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Araştırma Makalesi/Research Article *2023 - 5(2)*

Examination of Care Burden and Hopelessness Levels of Parents with Children with Epilepsy*

Epilepsi Tanılı Çocuğu Olan Ebeveynlerin Bakım Yükü ve Umutsuzluk Düzeylerinin İncelenmesi

***Yakup SARPDAĞI*[1] *Cantürk ÇAPIK*[2]

[1] *Atatürk University, Graduate School of Health Sciences, Erzurum, Türkiye.*

[2] *Atatürk University, Faculty of Nursing, Public Health Nursing Department, Erzurum, Türkiye.*

Abstract

Objective: The aim of this study was to examine the relationship between care burden and hopelessness levels of parents with children with epilepsy.

Methods: The sample of this descriptive and correlational study consisted of 384 parents with children diagnosed with epilepsy between the ages of 0-18. The data of the study were collected in the Pediatric Neurology and General Pediatric Outpatient Clinics of Health Sciences University Van Training and Research Hospital between October 2017 and January 2018. Socio-demographic Data Form, Zarit Care Burden Scale and Beck Hopelessness Scale were used to collect the data.

Results: In the study, it was determined that the mean care burden score of the parents was moderate (40±9.63) and the mean hopelessness score was mild (7.97±4.43). It was determined that the participants' educational status, income status and the presence of another person in need of care in the family significantly affected both care burden and hopelessness levels. A significant positive correlation was found between the duration of diagnosis, the number of hospitalisations, the duration of care and the time spent on care in a day and care burden and hopelessness. In addition, a significant positive relationship was found between caregiving burden and hopelessness.

Conclusion: As the care burden of parents increases, the level of hopelessness also increases. Public health nurses working in Family Health Centres and nurses working in clinics should support families with children with epilepsy physically, socially and spiritually. Epilepsy should provide counselling services on seizures that occur due to the nature of the disease and issues that parents may be exposed to (such as guilt, family problems, hopelessness, economic difficulties, stigmatisation).

Keywords: Care burden, epilepsy, hopelessness, nurse, parents

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**Sorumlu Yazar: yakup_sys@hotmail.com

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Öz

Amaç: Bu çalışmanın amacı epilepsili çocuklara sahip ebeveynlerin bakım yükü ve umutsuzluk düzeyleri arasındaki ilişkiyi incelemektir.

Yöntem: Tanımlayıcı ve ilişki arayıcı tipte planlanan bu çalışmanın örneklemini 0-18 yaş aralığında epilepsi tanısı almış çocuğu olan 384 ebeveyn oluşturmaktadır. Çalışmanın verileri Ekim 2017-Ocak 2018 tarihleri arasında Sağlık Bilimleri Üniversitesi Van Eğitim ve Araştırma Hastanesi Çocuk Nöroloji ve Genel Çocuk Polikliniklerinde yürütülmüştür. Verilerin toplanmasında Sosyo-demografik Veri Formu, Zarit Bakım Yükü Ölçeği ve Beck Umutsuzluk Ölçeği kullanılmıştır.

Bulgular: Çalışmada ebeveynlerin bakım yükü puan ortalamasının orta düzeyde (40±9,63), umutsuzluk puan ortalamasının ise hafif düzeyde (7,97±4,43) olduğu belirlenmiştir. Katılımcıların eğitim durumu, gelir durumu ve ailede bakıma muhtaç başka bir bireyin olmasının hem bakım yükü hem de umutsuzluk düzeylerini anlamlı düzeyde etkilediği tespit edilmiştir. Tanı süresi, hastaneye yatış sayısı, bakım süresi ve bir günde bakım için harcanan süre ile bakım yükü ve umutsuzluk arasında anlamlı bir pozitif korelasyon bulunmuştur. Ayrıca bakım verme yükü ile umutsuzluk arasında pozitif yönde anlamlı bir ilişki bulunmuştur.

Sonuç: Ebeveynlerin bakım yükü artıkça umutsuzluk düzeyi de artmaktadır. Aile Sağlığı Merkezleri'nde çalışan halk sağlığı hemşirelerin ve klinikte çalışan hemşirelerin epilepsili çocuğa sahip aileleri fiziksel, sosyal ve ruhsal yönden desteklemeli. Epilepsi hastalığın doğası gereği meydana gelen nöbetler ve ebeveynlerinlerin maruz kalabileceği (suçluluk, aile içi sorunlar, umutsuzluk, ekonomik sıkıntılar, damgalanma gibi) konularda danışmanlık hizmetleri sunmalıdır.

Anahtar kelimeler: Bakım yükü, ebeveynler, epilepsi, hemşire, umutsuzluk

INTRODUCTION

Epilepsy is a chronic disease that is the most prevalent of all diseases of the nervous system and has an impact on people of all ages (Leal et al., 2020). Nearly 50 million people around the world are affected, and there are an estimated two million new cases of epilepsy each year. A total of 65 million people worldwide is affected, including 10.5 million under the age of 15, with at least 50% of cases beginning in childhood or adolescence (WHO, 2019). In a study conducted by Canpolat et al. (2014) to determine the prevalence of epilepsy in school-age children (aged 7-17 years) in Turkey, the prevalence of epilepsy was found to be 0.6% (Canpolat et al., 2014). Nurses are often the only health professional in resource-poor settings, providing comprehensive disease management and support to patients and families living with epilepsy. Often nurses have multiple roles requiring expertise in epilepsy care, patient/family self-management education, psychosocial care and clinical research (Prevos-Morgant et al., 2019).

When a child is diagnosed with epilepsy, parents may experience a subconscious feeling that they have lost a healthy child and that their child is isolated from normal children (Rani & Thomas, 2019). People with epilepsy are usually cared for by a family member, such as a parent, spouse or sibling, because epilepsy can be a lifelong, disabling condition (Epilepsy Society, 2022). Because of its negative effects, epilepsy deeply affects both children and their family members (Kampra et al., 2017). Due to the nature of the disease, its chronicity, disability and stigma, carers of people with epilepsy face severe emotional, economic and physical burdens (Senthil, 2016). As a result, carers of children with epilepsy can face a range of problems. These include fatigue, headaches, physical pain, family conflict and financial problems (de Lima et al., 2013). Providing care for children with epilepsy is a very demanding and stressful experience, associated with significant caregiver burden and psychological morbidity (Babalola et al., 2014). The burden of care is a multi-factorial construct that includes emotional, psychological, physical and economic impacts, and distressing emotions of humiliation, anger, guilt and self-blame (Awad & Voruganti, 2008). According to El-Mouty and Salem, caregiver burden in epilepsy constitutes an understudied area (El-Mouty & Salem, 2019).

Caregivers' perceptions and attitudes towards epilepsy can also affect them psychologically, as caregivers often experience negative emotions (Murugupillai et al., 2016). Studies have shown that depression and anxiety are experienced by almost half of all caregivers (Zhang et al., 2021). Carers may experience anxiety over various aspects of the condition, including physical, behavioural and cognitive function, psychological and social function, educational performance, and the future with regard to epilepsy and its management (Murugupillai et al., 2016). In addition, caregivers may experience economic problems, loneliness, hopelessness, isolation from society, fear, anger, depression and anxiety due to kinship ties with patients' relatives, as well as having to fulfill both their work and family responsibilities (Cross et al., 2021). According to Yıldırım and Kara, families with children with epilepsy have a hopeless attitude about the future of their children (Yıldırım & Kara, 2017). Hopelessness is a feeling frequently experienced by individuals with chronic diseases and their caregivers (Demir & Tercanlı, 2012). In addition, Pokharel et al. found that the burden on caregivers of patients with chronic diseases such as epilepsy can lead to mental health problems. This in turn affects adherence to treatment and the overall prognosis of the disease. It is noted that the impact of childhood epilepsy on the child's family is a neglected issue (Pokharel et al., 2020). In a study conducted by Çalışır et al. on mothers of children with cerebral palsy; it was determined that caregiver burden also affected the hopelessness levels of caregivers (Çalışır et al., 2018). In studies conducted, it has been determined that the level of hopelessness is high in individuals with chronic diseases and their families, and it has been reported that these individuals may be in the risk group in terms of hopelessness (Björquist et al., 2016; Caicedo, 2014; Whittingham et al., 2013). In this context, it is important to determine the hopelessness levels of parents who have children with epilepsy.

Epilepsy is a common neurological disease especially in childhood. This disease affects not only the child but also the family as well as the child. Caring for a child with epilepsy is as important as caring for palliative care patients, cancer patients, patients with psychiatric disorders, physically or mentally disabled individuals. In addition, there is no study on the level of hopelessness in families of children with epilepsy in Türkiye. This study was conducted to determine the relationship between care burden and hopelessness levels of parents with epileptic children.

METHODS

Study Design: This was a descriptive and correlational study.

Research Questions

1. What is the care burden of parents of children with epilepsy?
2. What is the level of hopelessness of parents of children with epilepsy?
3. Is there a relationship between care burden and hopelessness levels?

Variables of the Study: The independent variables were the gender, education level, monthly income, presence of another person in need of care in the family, age, length of care (years), daily care duration and the child's diagnosis time and hospital duration time. The dependent variables were the Zarit Care Burden Scale and Beck Hopelessness Scale scores.

Settings of the Study: This study was conducted between October 2017 and January 2018. The study population consisted of parents who applied to the Pediatric Neurology and General Pediatric outpatient clinics of Health Sciences University Van Training and Research Hospital for prescribing, regulating, and controlling the medication doses of their children with epilepsy.

Population of the Study: In the Pediatric Neurology and General Pediatric outpatient clinics, 346 children were diagnosed with epilepsy in the last 6 months. However, this number does not include only those living in Van province. In addition, there is no number in the hospital records covering all children with epilepsy living in Van. As a result, the entire population is not known in this study. For this reason, a sample calculation was made using the sampling formula for unknown cases and 384 people were included in the study. The following conditions were sought having a child diagnosed with epilepsy at least 6 months ago, being 18 years of age or older, being a family member caring for a child with epilepsy, not having a psychological disorder, having the ability to express oneself and voluntarily accepting the study. In the study, the sample calculation was made by using the sampling formula for situations where the universe is not known. This formula: $n = t^2.p.q/d^2$ It was calculated that (1.962)*0.5*0.5/0.052 = 384 individuals should be included in the study.

Data Collection: Interviews were held in the hospital, Socio-Demographic Questionnaire, Zarit Care Burden Scale (ZCBS) and Beck Hopelessness Scale (BHS) were used, and data were collected by the researcher through face-to-face interviews with 384 participants. The questionnaires were read to illiterate participants through face-to-face interviews and their answers were marked according to their self-reports. Interviews were held in the pediatric neurology outpatient clinic, and it took approximately 10 minutes to fill out all the data forms. Data were collected using the Socio-demographic Form, ZCBS and BHS.

Data Collection Tools

Socio-demographic Questionnaire: The sociodemographic questionnaire of the participants includes questions about gender, education level, monthly income, presence of another person in need of care in the family, age, length of care (years), daily care duration and the child's diagnosis time and hospital stay.

Zarit Care Burden Scale – ZCBS: It was developed by Zarit et al. (Zarit et al., 1980). Turkish validity and reliability were done by İnci and Erdem (İnci & Erdem, 2008). It is a 22-item scale used to examine the problems experienced by the individual in need of care and the caregivers. It is a Likert-type scale ranging from 0 to 4, never, rarely, sometimes, quite often, or almost always. The minimum score to be obtained in the scale is 0, and the maximum score is 88. If the total score is between 88-61, it is considered as severe burden, if it is between 60-41, it is considered as moderate, if it is between 40-21, it is considered as light moderate, if it is less than 21, it is considered as light or no burden. A high score on the scale indicates that the problems experienced are high (İnci & Erdem, 2008). The original Cronbach alpha value of the scale was .95. In this study, the Cronbach alpha was found to be .71.

Beck Hopelessness Scale – BHS: It is a scale developed by Beck et al. in 1974 to measure a person's pessimism about the future (Beck et al., 1974). BHS, consisting of 20 statements, answered as yes-no, is given 1 point for each answer that matches the answer key, and 0 points for each unmatched answer. Among these statements, there is a score range of 0-20 with 11 yes and 9 no answer keys. It is accepted that as the scores obtained increase, the level of hopelessness of the person also increases. In our country, the adaptation of the scale to Turkish was carried out by Durak and Palabıyıkoğlu. It is found Cronbach's alpha 0.85 and test-retest reliability .67. (Durak & Palabıyıkoğlu, 1994). Kuder-Richardson 20 (KR-20) developed by Kuder Richardson and used to determine the reliability coefficient of binary variables (yes/no). In scales with 10-15 items, a value as low as 0.50 is considered reliable. However, in a scale with more than 50 items, the KR-20 reliability coefficient is expected to be above 0.80 (Erdoğan et al., 2020). The KR-20 internal consistency coefficient of the scale in this study was .60.

Ethics Considerations: Ethical approval numbered 2017-4/3 was obtained from the ethics committee of Atatürk University Nursing Faculty, institutional permission and scale permissions were obtained from the institution where the study was conducted. Verbal and written informed consent were obtained from all participants who participated in the study and the purpose of the study was explained.

Data Analysis: Data were analyzed using the IBM SPSS (Statistical Package for Social Sciences) version 18. The normality distribution of data was evaluated using skewness and kurtosis statistics. Number, percentage, minimum-maximum values, mean and standard deviation were used in the analysis of the data. While t-test was used in independent groups to examine the difference between two-group variables, one-way analysis of variance analysis was used to examine the difference in more than two groups. Pearson correlation analysis was used to investigate the relationship between the variables. In addition, Cronbach's alpha value was used for the reliability of the scales and the significance level was taken as $p<.05$.

RESULTS

Three hundred and eighty-four (384) parents participated in the study. Sociodemographic characteristics of the caregivers (Table 1) are presented in detail. Table 1 shows that more than half (66.9%) of the caregivers were mothers, the mean age was 34.35±7.62, the mean duration of caregiving (years) was 4.69±4.13 and the mean duration of caregiving (hours) was 8.27±6.39 (Table 1).

Table 1. Distribution of parents according to descriptive characteristics (n=384)

	n	**%**
Gender		
Women	257	66.9
Men	127	33.1
Level of education		
İlliterate	85	22.1
Primary school	136	35.5
Secondary school	78	20.3
High school	67	17.4
University and above	18	4.7
Monthly Income		
Income more than expenses	26	6.8
Income equals expense	103	26.8
Income less than expenses	255	66.4
Presence of Another Person Needing Care in the Family		
Yes	46	12.0
No	338	88.0
	Mean±SD	**Min-Max**
Age	34.35±7.62	18-57
Care Period (year)	4.70±4.13	6 moon/18 year
Daily Patient Care Time	8.27±6.39	1-24 hour
Diagnosis time	4.51 ± 3.85	6 month/18 year
Number of Hospitalizations	2.32± 3.09	Never/9 times

The ZCBS mean of the participants was determined (40.00±9.63), and this score was accepted as a moderate burden in the Zarit scale. The participants' BHS mean score was found to be mild (7.97±4.43) (Table 2).

Table 2. Mean ZCBS scores and BHS scores of parents (n=384)

	Min.	Max.	Mean ± SD
ZCBS total score	0	88	40.00±9.63
BHS total score	0	20	7.97±4.43

Among the participants who care for children with epilepsy, it was determined that women have a higher care burden than men, those who have a university or higher education have a lower care burden compared to other education levels, employees have a lower care burden than those who do not work and housewives, those whose income is more than their expenses have a lower care burden than those whose income is equal to or less than their expenses, those who had a family member in need of care other than the child with epilepsy had a higher care burden than those who did not (p<.05). It was determined that the levels of hopelessness were higher in married people than in singles who care for children with epilepsy, those who have a university or higher education have a lower hopelessness level compared to other education levels, employees have a lower hopelessness level than those who do not work and housewives, those whose income is more than their expenses have a lower hopelessness level than those whose income is equal to or less than their expenses, those who had a family member in need of care other than a child with epilepsy had a higher hopelessness level than those who did not (p<.05) (Table 3).

Table 3. Comparison of the mean scores of ZCBS and BHS according to the descriptive characteristics of the parents (n=384)

	n	**ZCBS** Mean±SD	**BHS** Mean±SD
Gender			
Women	257	41.70±9.20	8.06±4.49
Men	127	36.50±9.62	7.78±4.31
		t=5.071 p=**.000**	t=0.571 p=.568
Level of education			
İlliterate (1)	85	40.25±7.92	9.96±4.26
Primary school (2)	136	40.99±10.61	8.68±4.14
Secondary school (3)	78	40.65±8.63	8.07±4.42
High school (4)	67	39.02±9.79	5.10±3.12
University and above (5)	18	32.16±9.90	3.38±3.41
		F=3.710 p=**.006**	F=20.427 p=**.000**
Monthly Income			
Income more than expenses (1)	26	33.15±8.17	4.38±3.26
Income equals expense (2)	103	37.96±9.43	6.48±4.27
Income less than expenses (3)	255	41.52±9.42	8.93±4.25
		F=12.821 p=**.000**	F=22.623 p=**.000**
Presence of Another Person Needing Care in the Family			
Yes	46	43.80±9.12	9.51±4.03
No	338	39,53±9,60	7.75±4.46
		t=2.877 p=**.004**	t=2.545 p=**.011**

*Bonferroni; t=independent t-test; F=one way ANOVA; SD, standard deviation; ZCBS= Zarit Care Burden Scale, BHS=Beck Hopelessness Scale

As seen in Table 4, there is a moderately significant positive relationship between ZCBS and BHS (p<.05). There is a moderately significant positive correlation between ZCBS and duration of diagnosis, number of hospitalizations and duration of caregiving (p<.05). There is a highly significant positive correlation between daily caregiving time and ZCBS (p<.05). There is a low level significant positive correlation between the duration of diagnosis, number of hospitalizations, age of parents and duration of care giving and BHS (p<.05). There is a moderately significant positive correlation between daily caregiving time and BHS (p<.05) (Table 4).

Table 4. Examination of the relationship between some variables and the ZCBS and BHS scores

	ZCBS	BHS
Diagnosis Time	0.297**	0.218**
Number of Hospitalizations	0.360**	0.256**
Age of Participant	-0.058	0.118*
Duration of Care (years)	0.333**	0.255**
One-Day Caregiving Time	0.522**	0.363**
Zarit Care Burden	-	0.359**

*p<.05; **p<.01, Pearson Correlation Analysis

DISCUSSION

In this study, the factors affecting the level of care burden and hopelessness of parents with children with epilepsy and the relationship between care burden and hopelessness were examined. Caregivers were found to have a moderate level of care burden (40.00±9.63). Turan et al. found that caregivers of epilepsy patients in Turkey had a moderate level of care burden (Turan et al., 2021). Gutierrez-Angel et al. found that the care burden score was at a moderate level in their study on the families of epilepsy patients (Gutierrez-Angel et al., 2018). In the study conducted by Lai et al. on the families of Asian patients with epilepsy, it was found that they had a moderate level of care burden (Lai et al., 2019). Within the scope of the values of the Turkish society, caregiving is accepted as a responsibility and assuming this role is not perceived as a burden (Yılmaz Bahadır & Ata, 2017). The care burden score obtained in these studies was similar to our study.

Similar to studies conducted in different countries, the majority of caregivers in this study were women (Çalışır et al., 2018; Murugupillai et al., 2016). In most of the provinces located in the east of Turkey, women traditionally undertake the responsibility of caregiving due to the patriarchal family structure. This may be due to the status of women in the society and gender role. This may also be the reason why 66.9 per cent of the participants were women. Higher educational level of the caregiver was associated with better psychological health (Trinka et al., 2019), and it was estimated that this resulted from a better understanding of the person's medical condition and led to better coping strategies (Akandere et al., 2009). In this study, care burden decreased as the level of education increased. The higher the level of education of caregivers, the better prepared they will be. This is because they will have a better opportunity to develop awareness and competence and gain more accurate information on how to provide the desired care (Liu et al., 2020). In the study conducted by Turan et al. on the carers of patients with epilepsy, it was found that individuals with low education level had higher mean care burden scores (Turan et al., 2021). As the educational level of the participants increases, their sensitivity and perception of the severity of the disease may increase, complications that may arise due to the disease may be minimized with regular and rational use of medication, and this may positively affect the burden of care. Socioeconomic status (e.g. family income) is another important determinant of perceived burden among caregivers in rural/developing countries (Trinka et al., 2019). In this study, participants with low socioeconomic status had a higher burden of care. In this study, it was found that participants with low socioeconomic status had higher mean care burden scores. In the study conducted by Gutierrez-Angel et al. on primary caregivers of patients with epilepsy and in the study conducted by Lai et al. on caregivers of patients with epilepsy in Asian families, it was found that lower socioeconomic status was associated with higher care burden (Gutierrez-Angel et al., 2018; Lai et al., 2019). The results of the present study are similar to the studies in the literature. In the study conducted by Muslu et al. the mean social and physical burden subscale scores and total family burden levels of parents with more than one disabled child were found to be higher than those of parents with a single disabled child (Karayağız Muslu & Coşkun Cenk, 2018). In this study, it was found that care burden was higher in those who had another family member in need of care other than epilepsy. In the study conducted by Köse et al. on parents of children diagnosed with cancer, having a child with another chronic disease in need of care was associated with higher care burden (Köse et al., 2019). The presence of another individual in need of care other than epilepsy in the family may be associated with the interruption of the caregiver's daily life, more frequent family problems and financial burden.

In this study, the mean total hopelessness score of the parents was found to be 7.97±4.43. Considering the mean scores that can be obtained in the scale (min.-max., 0-20), it can be said that the mean hopelessness scores of the parents are low. In studies conducted on different sample groups using the hopelessness scale, it was found to be 5.13 ± 5.02 in the study conducted by Kasımoğlu and Arıkan on the parents of mentally disabled children, 7.01 ± 4.18 in the study conducted by Durat et al. on the parents of children with special needs, and 8.82 ± 5.24 in the study conducted by Altay and Arıkan (2015) on the parents of subacute sclerosing panencephalitis patients (Altay & Arıkan, 2015; Durat et al., 2017; Kasımoğlu & Arıkan, 2021). The result of the present study is similar to the studies in the literature. The low level of hopelessness of the parents may be associated with fatalism belief.

According to Kısa et al., one of the factors affecting the hopelessness level of individuals is the level of education (Kısa et al., 2019). In the study conducted by Durat et al. on the families of children with special needs, it was found that the level of hopelessness decreased significantly as the level of education increased (Durat et al., 2017). In this study, as the education level of the participants increases, their level of hopelessness decreases. It is thought that higher education level leads to increased awareness about children's conditions and competences/deficiencies and enables parents to have better access to official and social support that serves to facilitate the acceptance of their children, which in turn reduces the level of hopelessness (Konukbay & Arslan, 2015). In a study conducted by Akandere et al. on mothers and fathers with mentally and physically disabled children, the high level of education of parents facilitates them to collect information about their children's disabilities and what they can do in the future. It is thought that hopelessness will decrease with getting rid of the unknown and focusing on solutions rather than problems (Akandere et al., 2009). According to the study conducted by Cabar et al. it was found that parents with low socioeconomic status had higher levels of hopelessness (Cabar et al., 2019). Similarly, in this study, participants with low socioeconomic status were found to have higher levels of hopelessness. In addition, according to Cabar et al.; the care costs of the disabled child and the presence of privileged treatment and rehabilitation needs are a costly process for families. It can be thought that this situation may cause an increase in the hopelessness levels of parents, but it is thought that there may not be a difference between the hopelessness levels of parents due to the cultural and socioeconomic structure of societies (Cabar et al., 2019). Muslu et al. found that the hopelessness level of parents with more than one disabled child was significantly higher than those with only one disabled child (Karayağız Muslu & Coşkun Cenk, 2018). Köse et al. (2019) found that the presence of another chronic disease at home was significant on the level of care burden and anxiety and increased the level of care burden and anxiety in parents with children diagnosed with cancer (Köse et al., 2019). In this study, having another person in need of care at home increased the level of hopelessness of the parents. This situation may be associated with factors such as feeling punished, physical fatigue, economic problems, psychological depressions, lack of communication with the social environment, not being able to spare enough time for oneself, and looking at the future with anxiety.

In this study, a significant positive correlation was found between the duration of diagnosis, the number of hospitalizations, the duration of care and the time spent in care in a day and the level of care burden and hopelessness. Alahan et al. (2015), in a study on families with children with chronic diseases, concluded that the burden of care for parents increased as the duration of diagnosis increased (Alahan et al., 2015). Budak and Geçkil (2020) found that as the duration of diagnosis, the number of hospitalizations and the duration of care increased, the burden of care of parents increased and there was a significant difference between them (Budak & Geçkil, 2020). In a study conducted by Angel et al. in Mexico, a positive correlation was found between increasing duration of diagnosis and burden (Gutierrez-Angel et al., 2018). In other studies, higher burden was found to be associated with longer epilepsy and care duration (Babalola et al., 2014). As the age of onset of epilepsy decreases, the caregiving period lengthens, and the care of children becomes more physically and psychologically demanding. This may increase the stress on parents or carers (Pokharel et al., 2020). Considering the positive relationship between care burden and hopelessness level in this study, the results obtained in the literature review regarding care burden can be generalised to hopelessness level. Another important finding obtained in this study was that the level of hopelessness increased as the age of the participants increased. This study overlaps with the study conducted by Akandere et al. (2009) (Akandere et al., 2009).

In our study, a significant positive relationship was found between care burden and hopelessness level. The results obtained in studies conducted on children with special needs and chronic diseases in the literature (Çalışır et al., 2018; Karayağız Muslu & Coşkun Cenk, 2018), overlap with the results of this study. According to the qualitative study conducted by Björquist et al. (2016), among the situations that cause hopelessness in parents, parents' concerns about the child, concerns about the future of the child, and support needs were shown (Björquist et al., 2016). In their study, Muslu et al. revealed that as parents' hopelessness levels increased, their perceptions of deficiency; time requirements; economic, social, physical and emotional burdens increased (Karayağız Muslu & Coşkun Cenk, 2018). Similarly, Sivrikaya and Tekinarslan (2013) found that as the economic burden, emotional burden and time requirements of mothers increased, their pessimism increased (Sivrikaya & Çifci Tekinarslan, 2013). The fact that epilepsy continues lifelong in some individuals, the increase in emotionality with age, more anxiety about the future of the child, and the inversely proportional decrease in physical strength may support the relationship between the dependent variables in this study.

Limitations of the Study: The results of this study are limited to the opinions of the patients who were treated in the training and research hospital and accepted to participate in the study. The results of this study can only be generalized to parents of this epileptic child.

CONCLUSION

In this study, education level, income level and the presence of another person in need of care in the family significantly affected both care burden and hopelessness levels of caregivers. The gender of the participants significantly affected only the burden of care. It was determined that caregivers had moderate care burden and mild hopelessness. In addition, a significant relationship was found between care burden and hopelessness and age at onset of epilepsy, duration of care, duration of daily care and number of hospitalizations. Finally, a low and positive relationship was found between care burden and hopelessness. Families with children with epilepsy should be supported socially, economically and psychologically. Attempts should be made to increase the motivation of these families. It is recommended that qualitative studies should be conducted on the effect of the training given to the parents of children with epilepsy on the burden of care and hopelessness level or on the sample group in question.

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Acquisition of data for the study: YS

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