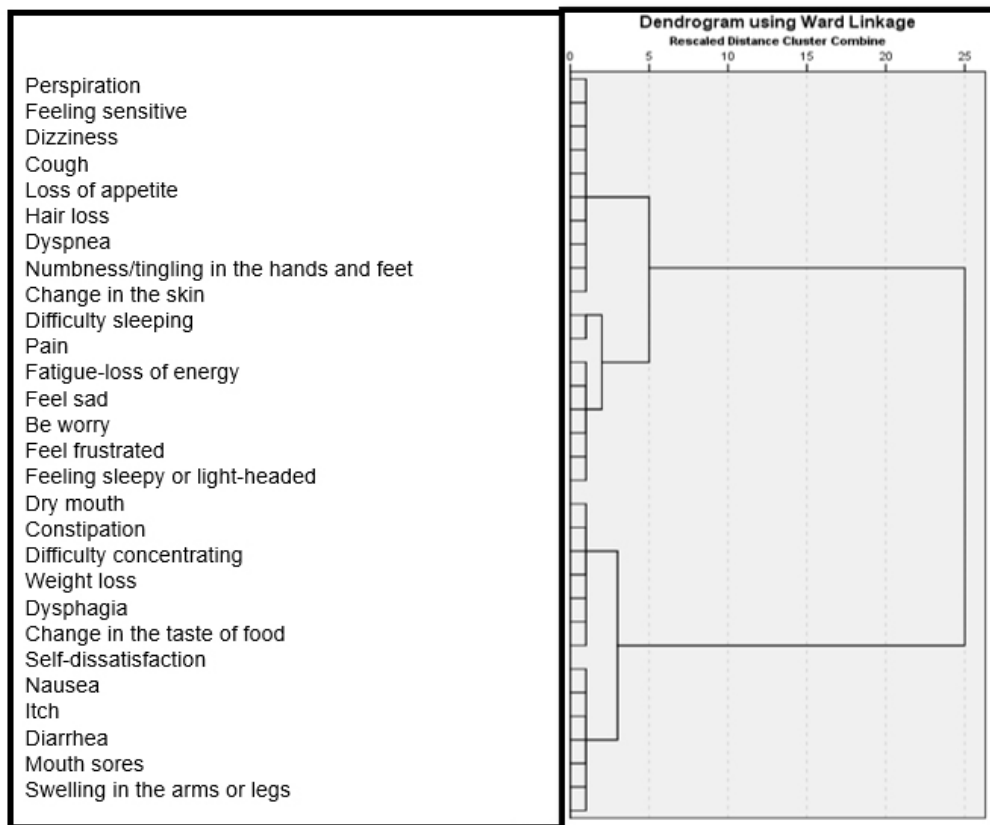
		Cluster 1		Cluster 2		p
		n	%	n	%	
Variables		76	40.6	111	59.4	
Gender	Woman	15	19.7	35	31.5	0.073
	Male	61	80.3	76	55.5	
Age group	≤64	42	55.3	50	45	0.170
	65≥	34	44.7	61	55	
Marital status	Married	34	44.7	20	18	<0.001
	Not married	42	55.3	91	82	
Level of study	Illiterate	9	11.8	13	11.7	0.472
	Primary	44	57.9	73	65.8	
	High school and above	23	30.3	25	22.5	
Employment status	Actively working	36	47.4	55	49.5	0.769
	Not actively working	40	52.6	56	50.5	
Body mass index	Slim	13	17.1	19	17.1	0.948
	Normal	42	55.3	59	53.2	
	Overweight/obese	21	27.6	33	29.7	
Anemia	There is	58	76.3	85	76.6	0.967
	No	18	23.7	26	23.4	
Diagnosis of the disease	Lung cancer	42	55.3	72	64.9	0.128
	Breast cancer	7	9.2	11	9.9	
	Bowel cancer	11	14.5	9	8.1	
	Prostate cancer	6	7.9	2	1.8	
	Stomach cancer	6	7.9	10	9	
	CNS malignancy	0	0	4	100	
	Other	4	5.3	3	2.7	
Time of diagnosis	1 month ago	44	57.9	72	64.9	0.137
	3 months ago	8	10.5	18	16.2	
	6 month ago	9	11.8	7	6.3	
	More than 1 year	9	11.8	12	10.8	
	More than 3 years	6	7.9	2	1.8	
Metastasis status	Yes	29	38.2	52	46.8	0.239
	No	47	61.8	59	53.2	

CNS: Central nervous system

Table 4. Evaluation of palliative care patients' symptom clusters with symptom assessment total score, sub-score and performance scale

		n	Average	Max	Min	Z	p
MSDS total score	Cluster 1	76	44.15	3355,5	429,5	-10.421	<0.001
	Cluster 2	111	128,13	14222,5			
MSDS-physical score	Cluster 1	76	47.27	3592,5	666,5	-9.770	<0.001
	Cluster 2	111	126	13985,5			
MSDS-psychological score	Cluster 1	76	59.95	4556,5	1630,5	-7.12	<0.001
	Cluster 2	111	117,31	13021,5			
Scale global distress index	Cluster 1	76	49.16	3736,5	810,5	-9.385	<0.001
	Cluster 2	111	124,7	13841,5			
KPS	Cluster 1	76	100,0	8064,5	3297,5	-2.674	0.007
	Cluster 2	111	85.71	9513,5			
Length of stay	Cluster 1	76	89.45	6798	3872	-0.952	0.341
	Cluster 2	111	97.12	10780			
B12 level	Cluster 1	76	87.88	6679	3753	-1.279	0.201
	Cluster 2	111	98.19	10899			

MSDS: Material safety data sheet, KPS: Karnofsky performance scale

**Graph 1.** Symptom clustering of patients

Discussion

This study was conducted to determine the frequency of symptoms and symptom clusters experienced by patients with cancer receiving palliative care services. Two main symptom clusters were identified in this study. In the first symptom cluster, physical symptoms related to cancer diagnosis and treatment (dyspnea, numbness/tingling in hands and feet, skin changes, difficulty sleeping, pain, weakness-loss of energy, worrying and feeling irritable) were observed. The second set of symptoms consisted mainly of symptoms related to the gastrointestinal system, such as changes in the taste of food, difficulty swallowing, nausea, bloating, vomiting, itching, unpleasant feeling, difficulty urinating, and other symptoms. It has been reported that patients with cancer experience an average of 11-13 symptoms simultaneously^(13,14). Our study is consistent with the findings. As a result of our study, fatigue loss of energy was the most common symptom was fatigue-loss of energy (88.8%), followed by pain (81.3%). In the study conducted by Süren et al.⁽⁹⁾, the most common symptom was fatigue (98.2%), and similar results were observed in many studies^(8,15,16). Symptoms such as fatigue and malaise, the sub-pathologies of which are not well known and often overlooked, negatively affect the quality of life, participation in life, and emotional state of patients during the day, and increase exposure to conditions that complicate the disease process, such as physical immobility⁽¹⁸⁾.

Gastrointestinal symptoms such as nausea, vomiting, and anorexia are some of the symptoms that form a cluster due to conditions such as palliative care patients being in the terminal period and treatment side effects^(19,20). In addition to the negative effects of gastrointestinal symptoms on nutrition, it may lead to a poor response to the treatments applied due to the inability to meet the energy requirement⁽²¹⁾. In the management of gastrointestinal symptoms observed in patients, it is useful for nurses to know the importance of early planning of interventions that will prevent or stop the increase in severity starting from the emergence of the symptom in terms of symptom burden^(22,23). In patients with cancer, one symptom may trigger other symptoms, or symptoms may occur independently of each other through different mechanisms. Our symptom clusters include psychological and physical symptoms. This situation, which is also encountered in the literature as one of the conditions that make symptom management difficult, can cause difficulties in understanding symptom management and its

etiology because of the mechanism of symptom occurrence, the multidimensionality of human beings as a being, and the fact that symptoms sometimes manifest themselves by causing a metabolic or endocrine disorder without causing a physical symptom finding⁽¹³⁾. In our study, males experienced symptom clusters more frequently. In some studies, it has been reported that women experience more symptom burden⁽¹³⁾, but there are also research findings with no difference between gender⁽²⁴⁾.

In our study, the group with the most frequent symptom cluster was newly diagnosed patients. Here, as health professionals, it is important to recognize that patients are at higher risk than other groups because of the negative effects of cancer treatments, the hospital process, and the weakening of social relations⁽⁸⁾. Early initiation of effective symptom management, holistic treatment of the patient, and multidimensional follow-up of the patient by the primary care nurse and physician will reduce the risk.

Study Limitations

The fact that the research was conducted in a single center is one of the limitations of the study.

Conclusion

Palliative care patients are at high risk of experiencing more than one complex and unmanageable situation from diagnosis to bereavement. Patients' reactions to the diagnostic process, coping with rapid and severe bed-related effects, especially at the end of chemotherapy treatment, withdrawal from social life, and role changes increase the symptom burden and make symptom management difficult. It is recommended that health professionals, especially those working in the field of palliative care, recognize symptoms, understand the complex process caused by symptom coexistence, plan symptom-specific management to prevent the formation of symptom clusters, and carry the knowledge to the field by sharing the results of research with health professionals in clinical practice.

Ethics

Ethics Committee Approval: Ethical approval for the current study was obtained from the Scientific Research Ethics Committee of University of Health Sciences Turkey, İzmir Tepecik Education and Research Hospital (approval number: 2018/8-9, date: 11.07.2018).

Informed Consent: Patients who agreed to participate were informed about the study and provided written informed consent.

Footnotes

Authorship Contributions

Concept: G.D, Y.K.Ö, Y.Y., Design: F.Ş.A. G.D., Data Collection or Processing: G.D, Y.K.Ö., Analysis or Interpretation: F.Ş.A, G.D, Y.K.Ö., Literature Search: G.D., Writing: G.D.

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