

Separation anxiety and depression in caregivers of epileptic patients

F. YAVLAL¹, A. CETIN²

¹Department of Neurology, Medicana International Istanbul Hospital, Istanbul, Turkey

²Psychological Sciences, Zey Health Service, Istanbul, Turkey

Abstract. – OBJECTIVE: Epilepsy is a common neurological disorder affecting both the patients and the caregivers psychologically. Caregivers of these patients might have to face several challenges throughout the course of the disease. This study examines the correlations between the separation anxiety and depression of caregivers of adult and child epileptic patients according to their relation to the patients (parent vs. partner).

PATIENTS AND METHODS: 50 participants (caregivers of epileptic patients) were included. A sociodemographic form, Beck Depression (BDI) and Anxiety (BAI) Scales, and Adult Separation Anxiety (ASA) Scale were applied to the participants.

RESULTS: 54% of the patients in the study had generalized seizures, whereas 46% had focal seizures. Our study has found the BAI of woman caregivers was higher compared to male caregivers. BAI and ASA were significantly higher for caregivers of patients with an illness duration lower than 5 years who were on multiple medications than for caregivers of patients who had an illness duration of more than 5 years who were on single medication ($p<0.05$). BDI, BAI and ASA scores were significantly higher in the generalized epilepsy group than in the focal epilepsy group ($p<0.05$). The ASA score was significantly higher in females than in males ($p<0.05$). The ASA score was significantly higher in the group with a low educational level than in the group with a high educational level ($p<0.05$).

CONCLUSIONS: The findings of this study inform healthcare professionals regarding the needs of caregivers of epilepsy patients, especially around emotional problems. Results of this study demonstrate significant association between epilepsy seizure type, and separation anxiety and depression. Our study is the first study focused on the separation anxiety of the caregivers of epileptic patients. Separation anxiety has a negative impact on the personal independence of the caregiver.

Key Words:

Caregivers of epileptic patients, Separation anxiety questionnaire, Beck anxiety scale, Beck depression inventory.

Introduction

Epilepsy is the most prevalent neurological disease in society after strokes, affecting around 50 million people worldwide¹. Causing severe physical, psychological, and social problems², epilepsy seriously impacts the quality of life.

Although a treatable disease with the help of several new antiseizure medications, epilepsy may weigh patients and their relatives with heavy psychosocial burdens. Many epileptic patients also suffer from various problems along with physical and psychological handicaps that may prevent them from leading independent lives. Fear of seizures, the cognitive outcomes of epilepsy, and treatment resistance may further prevent patients from leading independent lives.

Recently, the psychological burden suffered by caregivers of patients with chronic diseases has attracted increased interest. Social isolation³ and its impact on quality of life can be seen in the caregivers of epileptic patients as well as in the patients themselves. Previous studies⁴⁻⁶ have revealed comorbidity of depression and anxiety at rates reaching 58% in caregivers of epileptic patients. Many studies^{7,8} have revealed that the psychological comorbidities seen in caregivers, particularly depression and anxiety, are significantly correlated with the comorbidities encountered in their child and adolescent epileptic patients. The burden of epilepsy causes family problems by affecting the parent-child relationship, confidence in parenting skills, family stress, and parent psychopathology. These factors in turn have a significant impact on the symptoms of anxiety and depression^{9,10}.

While the caregivers of child and adolescent epileptic patients are typically the patients' parents, the caregivers of adult patients may be spouses, parents, children, siblings, or friends. While it is obvious that the caregivers of adult epileptic patients have a deep impact on their epilep-

tic patients, the results of studies^{3,8} conducted in various parts of the world have also demonstrated that negative results of the disease (e.g., drug-resistant seizures, increased numbers of seizure frequency, and so on) is also affecting the caregivers (i.e., emotional distress, the burden of care and a deterioration in the quality of life. Considering the inadequacy of the literature focusing on the caregivers of epileptic patients, this study investigates the problems caregivers face as ‘unseen patients’. The separation anxiety felt towards a patient suffering from the disease in the child age group has also begun to be identified in the adult age group¹¹. However, the correlation between the separation anxiety of adult caregivers and the quality of life of epileptic patients has not yet been researched. Psychiatric comorbidities such as anxiety and depression are prevalent in epileptic patients and heavily impact the quality of life¹²⁻¹⁴. Notably, psychiatric comorbidities in the caregivers of epileptic patients are also significantly correlated with the quality of life of the child and adolescent patients^{15,16}. Previous studies^{3,8,17} have found the burden suffered by caregivers of epileptic patients to be considerably heavy; this study aims to emphasize the correlation between the frequency of the psychopathologies of caregivers, particularly separation anxiety and depression, and the quality of life of the patient, not only for child patients but also for the adult patient group, independent of patient and family factors.

This study examines the separation anxiety and depression of caregivers of both adult and child epileptic patients. To this extent, we have studied the correlations between the separation anxiety and depression levels of caregivers, caregivers’ demographic characteristics, and epilepsy patients’ disease characteristics (i.e., age at seizure onset, duration of epilepsy, the severity of seizures, and the number of administered antiepileptic medications). In addition, this study examines the correlations between the anxiety and depression of caregivers and the sociodemographic characteristics of the caregivers and their relationship to their patients (e.g., parent or partner).

Patients and Methods

Subjects

This study was conducted in the neurology outpatient clinic of a private hospital serving middle-income earners in Istanbul. Fifty caregivers

($M_{age} = 41.94$, $SD_{age} = 12.6$) of epileptic patients were tested for the present study. Only the caregivers of patients who do not fit the following criteria are excluded from the study: Patients who suffered from an extra neurological illness, who had secondary reasons for epileptic seizures, who needed extra care due to mental disability, and who suffered from cardiovascular or musculoskeletal diseases. Also, caregivers who were diagnosed with a psychotic illness (e.g., schizophrenia or bipolar affective disorder) or who were not eligible to read and understand the sociodemographic forms were excluded. All caregivers were living together with their patients. The study was conducted prospectively. Informed consent was obtained from all participants included in this study. Approval was obtained from the Ethics Committee on 3 April 2019, with the number 2019-07/02.

Scales Applied to Caregivers

All participants completed the sociodemographic form, the Beck Depression Inventory (BDI)¹⁸, the Beck Anxiety Scale (BAI)¹⁹, and the Adult Separation Anxiety Questionnaire (ASA)²⁰.

Statistical Analysis

Mean, standard deviation, median, minimum, maximum, frequency, and ratio values were used in the descriptive statistics of the data. The distribution of variables was measured using the Kolmogorov-Smirnov test. An ANOVA test (Tukey’s), an independent samples *t*-test, the Kruskal-Wallis’ test, and the Mann-Whitney U test were all used in the analysis of the quantitative independent data. The SPSS 28.0 program²¹ (IBM, Armonk, NY, USA) was used in the analysis. *p*-values less than 0.05 were considered significant.

Results

Of the participants included in the study, 52% were under 40 years of age and 48% were over 40 years of age. Of the patients, 32 (64%) were male and 18 (36%) were female. Regarding educational status, 26 participants (52%) were literate, primary school graduates, or secondary school graduates, while 24 participants (48%) had undergraduate or graduate degrees. Of the caregivers, 74% were parents, 14% were partners and 12% were categorized as having ‘other’ degrees of relationship. Of the patients whose caregivers were included in the study, 46% were diagnosed with focal epilepsy and 54% with generalized epilep-

sy. The duration of illness was less than 5 years in half of the patients and more than 5 years in the other half of the patients. Of the patients, 72% were on a single type of antiepileptic drug, while 28% were on two or more antiepileptic drugs (see Table I).

BDI and BAI scores were significantly higher in females than in males ($p<0.05$). BAI scores did not differ significantly between the groups according to age, educational status, monthly income, or degree of relationship. BDI and BAI scores were significantly higher in the generalized epilepsy group than in the focal epilepsy group ($p<0.05$). BDI and BAI scores were significantly higher in caregivers of patients with a duration of illness of less than 5 years who were on multiple medications than in caregivers of patients with a duration of illness of more than 5 years who were on a single medication ($p<0.05$; see Tables II and III).

The ASA score was significantly higher in females than in males ($p<0.05$). The ASA score was significantly higher in the group with a low educational level than in the group with a high educational level ($p<0.05$). The ASA score did not differ significantly according to monthly income distribution ($p>0.05$). ASA scores did not differ significantly between the < 40 and > 40 age groups ($p>0.05$). ASA scores did not differ significantly in the parent, partner, or other degrees of relationship groups ($p>0.05$). The ASA score was significantly higher in the generalized epilepsy group than in the focal epilepsy group ($p<0.05$). The ASA score was significantly higher in caregivers of patients with a duration of illness of less than 5 years who were on multiple medications than in caregivers of patients with a duration of illness of more than 5 years who were on single medication ($p<0.05$; see Table IV).

Table I. Socio-demographic characteristics of the caregivers and the patients with epilepsy, and BDI, BAI, and ASA scores of the caregivers.

		Min-Max	Median	Mean±SD/n-%	
Caregiver Age	< 40 years			26	52.0%
	> 40 Years			24	48.0%
Gender	Female			32	64.0%
	Male			18	36.0%
Educational Status					
Literate, Primary School, Secondary School				26	52.0%
	University, Master's Degree		24	48.0%	
Monthly Income	< 1,500 (low)			8	16.0%
	1,500-3,000 (lower-middle)		16	32.0%	
	3,000-5,000 (upper-middle)		12	24.0%	
	> 5,000 (high)			14	28.0%
Degree of Relationship	Parent			37	74.0%
	Partner			7	14.0%
	Other			6	12.0%
Epilepsy Type	Focal			23	46.0%
	Generalized			27	54.0%
Duration of Illness	< 5 Years			25	50.0%
	> 5 Years			25	50.0%
Number of Antiepileptic Drugs	Single Medicine			36	72.0%
	Multidrug			14	28.0%
BDI Score		0.0	-42.0	12.5	15.7±12.3
BAI Score		0.0	-44.0	14.5	16.9±11.3
ASA Score		6.0	-61.0	26.0	26.8±14.6

Table II. BDI scores of the caregivers according to different demographics, relation to the patient, and illness characteristics.

		Beck Depression Inventory			P
		Min-Max	Median	Mean±SD	
Gender	Female	0.0-42.0	16.0	19.1±13.5	0.022^m
	Male	0.0-24.0	9.0	9.7±6.6	
Age	< 40 years	0.0-42.0	12.5	16.8±13.7	0.748 ^m
	> 40 Years	0.0-40.0	12.0	14.5±10.6	
Educational Status					
Literate, Primary School, Secondary School University, Master's Degree		2.0-42.0	13.0	19.0±14.1	0.115 ^m
		0.0-35.0	9.5	12.1±8.9	
Monthly Income Level	< 1,500 (low)	3.0-41.0	9.0	14.8±15.0	0.434 ^k
	1,500-3,000 (lower-middle)	0.0-42.0	13.0	17.1±13.4	
	3,000-5,000 (upper-middle)	0.0-37.0	9.5	11.8±10.1	
	> 5,000 (high)	3.0-40.0	17.5	18.0±11.4	
Degree of Relationship	Parent	0.0-42.0	14.0	16.6±12.4	0.443 ^k
	Partner	0.0-40.0	13.0	14.7±12.5	
	Other	2.0-35.0	7.0	11.2±12.1	
Epilepsy Type	Focal	2.0-24.0	9.0	10.8±6.8	0.041^m
	Generalised	0.0-42.0	15.0	19.9±14.4	
Duration of Illness	< 5 Years	0.0-42.0	19.0	19.9±13.6	0.020^m
	> 5 Years	0.0-36.0	9.0	11.5±9.2	
Number of Antiepileptic Drugs	Single Medicine	0.0-41.0	10.5	12.9±10.3	0.028^m
	Multidrug	4.0-42.0	21.5	23.0±14.3	

^kKruskal-Wallis/^mMann-Whitney U test.

Discussion

In our society, patient caregivers are most often women, in the role of mothers, partners or daughters in the same family as the patient. The fact that women constitute the greater number of caregivers in our study stems from this fact and is compatible with the customs of the country under study. Our results are therefore in line with the Turkish social structure, and 62% of the caregivers in our study were women.

Our study found the BAI of woman caregivers to be higher than that of male caregivers: the caregiver being a woman demonstrated a positive correlation with an increase in anxiety scores. However, a previous study²² observed no difference in the caregivers of epileptic patients in the child age group. A possible explanation for this difference could be that parents comprised a greater number of caregivers in our study. In addition, 60% of our

patients were under 20 years of age. Parent caregivers may experience more difficulties in effectively coping with the role imposed on them.

Our study results showed an increase in separation anxiety in caregivers of generalized epileptic patients that was also correlated with a higher number of antiepileptic medications used by the patient. In our study, the BDI in the caregivers of generalized epileptic patients was higher than that of caregivers of patients suffering from focal seizures. As emphasized in previous studies²³⁻²⁵, since generalized epileptic seizures are more severe than focal seizures, anxiety and depression are observed at higher rates in generalized epilepsy patients and their caregivers. While caring for a patient suffering from generalized seizures is obviously more difficult than caring for a patient suffering from well-controlled or focal seizures, the frequency of seizures was not taken into consideration in this study.

The depression scores of caregivers increased together with an increase in the duration of the disease, demonstrating a positive correlation. A similar observation was made in a previous study²⁶ involving patient-caregiver pairs in terms of the duration of the disease. Another observation we made was that ASA and BAI scores were also high in individuals presenting high BDI scores. It would not be wrong to add the frequency of separation anxiety found here to the frequency of depression demonstrated in previous studies^{27,28}.

Our results found that ASA scores in caregivers increased with the duration of epilepsy of the patient and the number of antiepileptics used by the patient. As expected, an increase in the disease's duration and the number of antiepileptic drugs used in generalized epileptic patients points towards more resilient epilepsy.

We identified an increase in separation anxiety as educational level drops. Separation anxiety

scores were higher in low-wage groups compared to those with higher monthly incomes. Separation anxiety in caregivers was found to be higher in parents compared to partners. As epilepsy is a chronic, unpredictable condition, a low caregiver educational level may result in an inadequate understanding of the disease, causing higher worry and anxiety about unpredictable seizures. Lower access to the health care system for lower-income caregivers might be the reason for higher anxiety, as it could be associated with poorly controlled seizures due to lack of appropriate treatment.

To date, literature has been focused on the caregivers of children and adolescents, especially parent caregivers. Some previous studies^{29,30} have focused on the anxiety and depression suffered by parents with respect to children and youths undergoing surgery. In this study, we demonstrated that the caregivers of adult epileptic patients suffer from psychological problems similar to those

Table III. BAI scores of the caregivers according to different demographics, relation to the patient, and illness characteristics.

		Beck Depression Inventory			
		Min-Max	Median	Mean±SD	P
Gender	Female	10.0-61.0	30.5	32.0±14.4	0.000^t
	Male	6.0-33.0	15.0	17.6±9.8	
Age	< 40 years	6.0-54.0	25.0	26.5±14.5	0.881 ^t
	> 40 Years	6.0-61.0	26.5	27.1±15.0	
Educational Status					
Literate, Primary School, Secondary School University, Master's Degree		6.0-61.0	28.0	31.2±15.6	0.025^t
		6.0-50.0	21.5	22.0±11.9	
Monthly Income Level	< 1,500 (low)	6.0-48.0	27.0	28.8±14.7	0.808 ^A
	1,500-3,000 (lower-middle)	6.0-54.0	24.0	28.4±17.2	
	3,000-5,000 (upper-middle)	10.0-61.0	26.5	27.7±14.7	
	> 5,000 (high)	6.0-46.0	22.5	23.5±12.0	
Degree of Relationship	Parent	6.0-61.0	27.0	27.5±14.4	0.823 ^A
	Partner	6.0-46.0	22.0	25.4±15.1	
	Other	9.0-50.0	17.5	23.8±17.4	
Epilepsy Type	Focal	6.0-35.0	23.0	19.5±10.0	0.001^t
	Generalised	12.0-61.0	33.0	33.0±15.1	
Duration of Illness	< 5 Years	10.0-61.0	29.0	32.8±14.2	0.002
	> 5 Years	0.0-50.0	17.0	20.8±12.5	
Number of Antiepileptic Drugs	Single Medicine	6.0-61.0	21.0	23.8±14.6	0.018^t
	Multidrug	19.0-54.0	32.0	34.5±11.8	

^AANOVA/^tIndependent samples *t*-test.

Table IV. ASA scores of the caregivers according to different demographics, relation to the patient, and illness characteristics.

		Separation Anxiety Score			<i>P</i>
		Min-Max	Median	Mean±SD	
Gender	Female	10.0-61.0	30.5	32.0±14.4	0.000^t
	Age	6.0-33.0	15.0	17.6±9.8	
	< 40 years	6.0-54.0	25.0	26.5±14.5	
	> 40 Years	6.0-61.0	26.5	27.1±15.0	
Educational Status					
Literate, Primary School, Secondary School University, Master's Degree		6.0-61.0	28.0	31.2±15.6	0.025^t
		6.0-50.0	21.5	22.1±11.9	
Monthly Income Level	< 1,500 (low)	6.0-48.0	27.0	28.8±14.7	0.808 ^A
	1,500-3,000 (lower-middle)	6.0-54.0	24.0	28.4±17.2	
	3,000-5,000 (upper-middle)	10.0-61.0	26.5	27.7±14.7	
	> 5,000 (high)	6.0-46.0	22.5	23.5±12.0	
Degree of Relationship	Parent	6.0-61.0	27.0	27.5±14.4	0.823 ^A
	Partner	6.0-46.0	22.0	25.4±15.1	
	Other	9.0-50.0	17.5	23.8±17.4	
Epilepsy Type	Focal	6.0-35.0	23.0	19.5±10.0	0.002^t
	Generalised	6.0-50.0	17.0	20.8±12.5	
Duration of Illness	< 5 Years	10.0-61.0	29.0	32.8±14.2	0.020
	> 5 Years	0.0-36.0	9.0	11.5±9.2	
Number of Antiepileptic Drugs	Single Medicine	6.0-61.0	21.0	23.8±14.6	0.018^t
	Multidrug	19.0-54.0	32.0	34.5±11.8	

^AANOVA/^tIndependent samples *t*-test.

suffered by the caregivers of children and adolescents. This topic has not been exhaustively discussed in the literature.

Limitations

This is a cross-sectional study in which we carried out a screening to evaluate depression and anxiety from among affective disorders.

This study was hospital-based. In low-income areas, access to hospitals and physicians is not easy. Therefore, the findings of this study may not reflect the situation in larger communities.

Conclusions

Our study is the first to focus on caregivers' separation anxiety while most of the previous

studies have focused on the total burden or individual coping strategies. Separation anxiety negatively impacts the personal independence of the caregiver. Considering our findings and the previous literature, healthcare professionals should take into account the needs of caregivers of epilepsy patients, especially around emotional problems.

Conflict of Interest

The authors declare that they have no conflicts of interest.

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Availability of Data and Materials

The datasets generated and/or analyzed during the current study are not publicly available due to privacy concerns. However, they are available from the corresponding author on reasonable request.

Authors' Contributions

F. Yavlal: Conceptualization, data curation, methodology, project administration, resources, supervision, writing (original draft), and writing (review and editing). A. Cetin: Formal analysis, methodology, visualization, and writing (review and editing). Each author gave final approval to the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Ethics Approval

The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was conducted prospectively between May 2019 and July 2020. Approval of the Bahçeşehir University Non-Pharmaceutical Clinical Research Ethics Committee was received on 3 April 2019 with the number 2019-07/02.

ORCID ID

Figen Yavlal: 0000 0002 6710 511X.
Aybeniz Cetin: 0000-0001-6565-3350.

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