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IDENTIFYING THE PHYSIOTHERAPY REQUIREMENTS OF PATIENTS IN PALLIATIVE CARE

ORIGINAL ARTICLE

ABSTRACT

Purpose: Palliative care has an important role in the late stages of diseases. Patients deal with many symptoms. Physiotherapy approaches are an essential part of palliative care in symptom control. This study was planned to investigate the level of independence of the patients, their performance status, symptoms, rehabilitation needs, and caregivers' expectations.

Methods: The study was designed as cross-sectional and descriptive. Ninety individuals aged between 18 and 65 years were included. Care needs during palliative care were assessed with the Palliative Performance Scale. Independence level was assessed by the Barthel Index. The severity of the symptoms that the patients frequently experienced was investigated. Caregivers reported their primary expectations from physiotherapy.

Results: The most common diagnosis was found to be cerebrovascular accidents. The mean age of the patients was 64±20 years. The mean age of the caregivers was 49±13 years. The mean the Palliative Performance Scale score was 31±17. Most of the patients were totally dependent according to the Barthel Index. Most of the patients faced symptoms, such as reduced muscle strength (94.44%), atrophy (93.33%) and swallowing problems (82.22%). Improved physical functions was the most reported expectation among caregivers.

Conclusion: Over 90% of the patients were totally dependent and they had to deal with many symptoms. This result highlights the importance of physiotherapy. Caregivers expected the patient to be able to meet their own needs independently. This is very important for the caregiver, and the patient and caregiver should be in cooperation with the physiotherapist.

Keywords: Caregivers, Expectations, Palliative care, Physiotherapists.

PALYATIF BAKIMDA HASTALARIN FİZYOTERAPİ GEREKSİNİMLERİNİN BELİRLENMESİ

ARAŞTIRMA MAKALESİ

ÖZ

Amaç: Palyatif bakımın hastalıkların geç evrelerinde önemli bir rolü vardır. Hastalar birçok semptomla baş etmektedir. Fizyoterapi yaklaşımları semptom kontrolünde palyatif bakımın önemli bir parçasıdır. Bu çalışma, hastaların bağımsızlık düzeylerini, performans durumlarını, semptomlarını, rehabilitasyon ihtiyaçlarını ve bakım verenlerin beklentilerini araştırmak amacıyla planlanmıştır.

Yöntem: Çalışma kesitsel ve tanımlayıcı olarak tasarlanmıştır. 18-65 yaş grubu 90 birey dahil edildi. Palyatif bakımdaki hastaların bakım ihtiyaçları Palyatif Performans Ölçeği ile değerlendirildi. Bağımsızlık düzeyi Barthel Endeksi ile değerlendirildi. Hastaların sıklıkla yaşadığı semptomların şiddeti araştırıldı. Bakım verenler, fizyoterapiden birincil beklentilerini bildirdiler.

Sonuçlar: En çok raporlanan tanı serebrovasküler olay oldu. Hastaların yaş ortalaması 64±20 idi. Bakım verenlerin yaş ortalaması 49±13 idi. Ortalama Palyatif Performans Ölçeği skoru 31±17 idi. Hastaların çoğu Barthel İndeksine göre tamamen bağımlıydı. Hastaların çoğu azalmış kas gücü (% 94,44), atrofi (% 93,33) ve yutma problemleri (% 82,22) gibi semptomlarla karşı karşıya kaldığını belirtti. Bakım verenlerin beklentisi, hastanın fiziksel fonksiyonlarının iyileşmesi yönündeydi.

Tartışma: Hastaların %90'ından fazlası tamamen bağımlıydı ve semptomlarla uğraşmak zorunda kaldıklarını belirttiler. Bu sonuç fizyoterapinin önemini vurgulamaktadır. Bakım verenler hastanın ihtiyaçlarını bağımsız olarak karşılamasını istediğini belirttiler. Bu durum bakım veren için oldukça önemlidir ve hasta ve bakımverenler fizyoterapistlerle işbirliği içinde olmalıdır.

Anahtar Kelimeler: Bakım verenler, Beklentiler, Palyatif bakım, Fizyoterapistler.

INTRODUCTION

Palliative care includes the management of symptoms experienced by terminally ill patients. According to the World Health Organization, palliative care is a healthcare procedure aiming to decrease symptoms and to improve patients' quality of life (QOL). Multidisciplinary healthcare is essential for the management of different aspects of the problems experienced by patients (1-3).

Symptoms of advanced cancer patients or those hospitalized for palliative care/hospice care have been reported previously. Based on these reports, patients hospitalized for palliative care may experience pain, fatigue, lack of energy, somatic complications, emotional problems, and immobilization-related side effects including pressure ulcers, muscle weakness, joint limitations, cardiopulmonary side effects, and physical and performance deficits (4, 5). These symptoms negatively impact patients' activities of daily living (ADL), functional capacity, and QOL (6, 7). Accordingly, supportive care interventions aiming for symptom management is an essential part of palliative care. There are a number of studies investigating the effects of physical therapy interventions in a palliative care setting. Physical therapists help individuals to decrease symptom severity and to increase independence and functionality in daily life during palliative care (8, 9). Management of physical problems includes improving mobility, strength, flexibility, endurance, coordination, balance, gait, breathing, exercise tolerance, and energy expenditure (7, 10). Symptom control by physical therapy is applicable in patients experiencing several symptoms such as pain, fatigue, weakness, joint limitations, cough, and shortness of breath (11, 12). In Turkey, there are limited data regarding physiotherapy assessments or interventions in terminally ill patients receiving palliative care. To plan effective physical therapy interventions in a palliative care setting, this study was planned to examine physical therapy needs and problems of palliative care patients. Therefore, the present study aimed to determine palliative care patients' independency level in activities of daily living, their performance status, symptoms, physical therapy and rehabilitation needs, and caregivers' expectations in a palliative care setting in Turkey.

METHODS

Study design and patients

This research was conducted between June 2018 and September 2019 in Republic of Turkey, Ministry of Health, Ulus State Hospital Palliative Care Centre. The study was designed as cross-sectional and descriptive. The Hacettepe University Ethics Committee for Non-Interventional Clinical Research approved the present study with the decision number GO 18\700. The present study was conducted in accordance with the principles defined in the Helsinki Declaration. Participants were informed about the study and a signed written consent form was obtained from all patients. The study included 18- to 65-year-old volunteers who were being treated at a palliative care unit. Patients who did not meet the inclusion criteria, did not sign the consent form, or withdrew were not included. Age, gender, height, weight, body mass index (BMI), hospitalization date, marital status, the presence of health insurance, diagnosis, and previous treatments were recorded.

Palliative Performance Scale

The Palliative Performance Scale is a reliable and valid tool that has been used to measure functional performance and predict survival among palliative care cancer patients. The PPS is a modification of the Karnofsky Performance Scale. PPS was originally developed for cancer patients and later adapted to be more generalizable to other end-of-life diagnosis. PPS was developed by Anderson et al. in 1996 to determine the care needs of patients receiving palliative care. It includes five sub-headings: ambulation, activity level and evidence of disease, self-care, oral intake, and level of consciousness. The item that best describes the patients' care need is determined in the scale and the percentage value (PPS%) of the items is recorded. Each of the five domains is divided into 11 levels ranging from 0% to 100% in 10%-point intervals, with 0% indicating death and 100% being fully ambulatory and healthy. Turkish validity and reliability study of this scale was done by Oğuz et al. (13, 14).

The Barthel Index

The Barthel Index (BI) was developed by Mahoney and Barthel to measure physical and social function in daily life. This index defines activity capacity with a scale ranging from 0 (full dependence) to 100 (full independence). The BI score is classified into five categories: total dependence (0-20 points), severe dependence (21-60 points), moderate dependence (61-90 points), slight dependence (91-99 points) and total independence (100 points). The higher scores represent higher functional independence. The BI includes 10 items: nutrition, bathing, personal care, dressing, toilet use, mobility on flat surfaces (immobile, wheelchair use, assisted or independent walking), transfer (wheelchair to bed and vice versa), stair climbing, bowel, and bladder continence. Turkish validity and reliability study of this scale was done by Küçükdeveci et al. (15, 16).

Determination of Physiotherapy Needs

In this section, patient evaluations were conducted in two parts. The results were obtained by evaluating the answers of the physiotherapist and the caregiver. Clinical evaluations about atrophy, muscle strength, rigidity, decubitus ulcer, spasticity, joint movement limitation, flaccidity, oedema, lymphedema, contracture, swallowing problems, phlegm, constipation, and coughing were performed by the physiotherapist. The items were answered as “yes” or “no”. Physiotherapy needs of the palliative care patients and the expectations of the caregivers were evaluated. Evaluations were gathered under three main titles as: improving physical functions, increasing participation in daily life activities, and relief of symptoms (9, 17, 18).

Statistical Analysis

Analyses were carried out using SPSS 22 (SPSS Inc. Chicago IL, USA) program. Descriptive statistics were calculated for all variables. Descriptive data were calculated as percentage, mean, and standard deviation.

RESULTS

A total of 90 palliative care patients (35 females, 55 males) were included in the present study. The mean age of the participants was 64±20 years (Ta-

Table 1. Demographic Information of The Participants

	Mean ± SD	
Age (years)	64±20	
Caregiver’s Age (years)	49±13	
Body Mass Index (kg/m²)	23.27±4.85	
Duration of Hospital Stay (day)	32±37	
Gender	**n**	**%**
Female	35	38.88
Male	55	61.12
Marital Status		
Single	28	31.11
Married	62	68.89
Separated	-	-
Widowed	-	-
Health Insurance Status		
Yes	84	93.33
No	6	6.67
Caregiver’s Gender		
Female	61	67.72
Male	29	32.28
Caregiver’s Degree		
Family	79	87.78
Nurse	11	12.22

SD:Standard Deviation, n: Number of Participants

Table 2. Diagnoses of The Participants

	n	%
Cerebrovascular Accidents	40	44.44
Cancer	26	28.89
Alzheimer's Disease	7	7.78
Chronic Obstructive Pulmonary Disease	4	4.44
Health Failure	3	3.33
Parkinson	3	3.33
Pneumonitis	2	2.22
Amyotrophic Lateral Sclerosis	1	1.11
Bullet Injury	1	1.11
Myopathy	1	1.11
Multiple Sclerosis	1	1.11
Anaphylactic Shock	1	1.11

n: Number of Participants

Table 3. The Barthel Index Scores of The Participants

	n	%
Total Dependence (0-20)	85	94.45
Severe Dependence (21-60)	3	3.33
Moderate Dependence (62-90)	2	2.22
Slight Dependence (91-99)	-	-
Total Independence (100)	-	-

n: Number of Participants

ble 1). Cerebrovascular accident (44.44%), cancer (28.89%), and Alzheimer (7.78%) were the most common diagnosis in palliative care patients (Table 2).

A mean score of the Palliative Performance Scale of patients was 31±17. The mean Barthel Index score was 5.79±13.50 points. According to the results, 94.45% of the patients were totally dependent, 3.33% were severely dependent, and 2.22% were moderately dependent (Table 3).

Poor muscle strength (94.44%), atrophy (93.33%), and swallowing problems (82.22%) were the most common problems (Table 4).

It was observed that 66.67% of the caregivers expect improvement in the physical function of the patients, 52.22% expect an increase in participation in daily life activities, and 13.33% expect an increase in relief of symptoms (Table 5).

DISCUSSION

This study documented a group of palliative care patients' functional status, physiotherapy needs, and mobility and performance levels. Majority of the participants were totally dependent in the present study. Muscle weakness, atrophy, and swallowing problems were the most prevalent symptoms that needed physiotherapy and rehabilitation. The most common expectations of the caregivers from the physiotherapy and rehabilitation were improvement in physical functions and activities of daily living, and decrease in symptoms.

It was shown that the functional level of patients receiving palliative care decreases (19). Patients faced severe constraints both in the palliative care process and in daily life. Uysal et al. reported the mean Palliative Performance Scale as 45 points in patients diagnosed with cancer (20). Özalp et al. calculated the mean Palliative Performance Score as 40 points in cancer patients receiving palliative

Table 4. Physical Problems and Symptoms of The Participants

	n	%
Poor Muscle Strength	85	94.44
Atrophy	84	93.33
Swallowing Problems	74	82.22
Phlegm	70	77.78
Coughing	61	67.78
Constipation	58	64.44
Joint Limitation	52	57.78
Contracture	46	51.11
Spasticity	29	32.22
Oedema	21	23.33
Flaccidity	17	18.89
Decubitus Ulcers	17	18.89
Rigidity	11	12.22
Lymphedema	5	5.55

n: Number of Participants

Table 5. Caregiver Expectations from Physiotherapy Service

	n	%
Improving physical functions	60	66.67
Increasing participation in daily life activities	47	52.22
Relief of symptoms	12	13.33

n: Number of Participants

care (90% metastasis) (4). The mean Palliative Performance Scale of the patients was 31 points in the present study. In the present study, most of the patients were hospitalized at the palliative care centre due to cerebrovascular accident, and their illnesses were severe. The average age was high, and the majority of the patients were from the geriatric group (64±20 years). These results may have been because the diseases were at an advanced stage and poor prognosis may have reduced the performance of the patients.

Motor symptoms (tremor, slowness in movements, walking disorders) and non-motor symptoms (pain, psychological problems, sleep disorders) negatively affect the life of patients (21, 22). The symptom reported most often in this study was reduced muscle strength. Atrophy, swallowing problems, phlegm, couching, constipation, joint movement limitation, and contracture were the other most prevalent symptoms, in this order. There are many studies in the literature assessing the symptoms of palliative care patients. A study indicated that dyspnoea (68%-98%), coughing (59%-94%), and depression (10%-49%) were observed in lung diseases, as well as sleep disorders, weight loss, fatigue, and anorexia (23). Fong et al. indicated that disease duration and treatment regimen may have an effect on symptoms on the musculoskeletal system problems (24). McLeod et al. investigated which exercises are preferred by physiotherapists in palliative care. They found that physiotherapists preferred mobilization, range of motion, massage, and breathing exercises, balance exercises, and transfer activities in routine rehabilitation programs. In addition, they stated that they provide training to patients who use assistive devices (25).

Caregivers and patients in the present study were asked about the condition they experienced most often after diagnosis, and their answers were: loss of functionality (walking, using their arms) and decreasing symptoms. Most caregivers have stated that patients wanted to be able to take care of themselves, stand up and walk independently. In a study including 53 patients and caregivers, the priorities of the caregivers and patients were similar. The expectations from physiotherapy are to return to the condition before the disease, to be able to move the arm and leg, and to meet basic needs (26). Studies have indicated that 85% of the patients need an assistive device in their daily life activities (19). A large proportion of patients experience difficulty maintaining their daily life. Roh et al. linked excessive restrictions and low levels of mobility in cancer patients to symptoms such as sleep disorder, fatigue, and pain (27). Restrictions may be due to the fact that the disease is at an advanced stage and the poor prognosis may have reduced the performance of the patients, both of which may be a factor that increases caregivers' responsibility. Similar to previous studies, we found how important function and meeting basic needs are in sustaining life. In this sense, physiotherapists have a very crucial role in returning patients to their pre-disease functionality. First, the needs must be determined correctly and the right targets must be identified. Objective-oriented exercises such as transfer exercises, strengthening exercises, and balance exercises will facilitate the use of limbs for a specific purpose and help them to perform basic self-care activities better.

This study had several limitations. The small sample size may have affected the results. We could not have a larger sample because there are few hospitals providing palliative care in Turkey. Our study was conducted in one centre, so the number of patients may have been insufficient. Another limitation was that the duration of hospital stay of the patients in the study was highly variable. This may have affected the caregiver's perspective on treatment and the patient's symptom level. Finally, the vast majority of the patients were fully dependent, so we were unable to identify symptoms and physiotherapy needs in dependent people.

This study evaluated palliative care patients' symptoms and independence levels, and caregivers' expectations from physiotherapy. Caregivers were aware of the importance and beneficial aspects of physiotherapy. The majority of the patients experienced several symptoms. Muscle weakness, atrophy, and swallowing problems were the most prevalent symptoms. With this study, we think that we highlighted the need for physiotherapy and rehabilitation services in patients receiving palliative care. Further studies, in parallel with the present study, involving an exercise program and a more standardized approach (age, duration of hospitalization, diagnosis) to determine symptoms are needed.

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