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Original Article

Assessment of the signs of anxiety and depression in relatives giving care to cancer patients hospitalized in the palliative care service

Palyatif bakım servisinde yatmakta olan kanser hastalarına bakım veren yakınlarının anksiyete ve depresyon belirtilerinin değerlendirilmesi

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ABSTRACT

Introduction: Previously, palliative care was an approach brought forward in terminal patients when treatment options were exhausted. However, today, the opinion that palliative care should be initiated in addition to other treatment modalities starting from the moment of diagnosing a life-threatening disease has become prominent. The symptoms of depression and anxiety are common in patients with chronic diseases such as cancer. Moving on from the fact that these findings also manifest in the relatives of patients, this study aims to identify the symptoms of depression and anxiety and to assess these symptoms in the relatives of patients hospitalized in the extensive palliative care center.

Methods: Designed as a descriptive cross-sectional study, this survey included a single group without control and was performed by conducting face-to-face interviews after obtaining consent from patient relatives. The questionnaire prepared consisted of the Beck anxiety scale (BAS), Beck depression scale (BDS), the hospital anxiety and depression scale (HADS) together with sociodemographic variables. The study included 102 volunteers and was carried out over a three-month period. Sociodemographic data of the patients were summarized using descriptive statistics. Subgroup analyses were performed using appropriate parametric and non-parametric tests.

Results: The study enrolled 102 participants providing care to a relative in the palliative care service. Among these, 61 (59.8%) were women, and 41 (40.2%) were men. The risk for depression was identified as 43.1% (n=44) according to the BAS, and as 91.2% (n=93) according to the HADS. The anxiety rate was 66.7% (n=68) according to the BAS. Among these, 36.7% (n=25) demonstrated mild anxiety, 30.8% (n=21) demonstrated moderate anxiety and 32.3% (n=22) demonstrated severe anxiety. According to HADS, the risk for anxiety was 72.5% (n=74).

Conclusion: The fact that the presence of depression and anxiety was significant in the caregivers of patients in the palliative care service warrants careful follow-up and necessary support of both the patients and their caregivers for mood disorders.

Keywords: Palliative care, cancer, caregivers, anxiety, depression.

ÖZ

Giriş: Palyatif bakım, önceleri, tedavi edici yaklaşımların tükendiği, son dönem hastalarda gündeme gelen bir yaklaşımken, günümüzde, yaşamı tehdit eden hastalıkların tanısından itibaren, tedavi edici yaklaşımlarla ek olarak gündeme gelmesi gerektiği görüşü hakimdir. Kanser gibi kronik hastalıklarda depresyon ve anksiyete belirtileri sık olarak saptanmakla birlikte hasta yakınlarında da bu bulguların saptanmasından yola çıkılarak tasarlanan bu araştırmada kapsamlı palyatif bakım merkezinde yatarak tedavi görmekte olan kanser hastalarının yakınlarında depresyon ve anksiyete belirtilerinin saptanması ve değerlendirilmesi amaçlanmaktadır.

Yöntem: Tanımlayıcı-kesitsel tipte tasarlanan araştırma kontrol grubu olmadan tek grup üzerinden yapılan bir anket çalışması olup, hasta yakınlarının onamı alındıktan sonra, yüz yüze görüşme tekniği ile uygulandı. Hazırlanan anket, sosyodemografik değişkenler ile beraber, Beck anksiyete ölçeği (BAÖ), Beck depresyon ölçeği (BDÖ), hastane anksiyete ve depresyon ölçeği (HADÖ) bölümlerinden oluşmaktadır. Çalışma, üç aylık bir sürede 102 gönüllü ile yapıldı. Hastaların sosyodemografik verileri tanımlayıcı istatistikler kullanılarak özetlendi. Uygun parametrik ve non-parametrik testler kullanılarak alt grup analizleri yapıldı.

Bulgular: Çalışmamıza palyatif bakım servisinde yakınına bakım veren 102 katılımcı dahil olmuştu. Bunların 61'i (%59,8) kadın ve 41'i (%40,2) erkekti. Depresyon sıklığını incelemek amacıyla yapılan anketler sonucunda kanser hastalarına bakım verenlerde BDÖ'ye göre %43.,1 (n=44), HADÖ'ye göre %91,2 (n=93) oranında depresyon riski saptanmıştır. Anksiyete sıklığına bakıldığında; BAÖ'ye göre %66,7 (n=68) oranında anksiyete mevcuttu. Bunların %36,7'sı (n=25) hafif , %30,8'i (n=21) orta, %32,3'i (n=22) şiddetli anksiyete gösteriyordu. HADÖ ile %72,5 (n:74) oranında anksiyete riski mevcuttu.

Sonuç: Palyatif bakım servisinde hastalara bakım verenlerde ihmal edilemeyecek düzeyde depresif ve kaygılı duygu durum izlenmiş olması, hastaların yanı sıra bakım verenlerin de duygu durum bozukluğu açısından iyi gözlenmesi ve gerekli desteğin sağlanması açısından önemlidir.

Anahtar Kelimeler: Paltatif bakım, kanser, bakım verenler, anksiyete, depresyon.

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Introduction

According to the World Health Organization (WHO) definition, palliative care is an approach that improves the quality of life of patients and their relatives who are facing problems associated with life-threatening diseases and focuses on the early detection and treatment of physical, psychosocial, social, and spiritual issues. Previously, palliative care was an approach brought forward in terminal patients when treatment options were exhausted. However, today, the opinion that palliative care should be implemented in addition to other treatment modalities starting from the moment of diagnosing a life-threatening disease has become prominent [1].

Survival rates of the diseases increased parallel to the medical advances. These improvements have brought new problems to deal with. The family units have shrunk, the number of individuals involved in business life in the family has increased, and the number of individuals who could take care of a family member struggling with chronic illnesses has decreased in the twenty-first century. Risk factors such as traumatic life events, physical disorders, family disputes and conflicts that trigger the emergence of mental disorders have been described in 2004 WHO report under the topic "prevention of mental disorders" [2]. It is emphasized in this report that the long-term (chronic) health problems increase the risk of depression. One of the physical health problems of long-term life threat, ranked as one of the risk factors for mental problems, is cancer [3]. Depending on their disease and treatment methods, cancer patients are experiencing many physical and psychological symptoms such as loss of appetite, fatigue, muscle aches, decreased energy, dry mouth, gastrointestinal complaints, shortness of breath, and depression [4]. Caregivers of cancer patients have difficulty in managing the patient's symptoms and performing routine daily activities. It has been pointed out that the challenges associated with symptom management of caregivers cause some significant problems such as stress, anxiety, depression, fatigue, insomnia, excessive sleeping, loss of appetite, decreased activity, self-blame, concentration problems, and difficulty in decision making [5].

Cancer that requires a long-lasting treatment can negatively affect the quality of life by causing socioeconomic and psychological problems. Depression, which is at the top of these psychological/mental problems, is often overlooked or misdiagnosed because it is often masked by another disease. On the other hand, anxiety often accompanies depression. Anxiety in depressive mood episodes is a condition that complicates depression and makes treatment difficult. The symptoms of depression and anxiety are common in patients with chronic diseases such as cancer. Moving on from the fact that these findings also manifest in the relatives of patients, this study aims to identify the symptoms of depression and anxiety and to assess these symptoms in the relatives of patients hospitalized in the extensive palliative care center.

Methods

This study was approved by the Local Ethics Committee of İzmir Kâtip Çelebi University Atatürk Training and Research Hospital (Date: 11.11.2013, No 219). The descriptive cross-sectional study consisted of a single group that included cancer patients who applied to the İzmir Kâtip Çelebi University Atatürk Training and Research Hospital Palliative Care and Support Services. There was no control group. This survey was performed by conducting face-to-face interviews after obtaining consent from patient relatives. The data collection tool consisted of the Beck anxiety scale (BAS), Beck depression scale (BDS), the hospital anxiety and depression scale (HADS) together with sociodemographic variables.

Hospital Anxiety Depression Scale (HADS): The hospital anxiety depression scale (HADS) was designed by Zigmond and Snaith to detect significant anxiety and depression in general medical patients. Validity and reliability studies for the Turkish version of this inventory were performed by Aydemir et al. The purpose of the scale is not to diagnose, but to identify the risk group by rapidly screening anxiety and depression. The scale can also be used to monitor changes in the patient's emotional state. HADS comprises 14 items, seven of which relate to anxiety symptoms and seven to depressive symptoms. In Turkey, the anxiety sub-scale cut-off score was found as 10/11, and the depression subscale cut-off score as 7/8. It was reported that an anxiety score that is greater than 10 and the patients having depression scores over 7 can be classified as "under risk" patients [6].

Beck Depression Scale (BDS): The BDS consists of 21 self-rated questions, each answer scored on a scale of 0–3 summing up to a total ranging from 0 to 63. Validity and reliability study of the Turkish version of this inventory was performed by Teğin (1980) and Hisli (1989) [7].

Beck Anxiety Scale (BAS): The BAS scale was developed by Beck et al. in 1988 in response to the need for a scale that was able to distinguish anxiety from depression. It is designed to measure the experienced severity of anxiety symptoms. The Beck Anxiety Inventory consists of 21 items and is scored from 0 to 3. The validity and reliability study of the Turkish version of this inventory was performed by Ulusoy et al. in 1998 [7].

Statistical Analyses

No sampling was done for the current study. However, it was aimed to reach all caregivers who were hospitalized for a minimum of three months. Caregivers were excluded from the study if they were not willing to participate in the survey, had missing answers to survey questions, diagnosed psychiatric distress, and used drugs that can trigger depression or anxiety. Statistical analysis was performed with the Statistical Package for the Social Sciences (SPSS, IBM, Armonk, NY, USA). Socio-demographic data of the patients were summarized using descriptive statistics. The Chi-square test was performed for subgroup analyses. The significance level was set at $p<0.05$.

Results

Our study included 102 participants giving care to a relative in the palliative care service. Among these, 61 (59.8%) were women and 41 (40.2%) men. The majority (75.5%) of the participants were married (n=77) while 20.6% (n=21) and 3.9% (n=4) of all caregivers were single and widowed/divorced respectively. Of the participants, 40.2% (n=41) were graduated from high school or university. The demographic data of caregivers are given in Table 1.

Table 1. Demographic data and characteristics of caregivers

		n	%
Gender	Women	61	59.8
	Men	41	40.2
Marital status	Single	21	20.6
	Married	77	75.5
	Widowed / Divorced	4	3.9
Education status	Illiterate	6	5.9
	Literate	2	2.0
	Primary school	37	36.3
	Secondary school	16	15.7
	High school	21	20.6
	University	20	19.6
Monthly income	<500 TL	18	17.6
	500-1000 TL	49	48.0
	1001-2000 TL	17	16.7
	2001-3000 TL	9	8.8
	>3000 TL	9	8.8
Degree of proximity	First-degree relative	56	54.9
	Second-degree relative	8	7.8
	Third-degree relative	2	2.0
	Other	36	35.3

Of the caregivers, 54.9% were first-degree relatives and 7.8% second-degree relatives. Most of the caregivers (83.3%, n=85) knew the diagnosis of their patients while 15.7% did not know. The most common diagnoses were breast cancer with 9.8% (n=10), then colon with 4.5% (n=5) and following cancer types with decreasing frequency: stomach, ovary, lung, liver, and testicular cancers. A group of caregivers (6.9%) had cancer-diagnosed relatives other than the current patient.

According to the questionnaires delivered to identify the frequency of depression in caregivers of cancer patients, the risk for depression was identified as 43.1% (n=44) according to the BAS, and as 91.2% (n=93) according to the HADS. The anxiety rate was 66.7% (n=68) according to the BAS. Among these, 36.7% (n=25) demonstrated mild anxiety, 30.8% (n=21) demonstrated moderate anxiety, and 32.3% (n=22) demonstrated severe anxiety. According to HADS, the risk for anxiety was 72.5% (n=74).

As a result of the analysis, no significant differences were found between the caregivers' depression status and all other variables such as gender, educational status, monthly income, marital status, the degree of proximity to the patient, knowing the diagnosis, and knowing another cancer patients in terms of BDS results. There was no significant difference between anxiety level and other variables in the light of BAS results whereas a significant relationship between the gender of caregivers and anxiety level (p=0.041) was determined.

After the detailed analysis of scale questions in terms of BAS results, a strong relationship has been detected between depression status and some other symptoms such as thought of not being able to relax (p=0.013), dizziness/vertigo (p=0.013), feeling of horror (p=0.006), sense of irritability (p=0.003), fear of losing control (p=0.001), sense of fear (p=0.001), dyspepsia (p=0.009), and feeling of faintness (p=0.044).

Discussion

High incidence of depression has been reported among cancer caregivers in various scientific studies performed both in the world and in Turkey. An increase in depressive and anxious findings was observed in the palliative care group, regardless of whether the caregivers were from family or professional health care workers. Having a palliative care patient is strongly related to mood state, daily quality of life, and sleep quality [8-13]. Many scientific studies have questioned the depressive mood status by using BDS. Depression status of caregivers in our study was assessed by HADS in addition to the BDS. The frequency of depression in HADS was found higher, depending on the questions included in the surveys. It is understood that it will be essential to apply both scales to assess caregivers' emotional states. BAS and HADS scales were also employed in our study to determine the anxiety status of caregivers. Many studies have focused only on the depressive mood of caregivers; however, we thought that the effects of anxiety, as well as depressive mood on the caregivers, were also of interest.

The HAD scale was used in a study performed in a regional cancer center in Ontario-Canada on a group of breast cancer patients and 89 educated health care providers. During the three-year period, both patients and caregivers were more depressed at similar rates (11% and 12% respectively). The notable finding in the mentioned study is that anxiety rates were found higher in caregivers than in patients (35% and 19%, respectively) (p=0.009) [9]. The rates obtained from our study were relatively high.

A study performed by Çivi et al. and focused on the factors affecting depression and quality of life in caregivers of cancer patients reported similar results with our research by using BDS. According to the study results, 65.5% of the caregivers were normal, whereas 24.5% had mild, 7.3% moderate, and 2.7% severe depression. The gender, occupation, education, and marital status of the caregivers did not affect the depressive condition (p>0.05) [10]. In another study, the HAD scale was applied to 33 cancer patients and 33 caregivers. Anxiety and depression were detected as 76% among patients and caregivers and among those who knew their diagnosis at the 2/3rd of the chemotherapy treatment, mild anxiety and depression were detected in 26% [14]. According to the data, it has been discovered that it is important to provide training, close follow-up and psychological support to the patients and their caregivers.

A study performed by Karabulutlu et al., which included 150 caregivers reported that 46% of the caregivers had anxiety and 72% of them had a depression risk [11]. The frequency of anxiety and depression of the mentioned study is parallel to our study. Grov et al. aimed to find out the relationship between SF-36 quality-of-life questionnaire and HADS in 49 female with breast cancer and 47 male with prostate cancer in their study. They reported that anxiety was found in both genders with equal rates and excess density, while no significant difference was detected regarding depression level. According to the HADS, depression rate is significantly more in female caregivers than the normal female population [13]. There was no significant difference in depression rates between both genders in our study.

Young Sun Rhee et al. investigated the effects of emotional burden on depression in 310 cancer caregivers and used BDS scale as well as the quality-of-life scale of cancer caregivers. They observed high levels of depression in 67% of caregivers and very high levels in 35% [15]. Depression frequency obtained from the mentioned study was nearly similar to the frequency of our research obtained with HADS.

Sarı et al. used the Pittsburgh Sleep Quality Index (PSQI) and the BDS questionnaires in 102 cancer caregivers. The vast majority of caregivers stated that they had a sleeping problem (85.3%) and 40.2% of them were experiencing symptoms of depression [16]. The depression symptom percentage of the mentioned study (40.2%) was almost the same as our percentage (43.1%). Cipolletta et al. compared the dependency scales of BAS and BDS in 50 cancer caregivers. Three different profiles about how caretakers use their facilities to give and/or get help were determined by this study. The obtained data has shown that if the status of providing support and experience and personality traits of caregivers are compatible, the anxiety and depression levels decreased; otherwise their levels increased. [17]. One possible limitation of our study may be related to the dependency of the variables.

Conclusion

The fact that the presence of depression and anxiety was significant in the caregivers of patients in the palliative care service warrants careful follow-up and necessary support of both the patients and their caregivers for mood disorders.

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Financial disclosure: None

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