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Research Article

Depression, anxiety and stress levels in caregivers of palliative patients: a descriptive, cross-sectional study

Palyatif bakım hastasına bakım verenlerde depresyon, anksiyete ve stres düzeyi: tanımlayıcı-kesitsel tipte bir çalışma

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ABSTRACT

Introduction: Caregiving of the palliative patient is a stressful and challenging condition, affecting the caregiver's physical, emotional, psychological, and social well-being. This study aimed to determine depression, anxiety, and stress levels of the caregivers of palliative care patients.

Methods: This cross-sectional study was conducted with caregivers (n=234) in a palliative care unit of a hospital in Balıkesir and Edirne between April 2018 and January 2019. The data were collected by a socio-demographic questionnaire and the Depression Anxiety Stress Scale (DASS).

Results: Severe and extremely severe depression was detected in 20.1% of the caregivers of palliative patients. Anxiety and stress were found in 32% and 12.4% of the respondents, respectively. The DASS score was higher in participants who had a chronic disease or were living with the patients.

Conclusions: Providing psychosocial support to caregivers of palliative patients may improve the quality of life of both the patients and the caregivers. Necessary interventions are recommended not only to the patients but also to the caregivers.

Keywords: palliative care, depression, anxiety, stress, caregiver

ÖZ

Giriş: Palyatif hastasına bakım vermek stresli ve zorlayıcı bir durum olup bakım verenin fiziksel, duygusal, psikolojik ve sosyal refahını etkilemektedir. Bu çalışmanın amacı palyatif bakım hastasına bakım verenlerin depresyon, anksiyete ve stres düzeylerinin ve bunları etkileyen faktörlerin incelenmesidir.

Yöntem: Kesitsel tipteki bu çalışma Balıkesir ve Edirne ilinde yer alan birer hastanenin palyatif bakım ünitesinde yatan hastaların bakım verenleri (n=234) ile yürütülmüştür. Çalışma Nisan 2018 ve Ocak 2019 tarihleri arasında yürütülmüştür. Veriler sosyo-demografik veri toplama formu ve Depresyon Anksiyete Stres Ölçeği (DASÖ) ile toplanmıştır.

Bulgular: Çalışmada da palyatif hastasına bakım verenlerin %20,1'inde ileri ve çok ileri düzeyde depresyon saptanmıştır. Bu değer anksiyete için %32, stres için %12,4 düzeyindedir. Kronik hastalığı olan ve hasta ile aynı yerde ikamet edenlerde DASÖ puanı daha yüksek düzeyde bulunmuştur.

Sonuç: Palyatif hastasına bakım verenlere psikososyal destek sağlanması hem hasta hem de bakım verenin yaşam kalitesini arttırabilir. Sadece hastaya değil bakım verene de gerekli müdahalelerin yapılması önerilmektedir.

Anahtar kelimeler: palyatif bakım, depresyon, anksiyete, stres, bakım veren

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Introduction

In 2002 the World Health Organization (WHO) defined palliative care as an approach that improves the quality of life of the patient and his/her family, facing the life-threatening diseases by means of an early detection, evaluation, and treatment of the pain and other physical, psychosocial, and spiritual issues [1]. This definition emphasizes that the patients and families should be served to start from the early diagnosis, and the families should also be supported after the death of the patient [2]. By definition, palliative care focuses on the multidimensional aspects of patients and their families, including physical, psychological, social, spiritual, and interpersonal care components [3].

The need for palliative care is a substantial source of stress for patients and their caregivers [4]. As caregiver responsibilities increase, the relationship between the caregiver and caretaker may turn into a unidirectional, dependent, constant, intensive, and long-term necessity, shouldered alone by the caregiver, which may lead to troubles in the caregivers' lives [5, 6]. The caregiving of patients with severe chronic diseases can result in a heavy physical and emotional burden in the caregivers, and can often result in withdrawal from their professional, family, and social lives [7]. The caregiver burden increases as the patient's condition deteriorates and the mental health status worsens [4]. Health changes seen in the families of patients receiving palliative care were mostly psychological disorders, depression, anxiety [8], sleep disturbances, lack of concentration [9, 10], fatigue, and increased risk of mortality [11]. It is also known that caregiving family members are coping with the feelings of grief and loss associated with not only caregiving but also the loss of their relatives [12].

The family/caregivers of palliative care patients are substantially affected by the difficulties of the disease [9]. Mostly due to time constraints, healthcare professionals often focus on the patient and may be reluctant to do extensive screening of the caregiver issues. The evaluation of the caregiver is usually informal and undocumented, and this makes the caregivers' need for support less visible. Besides, caregivers are often hesitant to express their needs [13].

It is thought that determining depression, anxiety, and stress levels of the primary caregivers caring for the palliative care patients may contribute to the current literature. Psychosocial support interventions for these individuals can be planned in this way. This research was carried out as a descriptive cross-sectional study to determine the levels of depression, anxiety, and stress of caregivers in the palliative care unit.

Research questions

1. What are the levels of depression, anxiety, and stress in caregivers of palliative care patients?
2. What is the relationship between depression, anxiety, and stress levels with socio-demographic data in the caregivers of palliative care patients?

Methods

This cross-sectional study was conducted with caregivers (n=234) in a palliative unit of two hospitals in Balıkesir and Edirne between April 2018 and January 2019. The study included volunteering caregivers without any communication problems, who had a patient in the palliative unit. No sampling was done, and the 234 participants who were reached within the specified time interval were included in this study. The data were collected by a socio-demographic questionnaire and the Depression Anxiety Stress Scale (DASS).

Socio-demographic Data Collection Questionnaire

This form contains 10 questions about the socio-demographic characteristics of the individuals and the following six questions: “How much time do you spend with the patient?”, “Since when are you giving care to this patient?”, “Are you living with the patient?”, “What is the most challenging issue during caregiving?”, “How do you cope with possible difficulties?”, and “What do you expect from healthcare professionals?”.

Depression Anxiety Stress Scales (DASS)

The Depression Anxiety Stress Scales (DASS) have 42 items, comprising three 14-item psychometric scales consisting of 4-point Likert-type questions, querying the symptoms of depression, anxiety, and stress. The validity and reliability study of the scale was performed by Akın and Cetin in 2007. Concerning the reliability of the Turkish version of the scale, Cronbach's alpha coefficients for depression, anxiety, and stress were calculated as 0.92, 0.86, and 0.88, respectively. The item total score correlations were 0.48-0.70 for depression, 0.33-0.59 for anxiety, and 0.43-0.70 for the stress parameters [14]. The interpretation of depression, anxiety, and stress levels is provided in Table 1.

Table 1. Interpretation of DASS scores

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely severe	28+	20+	34+

Ethical Approval

This study was approved by the Clinical Research Ethics Committee of Trakya University Faculty of Medicine (Approval date: 19.02.2018; no: TÜTF-BAEK 03/26), and the necessary permissions were taken from Edirne and Balikesir Provincial Health Directorates. Additionally, written/oral informed consent was obtained from each participant.

Statistical Analysis

Statistical analysis was performed with the Statistical Package for the Social Sciences version 21 (SPSS, IBM, Armonk, NY, USA). Frequency, percentage, mean, and standard deviation were given for the descriptive statistics. Normal distribution of the quantitative data was verified by the Kolmogorov-Smirnov and Shapiro Wilk tests. The Independent t-test and One-Way ANOVA were used for normally distributed variables, while the Kruskal-Wallis and Mann-Whitney U tests were used for skewed variables to compare more than two independent groups. The results were evaluated with a confidence interval of 95%, and the level of significance, p, was set at 0.05.

Results

Table 2 contains socio-demographic characteristics of the participants. The mean age was 49.1±15.2 years. The median caregiving duration was six months (minimum 1 month; maximum 300 months). The majority of the participants were women and married (75.6% and 74.4%, respectively). Of the participants, 55.6% were graduated from primary school, 79.9% had children, 55.3% were housewives, and 43.2% reported to have a moderate financial status. The majority of the participant had no chronic disease.

Regarding the degree of consanguinity, 30.8% of the caregivers were children, and 28.2% were spouses of the patients. More than half of the participants were living with the patients. On the other hand, almost half of the participants stated that they were spending approximately 13 hours per day with the patient. The caregivers were experiencing mostly (44.9%) physical stress during caregiving, and almost half of them reported that they did nothing to alleviate this suffering. Most of the caregivers requested that health professionals should increase caregiving.

Table 2. Socio-demographic characteristics of the participants

Socio-demographic characteristics	**Mean**	**SD**
Age	49.1	15.2
	Number	**%**
Sex		
Female	174	74.4
Male	60	25.6
Marital status		
Married	177	75.6
Single	44	18.8
Widowed	13	5.6
Educational status		
Primary school or below	130	55.6
Secondary school	67	28.6
High school or above	37	15.8
Having Children		
Yes	187	79.9
No	47	20.1
Occupational status		
Housewife	124	53.0
Government employee	26	11.1
Retired	34	14.5
Self-employed	50	21.4
Monthly income		
Below the minimum wage	40	17.1
Minimum wage	101	43.2
Above the minimum wage	93	39.7
Having Chronic Disease		
Yes	70	29.9
No	164	70.1
Degree of consanguinity with patient		
Caregiver	25	10.7
Parent	24	10.3
Sibling	10	4.3
Spouse	66	28.2
Child	72	30.8
In-law	20	8.5
Other	17	7.3
Living with the patient		
Yes	134	57.3
No	100	42.7
Daily duration of caregiving		
0-3 hours	48	20.5
4-7 hours	39	16.7

8-12 hours	42	17.9
13 hours and above	105	44.9
Difficulties while caregiving		
No difficulties	77	32.9
Physical difficulties	105	44.9
Emotional and psychological difficulties	52	22.2
Ways of coping with the difficulties during caregiving		
Nothing	112	47.9
Social support	46	19.7
Hobby	26	11.1
Spiritual belief	35	15.0
Support from medical staff	15	6.4
Expectations from healthcare professionals		
Nothing	154	65.8
The number of beds should be increased	15	6.4
Caregiving should be increased	57	24.4
Individuals should be kept informed	8	3.4

SD: Standard Deviation.

Table 3 presents scores received from the DASS. Severe and extremely severe depression was detected in 20.1% of the caregivers. This proportion was 32% and 12.4% for anxiety and stress, respectively.

Table 3. Distribution of the DASS scores.

Dependent variables	**Normal** n (%)	**Mild** n (%)	**Moderate** n (%)	**Severe** n (%)	**Extremely severe** n (%)
Depression	48.3 (113)	12.8 (30)	18.8 (44)	15.8 (37)	4.3 (10)
Anxiety	42.3 (99)	6.8 (16)	18.8 (44)	15.8 (37)	16.2 (38)
Stress	53.4 (125)	12.8 (30)	21.4 (50)	10.3 (24)	2.1 (5)

Table 4 shows the mean scores of DASS obtained by participants regarding their socio-demographic characteristics. Mean DASS scores of the participants with chronic diseases were statistically different from those without any chronic diseases; the mean DASS scores were higher in the participants with chronic illnesses. On the other hand, the mean DASS scores of the participants residing with the patients were statistically different from those who were residing somewhere else; the mean DASS scores were higher in the participants who were living with the patients.

Table 4. Comparison of the DASS scores according to the socio-demographic characteristics.

Socio-demographic characteristic		**Depression**	**Anxiety**	**Stress**
		Mean±SD	**Mean±SD**	**Mean±SD**
Sex	**Female**	2.19 (1.32)	2.67 (1.56)	2.0 (1.78)
	Male	2.03 (1.22)	2.29 (1.49)	1.78 (0.96)
		t=0.807 p= 0.421	t=1.662 p= 0.098	t=1.279 p= 0.202
Having chronic disease	**Yes**	2.46 (1.40)	2.99 (1.56)	2.33 (1.26)
	No	2.02 (1.23)	2.39 (1.51)	1.79 (1.08)
		t=2.401 p= 0.017	**t=2.734 p= 0.007**	**t=3.333 p= 0.001**
Living with patient	**Yes**	2.38 (1.34)	2.84 (1.54)	2.15 (1.25)
	No	1.84 (1.17)	2.20 (1.49)	1.68 (0.98)
		t=3.226 p= 0.001	**t=3.210 p= 0.002**	**t=3.108 p= 0.002**

Independent t test

The mean DASS scores were not statistically different concerning sex, marital status, educational status, having children, occupational status, monthly income, living with the patient, and the degree of consanguinity with the patient (p>0.05).

Discussion

Although DASS is not a diagnostic tool, the proportions of moderate or higher levels of depression, anxiety, and stress symptoms should be considered by health professionals.

In this study, 20.1% (n=47) and 32% (n=75) of the participants had severe and extremely severe depression and anxiety scores, respectively. In the literature, there have been other studies indicating the high levels of anxiety [15] and depression [2, 16] among the caregivers of palliative patients. A study performed by Götze et al. [17] stated the high level of depression and anxiety rate as 29.2% and 31.9%, respectively. Oechsle et al. detected that 55% of male and 36% of female caregivers had moderate or severe anxiety, while 36% of male and 14% of female caregivers had moderate or severe depression [16]. Additionally, Palacio et al. found that the anxiety scores of caregivers were higher than depression scores [18]. Also, Park et al. detected high levels of anxiety (4.6%) and depression (16.2%) scores in the caregivers of cancer patients [19]. Perez-Ordonez et al. detected 72% anxiety in the caregivers of palliative cancer patients [20]. In another study, the anxiety level in caregivers was found higher than normal individuals [15]. On the other hand, the mental health of the caregivers also affects the quality of caregiving. For this reason, healthcare professionals who focus on caring for the patients should also take into consideration that the caregivers need psychological support. Constant psychological support and interventions should also be provided, especially for the risk group.

In this study, stress levels of the participants were 12.4% (n=29) according to the DASS. A study performed with palliative cancer patients stated that 18% of cancer caregivers had high stress levels. It has been reported that caregiving for a palliative patient is stressful, challenging, and may affect the physical, emotional, psychological, and social well-being of the caregiver [6]. For this reason, it may be beneficial for caregivers to receive psychological education such as coping with stress, developing problem-solving skills, expressing their emotions, and increasing social support resources by healthcare professionals.

In this study, 44.9% (n=105) of caregivers stated that they experienced mostly physical strain during caregiving. Family or caregivers participate actively in caring activities of cancer patients such as eating/drinking, dressing, bathing, going to the toilet, clothing, massaging, and exercising, as well as their transport and deciding treatment options [21]. This may lead to physical strain for caregivers. It has been stated in the literature that family members often experience caregiver fatigue. The reason for this is that caregivers do not see alternative ways of getting help, or they may be the only person as a primary caregiver [9]. Besides, a study conducted with family members stated that they need training on how to respond to physical, social, spiritual, and psychological difficulties during caregiving [11]. In this sense, it is recommended that psychiatric nurses or Consultation Liaison Psychiatry (CLP) nurses should provide education, support, and counseling to caregivers.

It has been reported that information and support may be useful to support caregivers for palliative patients [17]. In this study, 19.7% (n=46) of the caregivers stated that they receive social support as a method of coping with difficulties during caregiving. In a study with caregivers of palliative cancer patients, the main coping strategies were defined as receiving support from God and prayers, family and friends, religious institutions, and the health and palliative team [6]. It was also detected in a study performed among cancer caregivers that most caregivers used cognitive restructuring and social support as coping strategies [18]. It is important to show caregivers the sources of social support and to teach how to use them. It is also recommended that healthcare professionals offer and show caregivers of palliative patients to use social support resources.

In this study, 24.4% (n= 57) of the individuals expect healthcare personnel to increase the given care, while 3.4% (n=8) want further information. Although it was not mentioned in the questionnaire, most caregivers mentioned during the interview that they were satisfied with the service of health professionals. The results obtained from qualitative interviews with family caregivers showed that continuity of personal, informational, and organizational caregiving could provide a sense of comfort, assurance, and control [17]. Knowledge can help caregivers solve problems, reduce anxiety, and increase control feelings [8]. Harding et al. performed a study with caregivers of palliative cancer patients and reported that individuals should be trained in being prepared for their caregiving roles, asked for clear and specific information about the patient's condition, and be emotionally supported by health professionals [10]. Therefore, it is crucial that healthcare professionals cooperate with caregivers and provide information support for caregiving.

In this study, the mean scores of depression, anxiety, and stress levels of caregivers with chronic diseases were higher than those who had no chronic diseases. In parallel with our findings, Geng et al. found a positive relationship between chronic diseases and depression [22]. Thus, it is thought that chronic diseases can trigger existing psychological problems.

The mean scores of depression, anxiety, and stress of the participants who were living with the patients were higher than those who were living somewhere else. Zyada et al. found that living in the same residence as the patient was a predictor of caregiver anxiety and depression [23]. However, in a study conducted with caregivers of schizophrenia patients, living with or without the patient did not affect the stress levels of caregivers [24]. In this study, caregivers with chronic disease and living with their patients constitute the risk group. Therefore, it is recommended to provide the necessary psychological support to this group of caregivers.

Limitations

A cross-sectional design was used in this study. Therefore, it is difficult to state a relationship between the observed predictors and depression/anxiety. Another limitation of this study was that the variables related to the patients were not asked. Furthermore, the diagnostic evaluation of the psychiatric conditions of the caregivers (such as previous medical care, use of psychotropic medications, etc.) was not performed. These dimensions should be considered in future studies.

Conclusion

If the caregiver cannot provide efficient care, the caregiving stress may harm the health and well-being of both the caregivers and patients [19]. Therefore, assessment and support for caregivers of palliative patients should be incorporated into clinical practice. Although the problems experienced by the caregivers of palliative patients are known, they do not receive sufficient support. In particular, monitoring the mental status of caregivers with regular screening methods, and making necessary interventions to the risk groups can prevent larger crises.

It was detected in this study that 20.1% of the caregivers of palliative patients had severe and extremely severe depression. This value was detected as 32.0% and 12.4% for anxiety and stress, respectively. As a result, it is important to provide stress relief training, social support, problem-solving skills, expressing emotions, forming interaction groups with similar caregivers, and necessary medical support. Empowering the caregiver improves the quality of life of both the caregiver and the patient.

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