

# Anxiety among caregivers of children with epilepsy from western China

## A cross-sectional survey

Chunsong Yang, MPH<sup>a,b,c</sup>, BingYao Kang, BD<sup>d</sup>, Yifei Mao, BD<sup>e</sup>, Qunfen Xu, BD<sup>a,b,c</sup>, Dan Yu, MD<sup>b,f,\*</sup>, Lingli Zhang, MD, PHD<sup>c,\*</sup>

### Abstract

The current study aimed to evaluate the status of anxiety among caregivers of children with epilepsy and examine the associated factors.

A cross-sectional study was conducted in western China, which consecutively recruited children with epilepsy in 2018. The self-rating anxiety scale (SAS) was used to assess the status of anxiety among caregivers of children with epilepsy. We collected information about aspects of sociodemographic data, disease status, attitude of caregivers towards the disease and family conditions as independent variables, using multiple linear regression to analyze factors related to the status of anxiety among caregivers.

A total of 334 participants were included in the study with a response rate of 95.4% (334/350). The mean age of children with epilepsy was  $6.05 \pm 4.11$  years. 7.2% (24/334) of patients were newly diagnosed and 55.4% (185/334) of patients presented with generalized epilepsy. A total of 25.7% (86/334) of caregivers among children with epilepsy presented the symptom of anxiety, with the scores of SAS  $44.31 \pm 10.558$ . SAS scores were negatively correlated with the children's age ( $B = -0.141$ ; standard error = 0.135;  $P = .008$ ), attitude towards seizures ( $B = -0.153$ ; standard error = 1.192;  $P = .004$ ) and medical expenses payment ( $B = -0.169$ ; standard error = 1.703;  $P = .002$ ).

Symptoms of anxiety are common among caregivers of children with epilepsy in western China. Healthcare providers should pay more attention to caregivers with younger children, difficult financial situation, and greater fear of seizures. Exploring mental health interventions for caregivers is important.

**Abbreviations:** ILAE = International League Against Epilepsy, SAS = self-rating anxiety scale.

**Keywords:** anxiety, caregivers, children, epilepsy

Editor: Massimo Tusconi.

CY and BK contributed equally to this study.

This study was funded by Wu Jieping Medical Foundation from Chinese Medical Association Clinical Pharmaceutical Branch: Construction of medication adherence Nomogram Prediction Model for Childhood with Epilepsy and Intervention Strategies Based on Risk Stratification. The sponsor had no role in the study design, writing of the manuscript, or decision to submit this or future manuscripts for publication.

The authors have no conflicts of interest to disclose.

<sup>a</sup>Department of Pharmacy, Evidence-based Pharmacy Center, West China Second Hospital, Sichuan University, <sup>b</sup>Key Laboratory of Birth Defects and Related Diseases of Women and Children (Sichuan University), Ministry of Education, China, <sup>c</sup>Department of Epidemiology, West China School of Public Health, and West China Fourth Hospital, <sup>d</sup>Department of Pediatric Clinic, West China Second Hospital, <sup>e</sup>West China School of Pharmacy, <sup>f</sup>Department of Children's Genetic Endocrinology and Metabolism, West China Second Hospital, Sichuan University, China.

\*Correspondence: Dan Yu, Department of Children's Genetic Endocrinology and Metabolism, West China Second University Hospital, Sichuan University, No. 16, Third Section, Renmin Nan Lu, Chengdu, Sichuan, 610041, China (e-mail: yd540@126.com); Lingli Zhang, West China Second University Hospital, Sichuan University, No. 20, Third Section, Renmin Nan Lu, Chengdu, Sichuan, 610041, China (e-mail: zhlingli@sina.com).

Copyright © 2020 the Author(s). Published by Wolters Kluwer Health, Inc. This is an open access article distributed under the Creative Commons Attribution License 4.0 (CCBY), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

How to cite this article: Yang C, Kang B, Mao Y, Xu Q, Yu D, Zhang L. Anxiety among caregivers of children with epilepsy from western China: A cross-sectional survey. *Medicine* 2020;99:8(e19237).

Received: 28 October 2019 / Received in final form: 29 December 2019 / Accepted: 16 January 2020

<http://dx.doi.org/10.1097/MD.00000000000019237>

## 1. Introduction

Epilepsy is one of common neurological disorders caused by paroxysmal abnormal discharge of brain neurons for a range of reasons, characterized by epileptic seizures.<sup>[1,2]</sup> The prevalence rate of epilepsy around the world is 6‰ to 7‰, with approximately 70 million patients suffered from epilepsy.<sup>[2-4]</sup> Among children, the lifetime rate of epilepsy is 1%, and the time-point prevalence rate is 6.3%.<sup>[5]</sup> In the United States, 2.5 million people, including 3,25,000 children under the age of 15, suffer from epilepsy.<sup>[6]</sup> In China, the prevalence rate of epilepsy is 1.43‰ to 7.98‰, and the prevalence rate among children is 3.9‰ to 5.1‰.<sup>[7,8]</sup> The influences of epilepsy on children and their caregivers are diverse, with medical, psychological, educational, personal, economic, and social effects.<sup>[5]</sup>

Anxiety is more frequent among people with epilepsy and their caregivers compared with the general population, at all ages.<sup>[9]</sup> Anxiety disorders not only affect a person's emotional state, but may also cause physical symptoms such as increasing heart rate and tremors. Several previous studies have evaluated the status of anxiety among parents of children with epilepsy. In 2016, a systematic review<sup>[10]</sup> was conducted to focus on symptoms of anxiety among parents of children with epilepsy, including 15 studies involving 1434 respondents. The results revealed that 9% to 58% of parents exhibited symptoms of anxiety, but the possible correlates of parental anxiety in childhood epilepsy that were considered varied widely across studies.<sup>[10]</sup> In addition, 3 of the studies included in the review were conducted in Beijing, China, and the factors affecting anxiety were inconsistent.<sup>[10]</sup> To the best of our knowledge, no

studies of populations in west China have been published. Therefore, the current study sought to:

- (1) assess anxiety among caregivers of children with epilepsy from western China; and
- (2) identify patient, medication, caregiver, and environment-related characteristics associated with anxiety among caregivers.

## 2. Methods

### 2.1. Setting

This cross-sectional study was conducted at West China Second Hospital, Sichuan University. The Hospital was located in the city of Chengdu, Sichuan Province, China, and is the largest and most authoritative center for the diagnosis and treatment of pediatric patients in western China.

### 2.2. Study design and sample selection

The participants in this study were examined from January to May in 2018 in the pediatric neurology clinic in West China Second Hospital. The inclusion criteria were:

- (1) the child was less than 18 years old;
- (2) epilepsy was clinically diagnosed according to the International League Against Epilepsy (ILAE) 2014 criteria;
- (3) the caregiver of the child with epilepsy was willing to participate in this study.

The exclusion criteria were:

- (1) other chronic diseases in the child with epilepsy, which could affect the emotional states of caregivers (i.e., congenital heart disease, diabetes);
- (2) the caregiver was illiterate; and
- (3) lack of consent.

### 2.3. Data collection

A questionnaire was designed by a trained physician and pharmacist and divided into 2 sections. The first section was focused on the characteristics of children with epilepsy, including:

- (1) children's basic characteristics (name, age, place of residence);
- (2) disease status (newly diagnosed patient or not, seizure type, family history of epilepsy, comorbidity, seizure frequency, regular review); and
- (3) medication status (quantity of medication, adverse reactions, time for medication use).

The second section was focused on the caregivers, including:

- (1) sociodemographic characteristics (caregivers, age of caregivers, caregivers' education level, caregivers' working status);
- (2) treatment attitude (caregivers' attitude towards seizures, confidence in treatment);
- (3) environmental factors (parents' marital status, total household income, medical expenses payment).

### 2.4. Instruments

The self-rating anxiety scale (SAS) was used to evaluate the symptoms anxiety of the caregivers. The SAS is reported to have good reliability and validity in the Chinese population.<sup>[10]</sup> The

SAS scale has 20 items and uses a 4-point scoring system to measure the frequency of symptoms (1: no or a little time, 2: a small part of the time, 3: a considerable amount of time, 4: most or all of the time). Of these, 15 items use negative words, which are scored according to the above method from 1 to 4, while the other 5 statements use positive words, which are scored from 4 to 1. Adding the scores of all items produces the rough score, and multiplying the score by 1.25 produces the standard score. The standard score on the SAS is graded according to the results of the scores (normal: <50 points; anxiety: >50 points).

### 2.5. Data analysis

Data analysis was conducted after data collection and initial processing in 2 parts.

First, quantitative data were expressed as mean  $\pm$  SD. Second, the normality of the data was tested using the Kolmogorov–Smirnov test. To compare quantitative variables between groups, the variance analysis or the Mann–Whitney *U* test were used for the normally distributed data and non-normally distributed data, respectively.

Factors with univariate  $P \leq 0.10$  were included in the multiple linear regression model for univariate analysis. Data analysis was performed using SPSS version 22, and the threshold for statistical significance was set at  $P < .05$ .

### 2.6. Ethical issues

The design of the study was in accordance with the Helsinki Declaration. The study began after the approval of the Office of Research Ethics Committees of West China Second Hospital. Voluntary written informed consent was provided by all participants at enrollment in the study.

## 3. Results

### 3.1. Demographic characteristics of the patients

In total, 334 patients participated in the study, with a response rate of 95.4% (334/350). The age of children with epilepsy ranged from 0.2 to 17.8 years, with a mean age of  $6.05 \pm 4.11$  years. Regarding the type of visit, 7.2% (24/334) of patients were newly diagnosed. Concerning seizure type, 55.4% (185/334) of patients presented with generalized epilepsy and 44.6% (149/334) of patients presented with focal/partial epilepsy. In total, 7.8% (26/334) of patients had a family history of epilepsy, and 39.2% (131/334) had comorbidities.

### 3.2. The prevalence of anxiety

A total of 25.7% (86/334) of caregivers among children with epilepsy presented with symptoms of anxiety, with a mean SAS score of  $44.31 \pm 10.558$ .

### 3.3. Factors influencing SAS score (Tables 1 and 2)

**3.3.1. Factors for children with epilepsy.** Univariate analysis revealed that the age of the children ( $P = .003$ ) and seizure frequency ( $P = .004$ ) were correlated with SAS scores.

**3.3.2. Factors for caregivers.** Univariate analysis revealed that caregivers' working status ( $P = .022$ ), caregivers' attitude towards seizures ( $P = .001$ ), confidence in treatment ( $P = .003$ ), and medical expenses payment ( $P = .000$ ) were correlated with SDS scores.

We included factors with univariate  $P \leq .10$  in the multiple linear regression model. The results revealed that SAS scores were

**Table 1**  
**Characteristics of the study population.**

	n	Anxiety score	F/Z/t	P
Age			-2.987	.003
Place of residence				
City	108	42.96 ± 10.418	1.908	.150
Suburb county	83	43.94 ± 9.176		
Rural	143	45.54 ± 11.314		
Newly diagnosed patient				
No	310	44.32 ± 10.767	0.008	.930
Yes	24	44.13 ± 7.503		
Seizure type				
Generalized epilepsy	185	44.73 ± 11.124	0.660	.417
Focal/partial epilepsy	149	43.79 ± 9.821		
Family history of epilepsy				
No	308	44.34 ± 10.734	0.030	.862
Yes	26	43.96 ± 8.350		
Comorbidity				
No	203	44.09 ± 10.741	0.224	.637
Yes	131	44.65 ± 10.300		
Seizure frequency				
No seizure	124	42.32 ± 8.712	3.555	.004
Everyday	40	46.68 ± 10.214		
Every week	13	48.15 ± 12.116		
Every month	53	48.38 ± 11.124		
Every year	81	43.22 ± 12.000		
Uncertain	23	43.17 ± 9.750		
Regular review				
No	16	46.000 ± 13.697	0.431	.512
Yes	318	44.22 ± 10.396		
Quantity of medication				
1	263	44.46 ± 10.431	0.255	.614
≥2	71	43.75 ± 11.073		
Adverse reactions				
No	299	44.16 ± 10.692	0.584	.445
Yes	35	45.60 ± 9.372		
Time for medication use				
≤6 mo	82	45.91 ± 10.360	2.527	.113
>6 mo	252	43.79 ± 10.589		
Caregivers				
Parents	300	44.19 ± 10.380	0.391	.532
Non-parents	34	45.38 ± 12.136		
Caregivers' age				
≤30 yr	119	45.75 ± 10.734	1.845	.139
31-44 yr	174	43.81 ± 10.517		
45-59 yr	34	41.38 ± 10.124		
≥60 yr	7	46.43 ± 8.080		
Caregivers' education level				
High school or below	208	43.66 ± 10.030	1.052	.350
Specialist	65	45.57 ± 10.749		
Bachelor degree or above	61	45.16 ± 12.020		
Caregivers' working status				
Employed	221	43.37 ± 10.727	5.265	.022
Unemployed	113	46.15 ± 10.012		
Caregivers' attitude towards seizures				
Fear	109	47.12 ± 11.009	11.842	.001
Not fear	225	42.95 ± 10.078		
Confidence in treatment				
No	106	46.81 ± 11.615	8.935	.003
Yes	228	43.14 ± 9.840		
Parents' marital status				
Married	305	44.17 ± 10.541	0.570	.451
Non-married	29	45.72 ± 10.820		
Medication adherence			1.036	.301

(continued)

**Table 1**  
**(continued).**

	n	Anxiety score	F/Z/t	P
Total household income (Chinese Yuan)				
≥20,000	31	46.03 ± 13.809	1.391	.237
10,000-20,000	44	43.84 ± 8.669		
5000-10,000	88	43.11 ± 10.565		
3000-5000	112	43.68 ± 9.115		
≤3000	59	46.73 ± 12.188		
Medical expenses payment				
Difficult to pay	42	49.88 ± 12.826	13.902	.000
Able to pay	292	43.51 ± 9.963		
Health education for patients				
No	73	43.79 ± 10.414	0.221	.639
Yes	261	44.45 ± 10.613		

negatively correlated with children's age ( $B = -0.141$ ; standard error = 0.135;  $P = .008$ ), attitude towards seizures ( $B = -0.153$ ; standard error = 1.192;  $P = .004$ ), and medical expenses payment ( $B = -0.169$ ; standard error = 1.703;  $P = .002$ ). Caregivers with younger children, those who were more afraid of seizures, and those who were unable to pay medical expenses were more likely to experience anxiety.

#### 4. Discussion

We conducted a cross-sectional study to evaluate anxiety status among caregivers of children with epilepsy, and examined which factors were associated with anxiety. The analysis included 334 participants, revealing that 25.7% (86/334) of caregivers of children with epilepsy presented symptoms of anxiety, with an average SAS score of  $44.31 \pm 10.558$ . The current results suggest that healthcare providers should pay more attention to psycho-emotional symptoms among caregivers of children with epilepsy.

Regarding the factors influencing symptoms of anxiety for caregivers of children with epilepsy, multiple linear regression revealed that SAS scores were significantly correlated with children's age, attitude towards seizures, and medical expenses payment. There are several possible reasons for these findings:

- (1) parents of younger children may worry more about their health, disease prognosis, and the impact of the disease on studying and working, causing caregivers to be more likely to experience anxiety;
- (2) the attitudes of the caregivers towards seizures have an important influence on anxiety, because, regardless of the disease severity, caregivers who understand more about seizures may have more confidence about treatment;
- (3) outpatient treatment is generally not publicly funded, and epilepsy treatment is long-term, so the cost of treatment represents a substantial disease burden for most families.

Being unable to afford treatment may induce anxiety among caregivers.

The prevalence of anxiety symptoms among caregivers in the current study was in accord with the range of 9% to 58% reported in a systematic review by Jones and Reilly.<sup>[11]</sup> However, the influential factors identified in the current study differed from those reported in some previous studies, such as Yong et al,<sup>[12]</sup> who found that parental anxiety was significantly correlated with children's seizure frequency, average monthly family income per person, and parents' knowledge about epilepsy ( $P = .000$ ). In

**Table 2**  
**Multiple linear regression analysis of factors influencing anxiety of caregivers of children with epilepsy.**

Variable	Non-standardized coefficient	Standard error	Standard coefficient	t	P
Constant	53.451	2.072		25.796	.000
Age	-0.362	0.135	-0.141	-2.680	.008
Seizure frequency	0.404	0.302	0.070	1.339	.181
Attitude towards seizures	-3.445	1.192	-0.153	-2.891	.004
Working status	1.829	1.184	0.082	1.544	.123
Confidence in treatment	-2.003	1.227	-0.088	-1.632	.104
Medical expenses payment	-5.358	1.703	-0.169	-3.147	.002

addition, Chapieski et al<sup>[13]</sup> reported that higher levels of maternal anxiety were associated with lower socioeconomic status, more family stress, and higher generalized anxiety. However, the factor of family income was likely to be related to the factor of medical expenses payment, because people with lower incomes would be expected to have more difficulty paying for medical expenses. Williams et al<sup>[14]</sup> reported that parental anxiety did not differ by seizure type or level of seizure control, in accord with the current results.

The current study involved several limitations, including:

- (1) participants were from hospital-based samples, which may not represent the whole population of children with epilepsy;
- (2) this study used a cross-sectional study design, which only allows for conclusions regarding correlation, not causation;
- (3) caregivers who visit the hospital may have relatively higher economic status than the general population of caregivers, possibly paying more attention to the disease and experiencing a higher level of anxiety.

Further studies should be conducted to overcome these shortcomings.

## 5. Conclusions

Symptoms of anxiety are common among caregivers of children with epilepsy in western China. Healthcare providers should pay more attention to caregivers with younger children, difficult financial situations, and greater fear of seizures. It will be important for future studies to explore mental health interventions for caregivers.

## Acknowledgments

We thank Benjamin Knight, MSc., from Liwen Bianji, Edanz Group China (www.liwenbianji.cn/ac), for editing the English text of a draft of this manuscript.

## Author contributions

**Chunsong Yang:** designed the review, collected data, carried out analysis and interpretation of the data, and wrote the review.

**BingYao Kang:** designed the review, collected data, checked the data, and wrote the review.

**Yifei Mao:** designed the review, collected data, checked the data, and wrote the review.

**Qunfen Xu:** designed the review, collected data, checked the data, and wrote the review.

**Dan Yu:** designed the review, collected data, checked the data, and wrote the review.

**Lingli Zhang:** designed the review, commented on drafts for previous version.

## References

- [1] Fisher RS, Acevedo C, Arzimanoglou A, et al. ILAE official report: a practical clinical definition of epilepsy. *Epilepsia* 2014;55:475–82.
- [2] Singh A, Trevick S. The epidemiology of global epilepsy. *Neurol Clin* 2016;34:837–47.
- [3] Ngugi AK, Bottomley C, Kleinschmidt I, et al. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. *Epilepsia* 2010;51:883–90.
- [4] Hirtz D, Thurman DJ, Gwinn-Hardy K, et al. How common are the “common” neurologic disorders? *Neurology* 2007;68:326–37.
- [5] Russ SA, Larson K, Halfon N. A national profile of childhood epilepsy and seizure disorder. *Pediatrics* 2012;129:256–64.
- [6] Modi AC, Rausch JR, Glauser TA. Patterns of nonadherence to antiepileptic drug therapy in children with newly diagnosed epilepsy. *JAMA* 2011;305:1669–76.
- [7] Chang L, Wang X. Progress in epidemiological investigation of epilepsy in China. *Int J Neurol Neurosurg* 2012;39:161–4.
- [8] Shan X, Chen R, Deng J, et al. Epidemiological survey of epilepsy in children aged 0–14 years in Jiangsu Province. *J Nanjing Med Coll* 1992;12:170–2.
- [9] Cianchetti C, Bianchi E, Guerrini R, et al. TASCA Study Group—Symptoms of anxiety and depression and family’s quality of life in children and adolescents with epilepsy. *Epilepsy Behav* 2018;79:146–53.
- [10] Tian Y, Wang Y, Li J, et al. Evaluation of reliability and validity of SAS and SDS Scale in clinical application of patients with liver cirrhosis. *J Pract Hepatol* 2019;22:105–8.
- [11] Jones C, Reilly C. Parental anxiety in childhood epilepsy: a systematic review. *Epilepsia* 2016;57:529–37.
- [12] Yong L, Cheng-YE J, Jiong Q, et al. Parental anxiety and quality of life of epileptic children. *Biomed Environ Sci* 2008;21:228–32.
- [13] Chapieski L, Brewer V, Evankovich K, et al. Adaptive functioning in children with seizures: impact of maternal anxiety about epilepsy. *Epilepsy Behav* 2005;7:246–52.
- [14] Williams J, Steel C, Sharp GB, et al. Parental anxiety and quality of life in children with epilepsy. *Epilepsy Behav* 2003;4:483–6.