

## The development of The Epileptic Seizure Parental Burden Scale: A validity and reliability study

Deniz Sumeyye Yorulmaz<sup>a,\*</sup>, Hilal Kurt Sezer<sup>b</sup>, Sibel Kucukoglu<sup>c</sup>

<sup>a</sup> Artvin University, Faculty of Health Sciences, Çayağzı, Lif Levha Sokak No:11E, 08000 Merkez Artvin, Turkey

<sup>b</sup> Niğde Omer Halisdemir University, Zubeyde Hanım Faculty of Health Sciences, Derbent Yerleşkesi, Atatürk Blv., 51200 Niğde Merkez, Turkey

<sup>c</sup> Selçuk University, Nursing Faculty, Ardiçlı, 42250 Selçuklu, Konya, Turkey

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### ABSTRACT

**Objective:** It is common for parents to shoulder the burden of care for their children with chronic diseases. However, there are no robust scales to measure the burden of care of parents of children with epilepsy. This study aimed to develop the “Epileptic Seizure Parental Burden Scale (ESPBS)” and evaluate its psychometric properties.

**Materials and methods:** This was a methodological study. The sample consisted of 333 voluntary parents of children with epilepsy. Data were analyzed using the Statistical Package for Social Sciences (SPSS v. 25) at a significance level of  $p < .05$ . Content validity, item-total correlation, explanatory factor analysis (EFA), confirmatory factor analysis (CFA), the “upper- and lower-27 percent rule,” Cronbach's alpha coefficient, and the split-half reliability method were used for psychometric analysis.

**Results:** The scale consisted of 15 items and two subscales. The Kaiser-Meyer-Olkin (KMO) was 0.961, for which Bartlett's test of sphericity was significant ( $X^2 = 5079.527, p < .001$ ), indicating sampling adequacy and correlation between the items for factor analysis. The scale had item-total item correlations of 0.311 to 0.741. The Explanatory Factor Analysis (EFA) revealed a two-factor structure. According to the confirmatory factor analysis,  $\chi^2/df$ , GFI, AGFI, CFI, and RMSEA were 2.012, 0.93, 0.91, 0.97, and 0.055, respectively. These values were very close to a good fit. The items had factor loadings of 0.508 to 0.890. The total scale explained 60.432% of the total variance. The scale had a Cronbach's alpha of 0.93. The split-half reliability indicated a significant ( $p < .001$ ) and high ( $r = 0.890$ ) correlation.

**Conclusion:** The Epileptic Seizure Parental Burden Scale (ESPBS) has high psychometric properties. It is a valid and reliable instrument that can measure the epileptic seizure burden of parents of children with epilepsy.

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### Introduction

Epilepsy is a chronic neurological disorder that results from different pathological processes in the brain and manifests itself with two or more unprovoked seizures. Epilepsy is the most common neurological disease in childhood, with a prevalence of 0.7% to 1.8%. Thirty-three million children worldwide have epilepsy, affecting >100 million individuals and families (Karakis et al., 2014; Karimi & Heidari, 2015).

Epilepsy increases the risk of premature death and affects mortality, morbidity, and comorbidity rates, quality of life, demand for care, and financial costs (Widjaja et al., 2021). People with epilepsy have a higher prevalence of asthma, migraine, diabetes, cardiovascular diseases, stroke, dementia, Alzheimer's, and major depression. Women with epilepsy have a higher prevalence of spontaneous abortion, premature

death, and prepartum and postpartum haemorrhage (Beghi, 2016; Ngugi et al., 2010). For general epilepsy populations, total direct healthcare costs per person range from \$10,192 to \$47,862, while indirect healthcare costs per person range from \$1022 to \$19,749. In Europe, the cost of neurological diseases is \$ 798 billion (37% direct medical costs, 23% direct non-medical costs, and 40% indirect costs) (Beghi, 2016). Research in the Netherlands, Canada, Spain, Finland, and the United Kingdom shows that people with epilepsy experience negative social consequences in the long term (participation in education, employment/unemployment, marital status/marriage, pregnancy, having children, obtaining a driver's license, driving, living arrangement, and independence) (Baca et al., 2017). Epileptic seizures may result in short-term loss of consciousness, accident, unintentional injury, burns, suffocation, and even death (Beghi, 2016; Hosoyama et al., 2017).

Epilepsy is an important public health problem that requires long-term and even life-long care. Epilepsy is a chronic disease with a high burden of care that significantly affects patients' and their

\* Corresponding author.

E-mail address: [denizyrlmz.20144@gmail.com](mailto:denizyrlmz.20144@gmail.com) (D.S. Yorulmaz).

family members' independence, psychological health, and emotional well-being (Beghi, 2016). Children with epilepsy have more behavioral problems than healthy children. Parents of children with epilepsy have higher stress and anxiety levels than those of healthy children (Eom et al., 2016).

Controlling seizure frequency in epilepsy is a top priority and often an outcome measure. Epileptic seizures significantly affect patients' and their family members' quality of life. However, we cannot understand the burden of seizures and their impact on family members if we focus only on the outcomes of seizure frequency. In recent years, researchers have proposed considering patient-centered outcomes reported by patients and their family members as additional criteria for evaluating treatment efficacy (Berg et al., 2019).

It is hard to understand how much burden epilepsy and seizures place on patients and their family members. However, we cannot fully assess the effect of treatment without understanding that burden. We should determine the burden of seizures on children with epilepsy and their family members so that we can improve their quality of life and help nurses plan care (Berg et al., 2019; Prevos-Morgant et al., 2019). Healthcare professionals need valid and reliable instruments to assess the burden of seizures on children with epilepsy and their family members and plan interventions to reduce that burden. We should determine the burden of seizures early to implement the necessary therapeutic interventions and promote patients' and their family members' quality of life. Various measurement tools are used to determine the effect of epilepsy on knowledge, attitudes, stigma, and quality of life of children with epilepsy and their family members, adults, caregivers, nurses, and society in Canada, America, Indonesia, Japan, United Kingdom, and Croatia (Bielen et al., 2014; Buck et al., 2007; Buelow et al., 2018; Espie et al., 2001; Jarvie et al., 1993; Kuramochi et al., 2021; Lim et al., 2012; Townshend et al., 2008). However, there is no valid and reliable instrument to assess the burden of seizures on children with epilepsy and their family members in Turkey. Given that epilepsy-related problems and seizure burden are affected by the family, community, and culture in which children and their parents live, we think that we need a valid and reliable instrument that can be used in Turkish society. Therefore, this study aimed to develop the Epileptic Seizure Parental Burden Scale (ESPBS) for healthcare professionals in Turkey. The new measurement tool will enable healthcare professionals to assess the seizure burden on children with epilepsy and their family members and to plan and implement appropriate interventions.

## Method

### *Research objective and type*

This study adopted a methodological research design to develop the ESPBS.

### *Population and sample*

The study population consisted of parents of children with epilepsy. A common rule of thumb for scale development and adaptation is to have a sample size five to ten times the number of items on the scale. The target sample was 130–260 parents because the pool initially consisted of 26 items. However, the World Health Organization and the International Test Center recommend a sample of 300 to 500 people to determine the psychometric properties of a scale (Çapık et al., 2018; International Test Commission (ITN), 2018). Therefore, the sample consisted of 333 parents of children with epilepsy to evaluate the psychometric properties of the ESPBS. The Holter value (default model) was used to determine sampling adequacy for CFA. The results showed that a sample of 209 would be large enough at a significance level of 0.05. These results indicated that our sample was large enough for a CFA.

### *Data collection tools*

Data were collected using a demographic characteristics questionnaire and the ESPBS Item Pool Form.

### *Demographic characteristics questionnaire*

The demographic characteristics questionnaire was based on a literature review conducted by the researchers (Baca et al., 2017; Berg et al., 2019; Karakis et al., 2014; Karimi & Heidari, 2015; Yorulmaz et al., 2021). The questionnaire consisted of 15 items and two parts. The first part consisted of items on sociodemographic characteristics (age, gender, education, monthly income, etc.) The second part consisted of items on epilepsy (diagnosis, medication, frequency of seizures, etc.)

### *Epileptic Seizure Parental Burden Scale (ESPBS)*

The Epileptic Seizure Parental Burden Scale (ESPBS) was based on a literature review conducted by the researchers. The literature search was conducted using the keywords “epilepsy, care, parent, care burden, economic burden, stigma” from Web of Science, Pubmed, Sciedirect, Embase, CINAHL databases, each keyword separately and using combinations of keywords. During the literature review, ILAE guide, current publication results and other studies were used to create an item pool. A total of 8 articles were used to create the scale question pool. Of these articles, two were studies with strong evidence (Level 1a; meta-analysis and systematic review), while six were studies with weak evidence (Level 3,4; case-control and descriptives) (Allers et al., 2015; Baca et al., 2017; Berg et al., 2019; International League Against Epilepsy (ILAE), 2022; Karakis et al., 2014; Karimi & Heidari, 2015; Owolabi et al., 2019; Yorulmaz et al., 2021). In addition, since there is no cultural measurement tool in Turkey to measure seizure burden, thorough interviews were conducted with the parents of 3 children with epileptic seizures, and then a draft scale consisting of 26 items was created. The draft scale prepared in line with the interviews and the literature was presented to five experts for review. Five experts (Faculty of Nursing members who have studies on epilepsy in the department of Child Health and Diseases Nursing. Doctors who have received their expertise in pediatric neurology and psychologist who have studies on epilepsy, with children with epilepsy and their families.) checked the draft for intelligibility and relevance. The draft scale was presented to expert opinion in Davis technique (1 = not relevant, 2 = relevant to some extent, 3 = relevant, 4 = completely relevant) (Davis, 1992). The draft scale was minimally revised based on expert feedback. No item was removed or added from the draft scale, as the experts reported highly positive opinions about the intelligibility or responses of the scale. A pilot study was conducted with 15 parents of children with epilepsy. The parents in which the pilot study was conducted were not included in the final sample of the study. In line with the feedback, no changes were made to the draft scale after the pilot test. Afterward, the 26-item scale was administered to 333 parents. The item-total correlation revealed that 1 item had a factor loading of <0.30. The explanatory factor analysis (EFA) revealed that ten items had a factor loading of <0.45 and/or were overlapped. Therefore, total 11 items were removed from the scale. The final scale consisted of 15 items and two subscales. Items 10, 11, 14, 15, 16, 17, 19, 20, and 21 were converted into items 1, 2, 3, 4, 5, 6, 7, 8, and 9 in the first subscale. Items 7, 23, 24, 25, 1, and 26 were converted into items 10, 11, 12, 13, 14, and 15 in the second subscale. The items are rated on a five-point Likert-type scale (1 = Strongly disagree, 2 = Disagree, 3 = Undecided, 4 = Agree, 5 = Strongly agree). The total score ranges from 15 to 75. There is no cut-off point. No items are reverse scored. Higher scores indicate a higher burden of seizures on the shoulders of parents of children with epilepsy.

### Item Pool

- 1-) Seizures, hospitalization, and treatment place an economic burden on our family.
- 2-) Seizures make it difficult for us to plan our daily lives.
- 3-) Seizures cause difficulties in our social life.
- 4-) We moved to another city that offered better treatment for epilepsy/seizures.
- 5-) We changed the school of our other children for the treatment of our child with epilepsy.
- 6-) We have some problems in our social life because we cannot leave our child with epilepsy alone at home.
- 7-) The treatment of our child with epilepsy affects the social life of our other children.
- 8-) When our child has a seizure outside the home, people look at it differently and react negatively.
- 9-) When our child has a seizure at school, his/her peers look at it differently and react negatively.
- 10-) The thought that our child might have a seizure alone worries us.
- 11-) The fact that we never know when our child might have a seizure worries us.
- 12-) It upsets my child when his/her peers talk about him/her when he/she has a seizure.
- 13-) It upsets my child when his/her peers call him/her names because of his/her epileptic seizures.
- 14-) We do not want our child to do sports alone because we never know when he/she might have a seizure.
- 15-) We are always on the alert because we never know when our child might have a seizure.
- 16-) We are worried that our child might get injured or have an accident because of a seizure.
- 17-) We are worried that our child might have ups and downs in his/her academic performance due to his/her epilepsy.
- 18-) We limit our child's social life due to epileptic seizures.
- 19-) Our child has ups and downs in his/her social life because of his/her seizures and treatment.
- 20-) We cannot leave our child home alone because we never know when he/she might have a seizure.
- 21-) We do not want our child to be outside alone because we never know when he/she might have a seizure.
- 22-) We do not have a private life because of our child's seizures.
- 23-) We hesitate to visit or invite our relatives and friends because of our child's seizures.
- 24-) The treatment is causing our family financial problems.
- 25-) Buying epilepsy drugs creates financial problems for our family.
- 26-) We cut down on our other expenses due to treatment and care expenses.

### Inclusion and exclusion criteria

The inclusion criteria were, 1; having a child with epilepsy, 2; having no communication problems, 3; volunteering. The exclusion criteria were, 1; having a chronic illness other than epilepsy and 2; declining to participate. The reason for excluding a second chronic disease (diabetes, asthma, rheumatism, etc.) was the thought that a different disease might much increase the care and economic burden of the parents. Therefore, this criterion was set to determine the exact burden of epileptic seizures.

### Data collection and setting and date

The data were collected between 01 September 2021 and 01 October 2021. The data were collected online because it was hard to contact parents of children with epilepsy face-to-face due to the Covid-19 pandemic' restriction. The self-reported data collection form was prepared on Google Forms. A link to the form was shared on social media

platforms (Gmail, WhatsApp, Facebook, Instagram, etc.) and forums to invite parents of children with epilepsy to the study. First of all, social media platforms used by parents were investigated by researchers. With the aim of opening the platforms, the follow-up purposes of the followers, their correspondence (questions asked, comments made, likes, etc.) were examined. Then, the most used social media platforms chosen Facebook (Page name: Epilepsy, number of followers: 8500) and Instagram (Page name: Children Resisting Epilepsy, number of followers: 7181). These social media platforms are used by parents with a child diagnosed with epilepsy to search and share information in Turkey. Before the research, the researchers contacted the administrators of these pages, then researchers gave information about the research and asked them to share the research link on the page. All parents were asked to read the informed consent form to brief them about the research purpose and procedure. Those who agreed to participate in the study were allowed access to the data collection form. Each participant filled out the form in 6–7 min. The researchers used social media platforms to answer participants' questions. Access to the forms is limited to 'once' in order to prevent participants from participating repeatedly.

### Data analysis

The data were analyzed using the Statistical Package for Social Sciences (SPSS, v 25.0) at a significance level of 0.05. Number, percentage, and mean were used for descriptive data. Content Validity Index (CVI) was used to evaluate expert opinions. CVI was calculated using the Davis technique, which was employed to evaluate experts' opinions on the relevance of the items (content validity) on a scale of 1 to 4 (1 = not relevant, 2 = relevant to some extent, 3 = relevant, 4 = completely relevant) (Davis, 1992). EFA and CFA was used for construct validity, while the upper and lower 27% was used for internal validity. Total correlations, Kaiser-Meyer-Olkin (KMO) coefficient, and Bartlett's test of sphericity were used to determine whether the data was suitable for factor analysis. Cronbach's alpha item and split-half reliability analyses were performed for reliability. There was no missing data because the data were collected online. No missing data completion method was used during data analysis.

### Ethical considerations

The study was approved by the Ethics Committee of Artvin Coruh University Rectorate (E-18457941-050.99-12,456). All parents were briefed about the research purpose and procedure through Google Forms. Those who agreed to participate in the study clicked on "I agree to participate in this research." The study was conducted according to the principles of research and publication ethics.

### Results

Participants had a mean age of  $36.05 \pm 8.46$  years and a mean number of children of  $1.81 \pm 0.78$ . More than half the participants were mothers (67%). Less than half the participants had high school degrees (44.7%) and a low income (40.2%). Half the participants lived in city centers (49.5%). Less than half the participants had a consanguineous marriage (39.3%) and had a family member with epilepsy (36.6%). More than half the participants received no training in epilepsy (69.4%) (Table 1). The mean number of medications taken per child was 2.5. Children had epilepsy for five years on average. More than half the children were the eldest children in their families (61.3%). Less than half the children had seizures once a month or less (42.6%) and used three or more medications per day (45.4%). Most participants were responsible for monitoring their children's medication use (86.2%) (Table 1).

**Table 1**  
Sociodemographic and Disease-Related Characteristics (n:333).

Sociodemographic Characteristics		Disease-Related Characteristics			
Age: 36.05 ± 8.46 years (Min: 20, Max: 68)		Disease duration: 5.03 ± 3.98 years (Min: 1, Max: 33)			
Number of children: 1.81 ± 0.78 (Min: 1, Max: 4)		Number of medications 2.67 ± 1.65			
	n	%	n	%	
<b>Gender</b>					
Mother	223	67.0	Child with epilepsy		
Father	110	33.0	Eldest	204 61.3	
			Second	104 31.2	
			Third	16 4.8	
			Youngest	9 2.7	
<b>Mother's education (degree)</b>					
Primary and middle school	114	34.2	Seizure frequency		
High school	118	35.4	≤ once a month	142 42.6	
Associate	50	15.0	> once a month	100 30.0	
Bachelor's or higher	51	15.3	≤ once a week	45 13.5	
			> once a week	46 13.8	
<b>Father's education (degree)</b>					
Primary and middle school	38	24.9	Number of medications		
High school	149	44.7	1	81 24.3	
Associate	42	12.6	2	101 30.3	
Bachelor's or higher	59	17.7	≥3	151 45.4	
<b>Family income</b>					
Negative (income < expense)		134	40.2	Monitoring medication use	
Neutral (income = expense)		118	35.4	Parent	287 86.2
Positive (income > expense)		81	24.3	Child	46 13.8
<b>Place of residence</b>					
City center	165	49.5			
District center	122	36.6			
Village	46	13.8			
<b>Consanguineous marriage</b>					
Yes	131	39.3			
No	202	60.7			
<b>Epilepsy in the family</b>					
Yes	112	36.6			
No	211	63.4			
<b>Receiving training in epilepsy</b>					
Yes	102	30.6			
No	231	69.4			

**Content validity**

CVI was used to determine the content validity of the ESPBS. Table 2 shows the lowest and highest scores and CVI given to the items by experts.

The CVI of the items included in the item pool ranged from 0.80 to 1.00 (Table 2).

Item reliability: Item 5 was removed from the draft scale because it had an item-total correlation of <0.30 (An item has been removed). The remaining items had an item-total correlation of 0.311 to 0.741 (Table 3).

The Kaiser-Meyer-Olkin (KMO) was 0.961, for which Bartlett's test of sphericity was significant ( $X^2 = 5079.527, p < .001$ ), indicating sampling adequacy and correlation between the items for factor analysis.

EFA and CFA was used for construct validity, while the upper and lower 27% was used for internal validity.

**Construct validity:** Explanatory factor analysis (EFA) was used for construct validity. First, the factor structure of the scale was determined based on the EFA results. There were two factors with an eigenvalue of >1, indicating that the scale consisted of two subscales. Items 2, 3, 4, 6, 8, 9, 12, 13, 18, and 22 had an item factor loading of 0.201, 0.153, 0.226, 0.193, 0.211, 0.193, 0.226, 0.227, 0.260, and 0.279, respectively (Ten items were removed). Therefore, ten more items were removed from the scale because they had a factor loading of <0.45 or were overlapped. Eleven items in the total item pool were removed. Therefore, the final scale consisted of 15 items loaded on two factors. The first factor

**Table 2**  
Item scores by experts and CVI (n = 5).

Items	X ± SD	Min-Max	KGI
1	3.80 ± 0.45	3.00–4.00	1
2	4.00 ± 0	4.00–4.00	1
3	4.00 ± 0	4.00–4.00	1
4	4.00 ± 0	4.00–4.00	1
5	4.00 ± 0	4.00–4.00	1
6	3.60 ± 0.90	2.00–4.00	0.8
7	4.00 ± 0	4.00–4.00	1
8	4.00 ± 0	4.00–4.00	1
9	4.00 ± 0	4.00–4.00	1
10	4.00 ± 0	4.00–4.00	1
11	3.60 ± 0.90	2.00–4.00	0.8
12	3.60 ± 0.90	2.00–4.00	0.8
13	4.00 ± 0	4.00–4.00	1
14	4.00 ± 0	4.00–4.00	1
15	4.00 ± 0	4.00–4.00	1
16	4.00 ± 0	4.00–4.00	1
17	3.80 ± 0.45	3.00–4.00	1
18	4.00 ± 0	4.00–4.00	1
19	3.80 ± 0.45	3.00–4.00	1
20	4.00 ± 0	4.00–4.00	1
21	4.00 ± 0	4.00–4.00	1
22	3.80 ± 0.45	3.00–4.00	1
23	3.80 ± 0.45	3.00–4.00	1
24	4.00 ± 0	4.00–4.00	1
25	4.00 ± 0	4.00–4.00	1
26	4.00 ± 0	4.00–4.00	1

consisted of nine items with factor loadings of 0.508 to 0.890. The second factor consisted of six items with factor loadings of 0.663 to 0.811 (Table 5). Fig. 1 shows the scree-plot graph of the final scale. The total scale explained 60.432% of the total variance.

A confirmatory factor analysis was performed to confirm whether the two-factor structure was consistent with the theoretical structure. Table 4 shows the common goodness-of-fit indices and scale values. According to the CFA,  $X^2$ , df,  $X^2/df$ , CFI, GFI, and RMSA were 177.071, 87, 2.012, 0.97, 0.93, and 0.055, respectively. The first subscale had factor loadings of 0.64 to 0.79, while the second subscale had factor loadings of 0.49 to 0.80 (Table 4, Fig. 2).

Based on the content of the items and the literature review, the researchers and experts decided to name the subscales “care burden” and “socioeconomic burden.”

**Internal validity:** Internal validity was determined using independent groups t-test. The test scores were ranked from lowest to highest, and 27% of the lowest group and 27% of the highest group were compared.

The results showed a significant difference between the upper and lower 27% groups ( $p < .05$ ), indicating that the ESPBS had discriminative power [care burden subscale ( $t = -28.993; p < .001$ ), socioeconomic burden subscale ( $t = -30.334; p < .001$ ), and total scale ( $t = -20.253; p < .001$ )]. Moreover, the AVE and CR values of the

**Table 3**  
Item-total correlations.

Item No	Item Correlation						
1	0.685	8	0.686	15	0.728	22	0.679
2	0.735	9	0.581	16	0.648	23	0.615
3	0.726	10	0.611	17	0.591	24	0.691
4	0.311	11	0.607	18	0.644	25	0.662
*5	0.156	12	0.621	19	0.733	26	0.706
6	0.701	13	0.645	20	0.701		
7	0.502	14	0.699	21	0.741		

\* Removed from the scale due to an item-total correlation of <0.30.

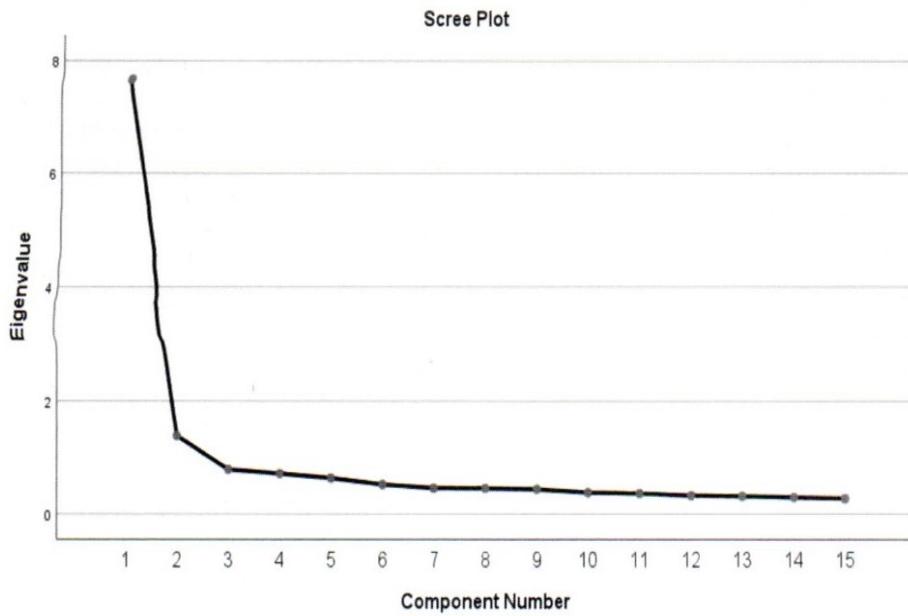


Fig. 1. Epileptic seizure parental burden scale scree-plot.

Table 4

Acceptable fit, perfect fit, and scale values for CFA.

Fit index	Acceptable fit	Perfect fit	Scale values
$\chi^2/df$	<5	<2	2.012
GFI	>0.90	>0.95	0.93
AGFI	>0.90	>0.95	0.91
CFI	>0.90	>0.95	0.97
RMSEA	<0.05	<0.08	0.055
RMR	<0.05	<0.08	0.052
NFI	>0.90	>0.95	0.94

$\chi^2$ : Chi-square, df: degrees of freedom,  $\chi^2/df$ : Chi-square /degrees of freedom, GFI: Goodness of Fit Index, AGFI: Adjusted Goodness of Fit Index, CFI: Comparative Fit Index, RMSEA: Root Mean Square Error of Approximation, RMR: Root Mean Square Residual, NFI: Normed Fit Index.

Table 5

Item factor loading values and percentage of variance explained.

Item No	Factor Loading	
	Factor 1	Factor 2
10	0.890	
11	0.856	
14	0.789	
16	0.777	
15	0.733	
17	0.669	
21	0.662	
20	0.616	
19	0.508	
23		0.811
24		0.795
26		0.713
1		0.707
25		0.704
7		0.663
Total	51.167	9.266
Variance	60.432	

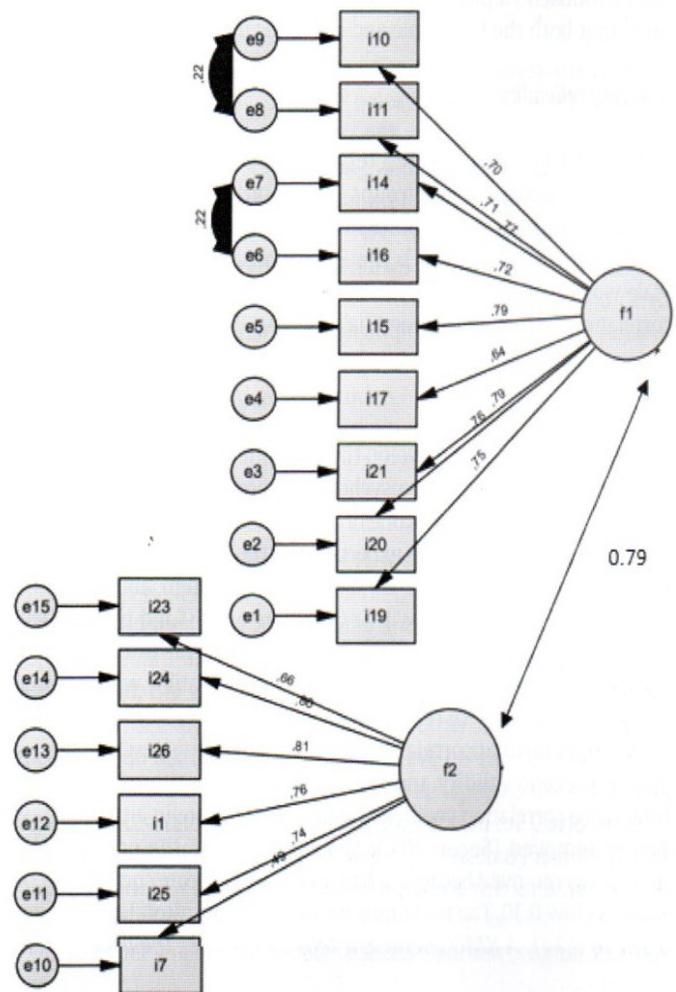


Fig. 2. CFA result ve PATH diagram.

Reliability

Cronbach's alpha reliability coefficient ( $\alpha$ ) and split-half reliability were used to test the reliability of the ESPBS.

Cronbach's alpha reliability

The total scale had a Cronbach's alpha of 0.93 (15 items). The "care burden" (nine items) and "socioeconomic burden" (six items) subscales

ESPBS were calculated separately for each dimension. The results for all dimensions are given in Table 6 below (Table 6).

In the evaluation of discriminant construct validity, the AVE value for each sub-dimension was calculated and given in Table 7.

**Table 6**  
Upper - lower 27% and AVE - CR analysis results.

Factor	Group	n	Mean	Standard Error	t	p
Factor 1	Lower	83	25.470	5.703	-28.993	0.000
	Upper	83	44.012	1.194		
Factor 2	Lower	83	14.518	4.010	-30.334	0.000
	Upper	83	23.386	1.124		
Total	Lower	83	43.325	11.729	-20.253	0.000
	Upper	83	70.205	2.937		
Model			AVE	CR		
Factor1			0.59	0.75		
Factor2			0.53	0.72		

**Table 7**  
Discriminant validity results.

Model	Factor1	Factor2
Factor1	0.761	
Factor2	0.335	0.730

had a Cronbach's alpha of 0.92 and 0.86, respectively. These scores indicated that both the total scale and subscales met the reliability criteria.

#### Split-half reliability

The split-half reliability test results showed a statistically significant correlation between the groups [care burden subscale ( $r = 0.87$ ;  $p < .001$ ), socioeconomic burden subscale ( $r = 0.74$ ;  $p < .001$ ), total scale ( $r = 0.89$ ,  $p < .001$ )]. The Spearman-Brown coefficient of the scale was calculated as 0.847, the Guttman coefficient as 0.847 and the correlation coefficient between halves as 0.735 (Table 8).

#### Discussion

This study aimed to develop the Epileptic Seizure Parental Burden Scale (ESPBS) and assess its psychometric properties.

Content Validity Index is one of the content validity methods used to evaluate the opinions of the experts about the items. In the literature, a CVI value of 0.80 and above is required for each item, and it is recommended to exclude items with a CVI value of 0.80 and below (Davis, 1992). Within the scope of this information, it was interpreted that the CVI values of the items in the scale were compatible with the literature and no items were removed. In scale development and adaptation research, item-total correlation, KMO, and Bartlett's test of sphericity should precede validity and reliability tests. If an item has an item-total score correlation coefficient below 0.30, it should either be modified or removed (Seçer, 2015; Şencan, 2005). In the present study, Item 5 was removed because it had an item-total score correlation coefficient below 0.30. The remaining items had an item-total correlation of 0.311 to 0.741. A KMO coefficient tells us whether the data matrix is

suitable for factor analysis and whether the data structure is suitable for factor extraction. A KMO should be higher than 0.60. Based on partial correlations, Bartlett's test of sphericity examines whether there is a relationship between variables. A significant chi-square statistic is proof of the normality of scores (Büyüköztürk, 2010). In the present study, the KMO was 0.961, for which Bartlett's test of sphericity was significant ( $X^2 = 5079.527$ ,  $p < .001$ ), indicating sampling adequacy and correlation between the items for factor analysis.

#### Validity

In this study, an EFA was performed to evaluate the construct validity of the ESPBS. Explanatory factor analysis is performed to determine how many factors or subscales the variables can be grouped under and what kind of relationship there is between them. The number of variables decreases with items grouped under factors or subscales, allowing us to examine the theoretical structure (Seçer, 2015). We obtained a two-factor structure after we removed the overlapped items and those with low factor loadings. We named the subscales based on the item content, literature review, and expert feedback. We named the first subscale "care burden subscale" because it consisted of items on epileptic care. We named the second subscale "socioeconomic burden subscale" because it consisted of items on the economic problems and consequences of epilepsy. Research in the Netherlands, Canada, Spain, Finland, and the United Kingdom shows that people with epilepsy experience negative social consequences in the long term (participation in education, employment/unemployment, marital status/marriage, pregnancy, having children, obtaining a driver's license, driving, living arrangement, and independence) (Baca et al., 2017). Epilepsy significantly affects patients and their family members socially and psychologically. Long-term care causes a burden of care. Anti-epileptic drugs and treatments cause economic problems (Beghi, 2016). The uncertain timing of seizures causes anxiety and stress, many parents fear that their child might die during a seizure, and anti-epileptic drugs strain families economically (Berg et al., 2019). These results indicated that the ESPBS subscales addressed the problems caused by epilepsy.

Confirmatory factor analysis is a structural equation model used to examine whether the factor structure of a measurement tool is compatible with the theoretical information. It is used to test the model obtained by EFA (Boateng et al., 2018; Çapık, 2014; Yaşlıoğlu, 2017). In the present study, the goodness-of-fit indices had acceptable values, which were very close to good fit values. The confirmatory factor analysis showed that the two subscales had factor loadings of 0.49 to 0.80 (Fig. 2). The CFA results were consistent with the literature. The EFA model was consistent with the theoretical model. The subscales were consistent with the scale. The items had acceptable associations with their subscales. A measuring instrument should explain at least 50% of the total variance (Şencan, 2005). The two-factor structure of the ESPBS explained 60% of the total variance, indicating high construct validity. Internal validity is another component of validity in scale development and adaptation research. The upper and lower 27% is used to

**Table 8**  
Split-half reliability (n = 333).

Factor	Split-half	X	Standard Error	r	p
1	Odd Items	20.3	4.430	0.865	0.000
	Even Items	16.3	3.418		
2	Odd Items	11.5	3.035	0.739	0.000
	Even Items	11.3	3.067		
Scale	Odd Items	31.8	6.763	0.890	0.000
	Even Items	27.6	5.825		
Scale total	Spearman Brown Coefficient	Guttman split-half Coefficient		Correlation between two halves	M ± SD (Min-Max)
	0.847	0.847		0.735	59.3 ± 12.2 (19–75)

determine internal validity. A statistically significant difference between the upper and lower groups of 27% for all items indicates high internal validity (Büyüköztürk, 2010; Sönmez & Alacapınar, 2016). In the present study, the item scores were ranked from lowest to highest, and 27% of the lowest group and 27% of the highest group were compared. There was a significant difference between the upper and lower groups of 27% for all items. The results showed that the scale could discriminately measure the structure it intended to measure, suggesting high internal validity. All these results indicated that the ESPBS was a valid scale. Items with an item-total correlation of 0.30 should be revised or removed (Şencan, 2005). An item should have a factor loading of  $\geq 0.45$  and a high load value under a single factor (Büyüköztürk, 2010). An invalid measurement tool will not give reliable results (Seçer, 2015). Therefore, Item 5 was removed from the scale because it had an item correlation of  $< 0.30$  (Table 3). Items 2, 3, 4, 6, 8, 9, 12, 13, 18, and 22 were removed from the scale because they either had a factor loading of  $< 0.45$  or overlapped.

Confirmatory factor analysis (CFA) is a subtype of Structural Equation Modeling. In structural equation modeling, it is assumed that there are linear relationships between latent variables and observed variables (Hoyle, 1995). In this context, it is assumed that the standard factor loads obtained by CFA are in a non-causal relationship. The CFA results obtained in this study support the assumption that there is a linear relationship between the latent variables and the observed variable. Convergent validity can be tested using different criteria. In one of these criteria, the standardized factor loadings obtained from CFA are high enough. These loads are expected to be at least  $> 0.5$  (Hair et al., 2010). Considering the standard factor loading values obtained by CFA analysis in this study, it is seen that each standard factor load is  $> 0.5$ . On the other hand, AVE and CR values need to be calculated to ensure convergent validity (Hair et al., 2010). The AVE value, which is the abbreviation of Average Variance Extracted, is obtained by the ratio of the sum of the squares of the covariances (factor loadings) of the items belonging to the factor to the number of items. This process is calculated for each factor structure obtained (Hair et al., 2010). In order to ensure the convergent validity of the measurement tool, the average explained variance (AVE) values of the items should be 0.50 and above (Bagozzi & Yi, 1988). The CR value, which is expressed as composite reliability (construct reliability), is calculated based on factor loads and error variance values obtained from CFA (İlhan et al., 2015). Composite reliability (CR) values are expected to be 0.70 and above. Accordingly, AVE and CR values of ESPBS were calculated separately for each dimension and it was concluded that convergent validity was provided for ESPBS. In order to examine whether the factors in a multidimensional measurement tool measure independent and different structures, discriminant construct validity should be provided (Bardakçı & Gürbüz, 2020). In determining the discriminant validity, the criterion is that the square root of AVE value of a factor is greater than the correlation values of this factor with other dimensions (Fornell & Larcker, 1981). Accordingly, the results for all dimensions are given in Table 7, and it was concluded that discriminant construct validity was achieved for ESPBS.

### Reliability

Various methods are used to calculate the reliability coefficients of scales on cognitive and affective characteristics. However, the internal consistency of a Likert-type measurement tool is generally evaluated using Cronbach's alpha coefficient (Boateng et al., 2018). A reliable measurement tool should have a Cronbach's alpha coefficient of at least 0.70. The higher the Cronbach's alpha coefficient, the higher the reliability (Karakoç & Dönmez, 2014). The ESPBS "care burden" and "socioeconomic burden" subscales had a Cronbach's alpha of 0.92 and 0.86, respectively. The total scale had a Cronbach's alpha of 0.93. These results indicated that the ESPBS had high reliability. Split-half reliability is another method used to determine reliability (Karakoç & Dönmez, 2014).

In other words, split-half reliability is a statistical method used to measure the consistency of the scores of a test. Split-half reliability is assessed by splitting the scale items in half (even items and odd items) and then calculating the scores for each half. The consistency between the two halves is calculated using the correlation coefficient ( $r$ ). The scale is reliable if the correlation coefficient is significant (Boateng et al., 2018; Seçer, 2015). In the present study, the items were split into two halves: the odd-numbered ones in one half and the even-numbered ones in the other. Afterward, the correlation between the two halves was calculated. The "care burden" and "socioeconomic burden" subscales had a correlation coefficient of 0.87 ( $p < .001$ ) and 0.74 ( $p < .001$ ), respectively. The total scale had a correlation coefficient of 0.89 ( $p < .001$ ). These results showed that the "care burden" subscale and the total scale had a very strong correlation, while the "socioeconomic burden" subscale had a strong correlation. In addition, the Spearman-Brown and Guttman Split-Half coefficients of 0.70 and above in the two-half reliability analyzes in the literature are interpreted as an indication of a strong and significant relationship between the two halves (Seçer, 2015). These results indicated that the ESPBS was reliable.

### Practice implications

The ESPBS is the first measurement tool to assess the burden of epilepsy seizures on parents. ESPBS helps nurses and health care professionals to determine the burden of epilepsy seizures and to compare parents with different socio-demographic characteristics (education level, economic status, residential area, etc.) and different disease history (seizure frequency, seizure type, disease year, etc.). It will help. Interventions for parents by ESPBS nurses and health care professionals will also be useful in evaluating the impact of treatment and care. In addition, it is thought that the evaluation of the validity and reliability of the ESPBS in different cultures will contribute to international comparisons of epilepsy seizure burden.

### Limitations

This study had some limitations. First, although there are many measurement tools measuring seizure burden in epilepsy in the world, there is no measurement tool with validity and reliability in Turkey. Therefore, we could not compare this scale with a similar measurement tool. Second, the sample consisted of participants who had internet access and used forums/social media platforms on epilepsy. Therefore, the results do not represent those who have no internet access and do not use forums/social media platforms on epilepsy. As there will be difficulties in re-accessing the sample group due to the Covid pandemic convenience sampling method was used in this study and for the data security both EFA and CFA were performed on the same sample. This is our third limitation. Four, our scale assesses care burden and socioeconomic burden but not the whole of seizure burden (stigma, emotional burden, etc.).

### Conclusion

The Epileptic Seizure Parental Burden Scale (ESPBS) is the first scale on the care burden of parents of children with epilepsy in Turkey. The scale consists of 15 items and two subscales. The scale has high psychometric properties, indicating that it is a valid and reliable scale that can determine the seizure burden of parents of children with epilepsy in Turkey. Healthcare professionals can easily administer the scale to parents and determine their seizure burden. They can use the data to plan holistic care, effective interventions, and training programs. Researchers should adapt the scale to other languages.

## Ethical considerations

The study was approved by the Ethics Committee of Artvin Coruh University Rectorate (E-18457941-050.99-12,456). All parents were briefed about the research purpose and procedure through Google Forms. Those who agreed to participate in the study clicked on “I agree to participate in this research.” The study was conducted according to the principles of research and publication ethics.

## Author contributions

Concept – DSY, HKS, SK; Design – DSY, HKS, SK; Supervision - SK; Resources – DSY,HKS; Materials – DSY, SK; Data Collection and/or Processing – DSY,HKS; Analysis and/or Interpretation - DSY, SK; Literature Search – DSY,HKS, SK; Writing Manuscript – DSY,HKS,SK; Critical Review – DYS,HKS,SK; Other – HKS,HKS, SK.

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## CREDIT statement

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## Declaration of Competing Interest

None.

## References

- Allers, K., Essue, B. M., Hackett, M. L., Muhunthan, J., Anderson, C. S., Pickles, K., ... Jan, S. (2015). The economic impact of epilepsy: A systematic review. *BMC Neurology*, 25 (15), 245. <https://doi.org/10.1186/s12883-015-0494-y>.
- Baca, C. B., Barry, F., Vickrey, B. G., Caplan, R., & Berg, A. T. (2017). Social outcomes of young adults with childhood-onset epilepsy: A case-sibling-control study. *Epilepsia*, 58(5), 781–791. <https://doi.org/10.1111/epi.13726>.
- Bagozzi, R. P., & Yi, Y. (1988). On the evaluation of structural equation models. *Journal of the Academy of Marketing Science*, 16(1), 74–94. <https://doi.org/10.1007/BF02723327>.
- Bardakçı, S., & Gürbüz, R. B. (2020). Marka Güven Ölçeğinin Türk Kültürüne Uyarlanması: Geçerlik ve Güvenirlik Çalışması. *İşletme Araştırmaları Dergisi*, 12(2), 1684–1692. <http://doi.org/10.20491/isarder.2020.937>.
- Beghi, E. (2016). Addressing the burden of epilepsy: Many unmet needs. *Pharmacological Research*, 107, 79–84. <https://doi.org/10.1016/j.phrs.2016.03.003>.
- Berg, A. T., Kaiser, K., Dixon-Salazar, T., Elliot, A., McNamara, N., Meskis, M. A., ... Rozek, C. (2019). Seizure burden in severe early-life epilepsy: Perspectives from parents. *Epilepsia Open*, 4(2), 293–301. <https://doi.org/10.1002/epi4.12319>.
- Bielen, I., Friedrich, L., Sruk, A., Prvan, M. P., Hajnšek, S., Petelin, Ž., ... Jacoby, A. (2014). Factors associated with perceived stigma of epilepsy in Croatia: a study using the revised epilepsy stigma scale. *Seizure*, 23(2), 117–121. <https://doi.org/10.1016/j.seizure.2013.10.008>.
- Boateng, G. O., Neilands, T. B., Frongillo, E. A., Melgar-Quinonez, H. R., & Young, S. L. (2018). Best practices for developing and validating scales for health, social, and behavioral research: A primer. *Frontiers in Public Health*, 6, 149. <https://doi.org/10.3389/fpubh.2018.00149>.
- Buck, D., Smith, M., Appleton, R., Baker, G. A., & Jacoby, A. (2007). The development and validation of the Epilepsy and Learning Disabilities Quality of Life (ELDQOL) scale. *Epilepsy & Behavior*, 10(1), 38–43. <https://doi.org/10.1016/j.yebeh.2006.10.010>.
- Buelow, J., Miller, W., & Fishman, J. (2018). Development of an epilepsy nursing communication tool: Improving the quality of interactions between nurses and patients with seizures. *The Journal of Neuroscience Nursing*, 50(2), 74. <https://doi.org/10.1097/JNN.0000000000000353>.
- Büyüköztürk, Ş. (2010). *Sosyal bilimler için veri analizi el kitabı* (4. bs). Ankara: Pegem Akademi.
- Çapık, C. (2014). Geçerlik ve güvenilirlik çalışmalarında doğrulayıcı faktör analizinin kullanımı. *Anadolu Hemşirelik ve Sağlık Bilimleri Dergisi*, 17(3), 196–205.
- Çapık, C., Gözüm, S., & Aksayan, S. (2018). Kültürlerarası ölçek uyarlama aşamaları, dil ve kültür uyarlaması: Güncellenmiş rehber. *Florence Nightingale Journal of Nursing*, 26 (3), 199–210. <http://doi.org/10.26650/FN397481>.
- Davis, L. L. (1992). Instrument review: Getting the most from a panel of experts. *Applied Nursing Research*, 5(4), 194–197. [https://doi.org/10.1016/S0897-1897\(05\)80008-4](https://doi.org/10.1016/S0897-1897(05)80008-4).
- Eom, S., Caplan, R., & Berg, A. T. (2016). Behavioral problems and childhood epilepsy: Parent vs child perspectives. *The Journal of Pediatrics*, 179, 233–239. <https://doi.org/10.1016/j.jpeds.2016.08.096>.
- Espie, C. A., Watkins, J., Duncan, R., Espie, A., Sterrick, M., Brodie, M. J., ... Curtice, L. (2001). Development and validation of the Glasgow Epilepsy Outcome Scale (GEOS): a new instrument for measuring concerns about epilepsy in people with mental retardation. *Epilepsia*, 42(8), 1043–1051. <https://doi.org/10.1046/j.1528-1157.2001.0420081043.x>.
- Fornell, C. V., & Larcker, D. F. (1981). Evaluating structural equations models with unobservable variables and measurement error. *Journal of Marketing Research*, 18(1), 39–50. <https://doi.org/10.2307/3151312>.
- Hair, J. F., Black, W. C., Anderson, R. E., & Babin, B. J. (2010). *Multivariate data analysis* (7th ed.). Prentice Hall: New Jersey.
- Hosoyama, H., Matsuda, K., Mihara, T., Usui, N., Baba, K., Inoue, Y., ... Arita, K. (2017). Long-term outcomes of epilepsy surgery in 85 pediatric patients followed up for over 10 years: A retrospective survey. *Journal of Neurosurgery: Pediatrics*, 19(5), 606–615. <https://doi.org/10.3171/2016.12.PEDS16197>.
- Hoyle, R. H. (1995). *Structural equation modeling: Concepts, issues, and applications*. Sage.
- İlhan, M., Çetin, B., & Kinay, İ. (2015). Standart Testlere Yönelik İnanç Ölçeği'nin (STYİÖ) Türkçe Uyarlaması: Geçerlik ve Güvenirlik Çalışması. *Mustafa Kemal Üniversitesi Sosyal Bilimler Enstitüsü Dergisi*, 12(29), 161–189.
- International League Against Epilepsy (ILAE) (2022). Guidelines. Access to <https://www.ilae.org/guidelines> (Access on: 04.04.2022).
- International Test Commission (ITN) (2018). Guidelines for translating and adapting tests. *International Journal of Testing*, 18(2), 101–134. <https://doi.org/10.1080/15305058>.
- Jarvie, S., Espie, C. A., & Brodie, M. J. (1993). The development of a questionnaire to assess knowledge of epilepsy: I General knowledge of epilepsy. *Seizure*, 2, 179–185. [https://doi.org/10.1016/S1059-1311\(05\)80125-6](https://doi.org/10.1016/S1059-1311(05)80125-6).
- Karakis, I., Cole, A. J., Montouris, G. D., San Luciano, M., Meador, K. J., & Piperidou, C. (2014). Caregiver burden in epilepsy: Determinants and impact. *Epilepsy Research and Treatment*, 2014. <https://doi.org/10.1155/2014/808421>.
- Karakoç, A. G. D. F. Y., & Dönmez, L. (2014). Ölçek geliştirme çalışmalarında temel ilkeler. *Tıp Eğitimi Dünyası*, 13(40), 39–49. <http://doi.org/10.25282/te.228738>.
- Karimi, N., & Heidari, M. (2015). Knowledge and attitudes toward epilepsy among school teachers in west of Iran. *Iranian Journal of Neurology*, 14(3), 130 Knowledge and attitudes toward epilepsy among school teachers in West of Iran - PMC (nih.gov).
- Kuramochi, I., Iwayama, T., Horikawa, N., Shimotsu, S., Watanabe, S., Yamanouchi, H., & Yoshimasu, H. (2021). Development and validation of the epilepsy self-stigma scale. *Epilepsia Open*, 6(4), 748–756. <https://doi.org/10.1002/epi4.12547>.
- Lim, K. S., Wu, C., Choo, W. Y., & Tan, C. T. (2012). Development and validation of a public attitudes toward epilepsy (PATE) scale. *Epilepsy & Behavior*, 24(2), 207–212. <https://doi.org/10.1016/j.yebeh.2012.03.038>.
- Ngugi, A. K., Bottomley, C., Kleinschmidt, I., Sander, J. W., & Newton, C. R. (2010). Estimation of the burden of active and life-time epilepsy: A meta-analytic approach. *Epilepsia*, 51(5), 883–890. <https://doi.org/10.1111/j.1528-1167.2009.02481.x>.
- Owolabi, L. F., Owolabi, S. D., Taura, A. A., Alhaji, I. D., & Ogunniyi, A. (2019). Prevalence and burden of epilepsy in Nigeria: A systematic review and meta-analysis of community-based door-to-door surveys. *Epilepsy & Behavior*, 92, 226–234. <https://doi.org/10.1016/j.yebeh.2018.12.017>.
- Prevos-Morgant, M., Leavy, Y., Chartrand, D., Jurasek, L., Shafer, P. O., Shinnar, R., & Goodwin, M. (2019). Benefits of the epilepsy specialist nurses (ESN) role, standardized practices and education around the world. *Revue Neurologique*, 175(3), 189–193. <https://doi.org/10.1016/j.neuro.2018.10.003>.
- Seçer, İ. (2015). *SPSS ve LISREL ile pratik veri analizi [practical data analysis with SPSS and LISREL]*. Ankara: Anı Yayıncılık.
- Şencan, H. (2005). *Reliability and validity in social and behavioral measurements*. Ankara: Seçkin Publishing.
- Sönmez, V., & Alacapınar, G. (2016). *Sosyal bilimlerde ölçme aracı hazırlama*. Anı Yayıncılık.
- Townshend, K. H., Dorris, L., McEwan, M. J., Aylett, S. E., Brodie, M. J., O'Regan, M., & Espie, C. A. (2008). Development and validation of a measure of the impact of epilepsy on a young person's quality of life: Glasgow epilepsy outcome scale for young persons (GEOS-YP). *Epilepsy & Behavior*, 12(1), 115–123. <https://doi.org/10.1016/j.yebeh.2007.09.008>.
- Widjaja, E., Guttmann, A., Tomlinson, G., Snead, O. C., III, & Sander, B. (2021). Economic burden of epilepsy in children: A population-based matched cohort study in Canada. *Epilepsia*, 62(1), 152–162. <https://doi.org/10.1111/epi.16775>.
- Yaşlıoğlu, M. M. (2017). Sosyal bilimlerde faktör analizi ve geçerlilik: Keşfedici ve doğrulayıcı faktör analizlerinin kullanılması. *İstanbul Üniversitesi İşletme Fakültesi Dergisi*, 46, 74–85.
- Yorulmaz, D. S., Çınar, S., & Kanbay, Y. (2021). Epilepsi Tanısı Alan Çocukların ve Ailelerinin Deneyimleri ve Nöbet Yükleri: Fenomenolojik Bir Araştırma. *Türkiye Klinikleri J Health Sci*, 6(4), 734–744. <https://doi.org/10.5336/healthsci.2020-80352>.





