



Original Article

Care burden and depression levels in the relatives of patients with bipolar disorder

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Abstract

Objectives: Bipolar disorder (BD) is an affective disorder characterized by a chronic course and places a heavy financial and moral burden on caregivers. The study was carried out to identify care burden, depression, and related factors in the caregivers of bipolar patients.

Methods: This descriptive and cross-sectional study was conducted on the relatives of 71 BD-diagnosed patients hospitalized in the psychiatry clinic of a tertiary hospital. Data were collected using the introductory information form, the Zarit Caregiver Burden Scale, and the Beck Depression Inventory (BDI).

Results: The mean age of the caregivers was 47.55 ± 9.03 , and 52.1% of them were women. A significant difference was evident between the BDI scores of caregivers, being single, having a low education level, not working in any job, not having any social security, living in an extended family, needing a helper in caring for their patients, having a physical illness and increasing the number of children they have ($p < 0.05$). The relationship between the Zarit Scale scores and the caregivers' lack of social security, closeness to their patients as a spouse, child, or sibling, and living in a different house from the patients also yielded a significant difference ($p < 0.05$).

Conclusion: Providing psychoeducation to caregivers concerning coping skills, stress management, and symptoms and episodes of the disease may bring benefits in alleviating their care burden and depression symptoms.

Keywords: Bipolar disorder; care burden; depression; psychiatric nursing.

Bipolar disorder (BD) is an affective disorder characterized by a chronic course and a prevalence rate of 0–5%, which includes manic and depressive episodes or mixed episodes in which both are observed, and may recur in certain periods or have well-being. With a high mortality rate, BD is associated with biological, genetic, and psychosocial factors, adversely affects patients' daily lives, and places a heavy financial and moral burden on caregivers.^[1,2]

Daily responsibilities in private and social life coupled with the intense, complex, and prolonged caregiving process lead eventually to the emergence of burden on caregivers and degrade their quality of life.^[3,4] Some lines of evidence reveal the associ-

ation between the burden of caregiving and the development of physical and mental health problems in caregivers.^[3,5]

Perlick et al.^[6] found that 89% of caregivers of patients with BD experienced a care burden, whereas Blanthorn-Hazell et al.^[7] reported that caregivers experienced a heavy burden in their study. In our country, Ayyıldız and Babacan Gümrük reported that caregivers of patients with BD experienced a care burden.^[8]

Depression is one of the most common mental health problems in caregivers of patients with BD.^[9,10] Caregivers with no social support who have to grapple with problems on their own are reported to experience feelings, such as stress, anger, helplessness, anxiety, despair, and burnout.^[9,11] In a study con-

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ducted on caregivers of patients with BD, it was reported that caregivers had high levels of depression.^[6] Depression negatively affects the quality of life, social and occupational functionality, and close relationships.^[9,12] Such feelings along with failure to receive help during caregiving, are likely to degrade the quality of this process, contributing to the development of burnout and depression in caregivers.^[6,10]

Considering all these, psychiatric nurses should not only focus on the patient but also observe the caregivers and should be aware that the caregivers are under great risk and evaluate the families and caregivers with the protective, consultant, and educator roles of psychiatric nursing in mental health and make the necessary practices, plans, and interventions.^[13] Psychiatric nurses, who are important members of the treatment team, should observe the difficult process experienced by the family, identify their problems, and provide families with the psychoeducation they need.^[14] It has been found that the amount of burden on caregivers decreases with the increase in caregivers' knowledge about the disease process and learning effective coping methods with their patients.^[14,15] In a study by Lim and Ahn, it was found that the less information the caregiver has about the disease process, the more the caregiver and other members of the family use more negative coping methods and this increases the amount of burden in the caregiver.^[16]

Within this context, this study set out to identify the caregiver burden, depression, and associated factors in the relatives of BD patients.

Research Questions

1. Do demographic characteristics of caregivers play a significant role in their care burden?
2. Do demographic characteristics of caregivers play a significant role in their depression levels?
3. What is the relationship between depression and care burden in caregivers?

Materials and Method

Study Design

This is a descriptive and cross-sectional study performed to identify the caregiver burden, depression, and associated factors in the relatives of BD patients.

Study Context and Duration

The present study was conducted on the relatives of BD-diagnosed patients hospitalized in the psychiatry clinic of Pamukkale University Health Research and Practice Center between September 1, 2017, and March 1, 2018. This research was supported by a grant from Aydin Adnan Menderes University Scientific Research Projects Fund (HF-17021).

What is presently known on this subject?

- Bipolar disorder (BD) is an affective disorder characterized by a chronic course and places a heavy financial and moral burden on caregivers. The burden of caregiving reveals the development of physical and mental health problems in caregivers. Lack of help during caregiving contributes to the development of burnout and depression in caregivers.

What does this article add to the existing knowledge?

- It has been shown that psychoeducation of caregivers about coping skills and stress management, as well as disease symptoms and periods, can be beneficial in alleviating the burden of care and depression symptoms.

What are the implications for practice?

- While providing care and treatment, psychiatric nurses should have a holistic approach that includes not only the patients but also the caregivers of the patients.

Study Population and Sampling

As far as official documents are concerned, 590 BD-diagnosed patients were hospitalized in our psychiatry clinic between January 1, 2016, and January 1, 2017. Excluding repeated hospitalizations, the number of in-patients diagnosed with BD during this 1-year period amounted to 105.

A power calculation was performed using the G*Power analysis program to predict the number of participants required to specify the factors impacting the caregivers of BD patients. Using a significance level of $p=0.05$, 80% power, effect size of 0.3, and an alpha level of 0.05, it was calculated that 71 participants (one caregiver per patient) needed to be assigned to each group.

Inclusion and Exclusion Criteria

The inclusion criteria were specified as the absence of hearing, comprehension, or vision problems, being a caregiver of a BD-diagnosed patient, giving informed consent for participation in the study, and being 18 years or older. Exclusion criteria consisted of having hearing, comprehension, or vision problems and being an acquaintance who is not a relative of the patient.

Ethical Considerations

The ethical approval of the study was granted by the Non-Interventional Clinical Research Ethics Committee of Aydin Adnan Menderes University (number: 2017/32; date: August 23, 2017). In addition, the required approval was also received from the Psychiatry Department of Pamukkale University, where the study was conducted. The participants were provided with an informed consent form containing information about the aim of the study, and their verbal consent was obtained. To ensure that the participants would give sincere and truthful responses, it was stressed in the questionnaire that the information received would be kept completely confidential. The study was carried out in accordance with the Helsinki Declaration.

Data Collection

A questionnaire with three forms, including a Personal Information Form containing sociodemographic information about the respondents, the Zarit Caregiver Burden Scale (ZCBS), and the Beck Depression Inventory (BDI), was administered as the data collection tool. The purpose, method, scope, and duration of the study were explained to the participants. They were accompanied by the researcher while responding to the questionnaire items. The task of filling out the questionnaires took roughly 20–30 min and the resulting data were collected during 6 months.

Personal Information Form

This form consists of multiple choice items questioning caregivers' demographic characteristics, family and life characteristics, the status of smoking and alcohol use, health status, the presence of psychiatric history in the family, characteristics of the patients they care for, and the support they receive during caregiving. The form also includes one open-ended item regarding what sort of support should be provided to caregivers.^[6]

BDI

BDI, whose original form was constructed by Beck et al.,^[17] was adapted into Turkish by Hisli in 1989.^[18] Each item is scored between 0 and 3, and the score to be obtained from the inventory ranges between 0 and 63 points.^[17] Its Cronbach's alpha coefficient was 0.80, and the cutoff point was set at 17.^[18] The intervals 11–17, 18–29, and 30–63 are defined as "mild," "moderate," and "severe," respectively. The Cronbach's alpha coefficient of the inventory was 0.92 in our study.

ZCBS

Constructed by Zarit et al.^[19] in 1985, this scale is made up of five subscales, such as psychological tension and impaired private life, irritability and restrictedness, impairment in social relations, economic burden, and dependence. Its validation and reliability assessment in Turkish was carried out by Özlu in 2009.^[20] In the Zarit scale, composed of 19 questions and scored between 19 and 95, high scores implicate high levels of distress suffered by the caregiver.^[19] While Cronbach's alpha coefficient of the Turkish version of the Zarit scale was 0.83,^[20] that of our study was found as 0.82.

Data Analysis

SPSS version 22 (the Statistical Package for the Social Sciences) package program was used to evaluate the data and the assumption of normal distribution was checked by Kolmogorov–Smirnov test. Descriptive statistics, Student's t-test, ANOVA, Mann–Whitney U, and Kruskal–Wallis statistical tests were used to compare the mean scores in the independent groups. The relationship between the two variables was analyzed through the Pearson correlation test. The study was analyzed at 95% confidence level and statistical significance was determined as $p<0.05$.

Results

As the descriptive statistics reveal, the mean age of the participating caregivers of the BD patients was 47.55 ± 9.03 , 37 (52.1%) were women, and 63 (88.7%) were married. Considering their education level, 33 (46.5%) were primary school graduates. In relation to their financial status, 47 (66.2%) were employed, and 67 (94.4%) were entitled to social security. Given their perceived status of income, 44 (62%) of them considered their income to be equal to or more than their expenses. The socio-demographic data suggest that 41 (57.7%) caregivers resided in the urban center and that a large majority lived in a nuclear family. Moreover, the patients for whom they provided care were either their spouses, children, or siblings, and they shared the same house with the patient. The self-reports of the caregivers also indicate that they received no social support for patient care and treatment. The habit-wise analysis of the caregivers revealed that 38 (53.5%) did not smoke and that 50 (70.4%) did not consume alcohol. While a large majority of the caregivers were not afflicted with a physical illness, there was no individual with a history of psychiatric disorder other than the patient among the family members (Table 1). Fifty-one (71.8%) caregivers stated that their relatives were hospitalized at their own request/by force. Fifty-nine (83.1%) caregivers reported not having attempted suicide (Table 2). In addition, the disease duration of their patients ranged between 1 and 26 years, and the mean duration of the disease was 8.07 ± 5.23 . The number of hospitalizations ranged from 0 to 15, and the average number of hospitalizations was 2.77 ± 2.13 .

The mean BDI score of the caregivers was 3.61 ± 6.52 , and their depression levels turned out to be minimal. The mean score for the Zarit scale was 45.63 ± 9.15 , and the caregiver burden was noted as moderate. No significant difference was evident between the mean BDI and Zarit scale scores in terms of gender, income status, place of residence, smoking and alcohol use, presence of psychiatric history in the family members other than the patient, and way of hospitalization of their patients ($p>0.05$). The mean BDI and Zarit scale scores of the participants deprived of social security were significantly higher than those entitled to social security ($p=0.000$; $p=0.017$). The caregivers who were single, graduated from primary–secondary school, were unemployed, lived in an extended family, needed a person to assist them during caregiving, suffered from physical illness, and had attempted suicide had significantly higher BDI scores ($p=0.021$; $p=0.033$; $p=0.012$; $p=0.013$; $p=0.000$; $p=0.003$; $p=0.001$, respectively), but no significant difference was noted between these characteristics and the mean Zarit scale scores. On the other hand, the caregivers whose patients were either their spouses, children, or siblings, and those who shared the same house with the patient had significantly higher Zarit scale scores ($p=0.048$ and $p=0.015$, respectively), yet no significant difference was established between these characteristics and the mean BDI scores (Tables 1, 2).

Table 1. Comparison of demographic characteristics of caregivers with mean BDI and Zarit scores

Demographic characteristics	Beck depression inventory ±SD	Test results	Zarit caregiver burden scale ±SD	Test results
Gender				
Female (n=37, 52.1%)	3.68±5.51	Z=-0.46 p=0.648	46.51±10.82	Z=-0.254 p=0.800
Male (n=34, 47.9 %)	3.53±7.55		44.68±6.92	
Marital status				
Single (n=8, 11.3 %)	5.13±5.22	Z=-2.31 p=0.021*	49.13±9.22	Z=-1.83 p=0.066
Married (n=63, 88.7 %)	3.41±6.68		45.19±9.12	
Educational status				
Primary–Secondary School (n=33, 46.5%)	5.24±8.21	kw=6.83 p=0.033*	46.85±11.11	kw=0.444 p=0.801
High School (n=27, 38%)	1.78±3.86		44.63±6.93	
University (n=11, 15.5%)	3.18±5		44.45±7.5	
Employability				
Unemployed (n=24, 33.8 %)	7.22±9.01	Z=-2.50 p=0.012*	47.96±13.14	Z=-0.11 p=0.913
Employed (n=47, 66.2%)	1.39±2.61		44.2±5.13	
Income status				
Income less than expenses (n=27, 38%)	5.78±9.21	Z=-0.807 p=0.420	47.37±11.98	Z=-0.421 p=0.190
Income equal to or more than expenses (n=44, 62%)	2.27±3.62		44.57±6.8	
Social security				
Available (n=4, 5.6%)	23.75±10.31	Z=-3.53 p=0.000*	60.75±18.03	Z=-2.38 p=0.017*
Unavailable (n=67, 94.4%)	2.4±3.77		44.59±7.06	
Residence				
Village and town (n=30, 42.3%)	2.47±4.7	Z=-1.49 p=0.137	45.77±7.64	Z=-0.752 p=0.452
Urban centre (n=41, 57.7%)	4.44±7.53		45.54±10.2	
Family type				
Nuclear (n=63, 88.7%)	2.79±5.86	Z=-2.49 p=0.013*	44.59±7.06	Z=-1.21 p=0.226
Extended (n=8, 11.3%)	10±8.25		53.88±17.53	
Closeness				
Parents (n=63, 11.3%)	2.68±4.26	Z=-1.80 p=0.071	44.7±7.85	Z=-1.97 p=0.048*
Spouse and others (n=8, 88.7%)	10.88±13.99		53±14.86	
Status of living together with the patient				
Not sharing the same home (n=7, 9.9%)	4.71±6.37	Z=-1.02 p=0.308	54±10.58	Z=-2.42 p=0.015*
Sharing the same home (n=64, 90.1%)	3.48±6.57		44.72±8.58	
Need for others to help the caregiver with patient care				
No (n=62, 87.3%)	2.55±5.92	Z=-3.72 p=0.000*	45.11±9.13	Z=-1.34 p=0.180
Yes (n=9, 12.7%)	10.89±6.03		49.22±8.93	
Smoking status				
Non-smoker (n=38, 53.5%)	3.89±5.54	Z=-1.33 p=0.182	46.37±11.04	Z=-0.09 p=0.926
Smoker (n=33, 46.5%)	3.27±7.56		44.79±6.38	
Alcohol status				
No (n=50, 70.4%)	3.54±6.8	Z=-0.40 p=0.968	46.14±10.31	Z=-0.17 p=0.865
Yes (n=21, 29.6%)	3.76±5.94		44.43±5.49	

Table 1. Cont.

Demographic characteristics	Beck depression inventory ±SD	Test results	Zarit caregiver burden scale ±SD	Test results
Physical disorder				
No (n=54, 76.1%)	2.87±6.64	Z=-3.01 p=0.003*	44.57±8.91	Z=-1.74 p=0.082
Yes (n=17, 23.9%)	5.94±5.67		49±9.33	
History of psychiatric disorders in other family members				
No (n=56, 78.9%)	3.2±6.42	Z=-1.36 p=0.173	44.38±7.52	Z=-1.89 p=0.058
Yes (n=15, 21.1%)	5.13±6.88		50.33±12.88	

*: p<0.05 kw: Kruskal-Wallis test, Z: Mann-Whitney U test. BDI: Beck Depression Inventory; SD: Standard deviation.

Table 2. Comparison of patient characteristics with mean BDI and Zarit scores of caregivers

Patient characteristics	Beck depression inventory ±SD	Test results	Zarit caregiver burden scale ±SD	Test results
Way of hospitalization				
On his/her own request (n=20, 28.2%)	6.45±9.38	Z=-1.65 p=0.099	45.4±9.41	Z=-0.47 p=0.613
On his/her caregiver's request/by force (n=51, 71.8%)	2.49±4.64		45.73±9.13	
Attempted suicide				
No (n=59, 83.1%)	3.08±6.76	Z=-3.21 p=0.001*	45.78±9.4	Z=-0.41 p=0.684
Yes (n=12, 16.9%)	6.17±4.61		44.92±8.12	

*: p<0.05. Z: Mann-Whitney U test. BDI: Beck Depression Inventory; SD: Standard deviation.

Table 3. Correlation between mean BDI and Zarit scores of caregivers and their age, number of children, patient's duration of illness, and patient's number of hospitalizations

Demographic characteristics	Beck depression inventory		Zarit caregiver burden scale	
	r	p	r	p
Age	0.14	0.239	0.19	0.121
Number of children	0.28	0.019*	0.11	0.366
Patient's duration of illness	0.28	0.019*	0.11	0.366
Patient's number of hospitalizations	0.31	0.008*	0.18	0.133

*: p<0.05. r: Pearson correlation test. BDI: Beck Depression Inventory.

As presented in Table 3, a significant positive low correlation was identified between the caregivers' number of children, their patient's duration of the disease, and the number of hospitalizations of their patient and the mean BDI scores ($p=0.019$, $p=0.019$, $p=0.008$, respectively).

Discussion

BD is a chronic disorder responsible for psychological devastation in patients, adversely affecting the emotional state of the caregivers and creating a heavy financial and moral burden. Due

to its growing importance and prevalence as well as the tremendous strain on budget and mental well-being, the pace of research on caregivers of BD patients continues unabated. The results of our study are indicative of minimal depression levels and moderate burden of the caregivers, which is confirmed by the available literature.^[12,21] In addition, there is published research output on the moderate-to-severe level of caregiver burden.^[21,22]

Our findings revealed that the depression and caregiver burden levels were unaffected by some parameters, including gender, income status, place of residence, status of smoking and alcohol use, history of psychiatric disorders in other fam-

ily members, and way of hospitalization of the patient. In the first place, the non-significant relationship between gender and caregiver burden might be linked to gender equality in all spheres of contemporary society and the similar emotional impact of patient care on caregivers, irrespective of gender. Although gender is not a significant parameter in caregiver burden and depression levels in many studies on psychiatric diseases,^[12,22–26] some reports point to a higher level of caregiver burden among the female population.^[3,27] The results concerning income status may be because the patients were entitled to health insurance as a result of the health policies implemented in our country or because the poverty-stricken citizens did not pay the medical treatment fee due to the green card system. The research on this issue has only produced mixed results so far. Some studies report that discrepancies in income levels may not be an influential factor in the level of caregiver burden,^[12,28,29] whereas others indicate that caregiver burden is negatively correlated with income status, that is, caregiver burden tends to increase as income level decreases.^[25,26,30,31] The findings regarding place of residence can be explained by easier access to health-care services. In addition, one of the interpretations concerning our survey results is the lack of a significant correlation between the status of smoking and alcohol use of caregivers and care burden, which is also supported by other investigations.^[28] As in the research on income status, the literature documents conflicting results in relation to the association between caregiver burden and history of psychiatric disorders in other family members. As also underlined in our research, some studies show that depression and caregiving burden bear little relation to this parameter,^[25] whereas the counter-argument suggests that the presence of psychiatric disorders in other family members further increases caregiver burden.^[28,32] Moreover note that these contradictory results may be affiliated with caregivers' future anxiety, despair, and adoption of ineffective coping methods. Finally, the absence of a strong relationship between caregiver burden and the way of hospitalization of the patient might be attributed to the caregivers' assumption that their patients will be cured and eventually restore their former well-being.

Our findings reveal that being single, living in an extended family, having a poor educational level, being unemployed, needing a helper for patient care, having a history of physical illness, and the suicide attempt of the patient tended to elevate the depression levels of the caregivers. Assuming responsibility for their patients alone and receiving less social support than their married counterparts are suggestive of the development of depression in single caregivers. Although numerous studies report no notable difference in caregiver burden in terms of marital status,^[3,12,33] other lines of evidence identify a greater care burden in married caregivers.^[9,11] Moreover, higher levels of depression among caregivers with low

educational status may be attributed to their poor knowledge of BD, inappropriate and ineffective care during the treatment process as well as feelings of anxiety, unhappiness, grief, and despair caused by reasons such as underutilizing support resources. Our results regarding the parameters of educational status are consistent with those of many relevant studies.^[12,25,26,29,34–37] Care burden has also been shown to decrease as educational level increases.^[3,26,28,30,33,38–40] In regard to the parameter of unemployment, increased levels of depression in non-working caregivers might be linked to their unhappiness, anxiety, future anxiety, demotivation, and negative beliefs which unfold due to limited or missing sources of income and the necessity to quit work because of the prolonged duration of the illness. Similar to our findings, some research indicates that caregiver burden is unaffected by non-working conditions,^[12,22] yet other studies report greater^[32,35] and lower caregiver burden.^[25] As for the variable of family type, negative emotional exchanges in an extended family between caregivers and other family members may add to their depression levels. However, the type of family in which the caregivers live might not be directly related to their care burden.^[41] The fact that caregivers are left alone during patient care is physically and emotionally harsh and backbreaking, but the need for a helper in patient care does not exert a significant effect on their depression level and care burden.^[25,40] The elevated levels of depression in caregivers with a history of physical illness may be due to the feelings of anxiety, stress, inadequacy, and sorrow caused by disruptions in the caregiving process related to impaired functioning. We identified a non-significant relationship between caregiver burdens and having a history of physical illness, which also accords with earlier observations.^[28] The suicide attempts of patients exerted a traumatic effect on the caregivers, elevating their depression levels owing to feelings such as anxiety and fear. However, Aydin et al.^[40] report, similar to our study, that there is no difference in the level of care burden among the caregivers with respect to suicide attempts of patients. Finally, we identified increased depression levels and greater care burden in the caregivers lacking social security. This might have arisen from the fact that the patient was not entitled to social security and green cards provided to the poor as well as not paying for their health insurance premium. It is also plausible that the absence of social security added to the economic burden of caregivers and contributed to feelings of sorrow, uneasiness, and rage.

As far as our results are concerned, the parameters of closeness to the patient and living together with them did not act on the depression of the caregivers, but those who were the spouses, children, and siblings of the patients and lived together with them turned out to suffer a considerable level of care burden. This resulting situation can be explained by the financial and moral burden experienced by the young caregivers and care-

giving spouses who provided more care than other people. The caregivers who were spouses, children, or siblings of the patient were reported to suffer increased levels of depression^[34] and a greater care burden.^[16,28] However, some other studies documented the higher care burden experienced by the mothers as caregivers.^[30,31,38,42] Yet other investigations did not identify a significant difference between caregivers' closeness levels in terms of care burden.^[35,43] Taking on more responsibilities, devoting most of their time to their patients, disrupting their work routine, and restricting their own family and social lives may account for the increased care burden suffered by those not living together with their patients. As identified by some studies, caregivers sharing the same house with their patients experience a greater care burden.^[6,44]

The lack of association between caregiver burden and an increase in the patient's disease duration is well-established.^[24,25,33,35,37] The level of depression and care burden does not manifest a change in terms of the increase in the number of hospitalizations of the caregivers' patients.^[25,37] In contrast, other lines of evidence reveal that caregivers' care burden tends to increase as the number of hospitalizations increases.^[32,40,42] No correlation was noted between the age of caregivers and their depression and care burden.^[25,26,28–30,32,34,40] Our dataset demonstrates that the age levels of the caregivers did not act on their burden care and level of depression. The increase in the number of children, the patient's disease duration, and the number of hospitalizations were highly likely to result in elevated depression levels of the caregivers, although their care burden remained unchanged. This result may arise from the fact that the caregivers were exposed to such feelings as stress, uneasiness, anxiety, and inadequacy since they were torn between their private lives and parenting roles and the role of caregiving.

Strengths and Limitations

This study was performed only on the caregivers of BD patients treated as outpatients in the psychiatry department of a tertiary hospital. Due to the relatively small sample size, the reported results may not be generalizable to the whole population. Furthermore, another limitation could be stated as not considering the subscales of the existing scales.

Conclusion

It has been observed that care burden and depression in caregivers of patients with BD are affected by the characteristics of the patients as well as the characteristics of the caregivers themselves. Our findings revealed that being single, living in a large family, having a low level of education, being unemployed, needing a helper for patient care, having a history of physical illness, and the patient's suicide attempt tended to increase caregivers' depression levels. It was revealed that

caregivers who were spouses and children and who lived in the same house with the patient had a higher care burden.

Carried out with the caregivers of BD patients within the euthymic period, this study provides useful information to guide in which areas these caregivers should receive psychoeducation. The care of BD patients contributes to limitations preventing caregivers from maintaining their social and intrafamily relations. Providing psychoeducation to caregivers concerning coping skills and stress management as well as the symptoms and episodes of the disease may bring benefits in alleviating care burden and depression symptoms.

Ethics Committee Approval: The study was approved by the Aydın Adnan Menderes University Non-Interventional Clinical Research Ethics Committee (No: 2017/32, Date: 23/08/2017).

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