

Prevalence and influencing factors of depression of caregivers in children with epilepsy in southwestern China: a cross-sectional study

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Abstract

This study investigated the epidemiological status of depression and its influencing factors among caregivers of children with epilepsy in southwestern China.

This was a cross-sectional study. Caregivers of children with epilepsy were recruited from February to June 2018 at the Pediatric Neurology Department of the West China Second Hospital. Depression status was assessed using the Zung Self-Rating Depression Scale. Multiple linear regression analysis was used to assess correlations between depression status and its influencing factors.

A total of 319 participants were included. The mean Zung Self-Rating Depression Scale score was 36.37 ± 10.178 and 5.3% (17/319) of participants were classified as depressed. Regression analysis showed that place of residence ($B=0.114$; standard error=0.643; $P=.039$), attitude towards seizures ($B=-0.121$; standard error=1.215; $P=.029$), medical expenses payment ($B=-0.111$; standard error=2.002; $P=.044$), and children's medication adherence ($B=-0.124$; standard error=0.393; $P=.025$) were related to depression.

Some caregivers of children with epilepsy in southwestern China experience depression. Health care providers should pay particular attention to caregivers who live in rural areas, who fear seizures, who experience difficulty paying medical expenses, and whose children show low medication adherence.

Abbreviation: SDS = Zung Self-Rating Depression Scale.

Keywords: depression, caregivers, epilepsy, children, southwestern China

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CY and YT contributed equally to this study

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The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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1. Introduction

Epilepsy is a chronic disease characterized by transient brain dysfunction caused by sudden abnormal neuronal discharges in the brain. Epidemiological data indicates that there are at least 50 million patients with epilepsy worldwide.^[1] According to the Centers of Disease Control and Prevention, 5.1 million children and adults in the United States have epilepsy.^[2] In China, the prevalence of active epilepsy is 0.48% to 8.5%^[3]; there are approximately 9 million people with epilepsy in mainland China, two-thirds of who are children.^[4]

The risk of death in epilepsy patients is 2 to 3 times greater than in the general population. The most common comorbidities of epilepsy are mental health problems, with a reported prevalence of 29% to 40%, which is 7 to 10 times higher than in the general population. The most common comorbidities are depression (23.1%) and anxiety (20.2%).^[5] In addition to its effect on patients, childhood epilepsy has a large impact on parents, including heavy economic burden, anxiety, and depression. One survey indicated that 53.3% of parents believe that others express negative reactions to their epileptic child; this limits family social interactions, resulting in emotional reactions such as anger, guilt, fear, anxiety, and depression.^[6] These responses inevitably lead to anxiety and depression in parents of children with epilepsy.

A 2019 study by Carmassi et al of 199 pediatric parent caregivers with chronic illness found that 7.5% of parents had major depressive disorder.^[7] In 2018, Reilly et al explored the prevalence of symptoms of depression in parents of children with epilepsy. They found that, compared with a control group, such parents were more likely to be at risk for depression; the prevalence of depression in mothers and fathers was 55% and 33%, respectively.^[8] Lv et al^[9] assessed the impact of epilepsy on the mental health of caregivers in northern

China. They used the Zung Depression Scale to measure symptoms of depression and found that the prevalence of depression among caregivers of epileptic children was 38.40%. However, there is a lack of related data for southwestern China. Therefore, this study aimed to investigate the epidemiological status of depression and its influencing factors among caregivers of children with epilepsy in southwestern China.

2. Method

2.1. Study design

This was a cross-sectional study conducted at the Pediatric Neurology Department of the West China Second Hospital.

2.2. Sample selection

A consecutive sample of children with epilepsy and their caregivers was recruited from February to June 2018. The study inclusion criteria comprised:

- (1) children under the age of 18 years;
- (2) children with a definitive diagnosis of epilepsy based on the International League Against Epilepsy (2018);
- (3) principle caregivers of children with epilepsy, defined as the individuals who had most responsibility for the child's care.

Exclusion criteria were as follows:

- (1) children with other chronic diseases (e.g., asthma, leukemia);
- (2) caregivers with diagnosed psychiatric disorders (e.g., insomnia, depression, anxiety) or other chronic comorbidities that affect emotion (e.g., congenital heart disease, diabetes);
- (3) refusal to provide reliable and authentic information for the questionnaire;
- (4) caregivers who were illiterate or unable to read and fill in the questionnaire.

2.3. Data collection

Questionnaires were used to collect participant information, including

- (1) sociodemographic information for both patients and caregivers (age, gender, place of residence, relationships between caregivers and patients, education, employment, marital status, and socioeconomic status);
- (2) disease characteristics (newly diagnosed patient or not, seizure type, epilepsy type, family history of epilepsy, comorbidity, seizure frequency, attitude towards seizures), and
- (3) medication status (quantity of medication, adverse reactions, duration of medication use, medication adherence, medical expenses payment).

The study team included doctors, clinical pharmacists, and research assistants. All researchers were trained to understand and conduct the research procedures. Participants were required to complete the depression status assessment and fill out the questionnaire on the day of recruitment. Research assistants collected and checked all questionnaires as soon as possible to prevent missing information.

2.4. Instruments

The study used the Zung Self-Rating Depression Scale (SDS) to assess the mental status over the last week of caregivers of

children with epilepsy. The Chinese version of the SDS was published in 1985 and has high reliability and validity.^[10,11] The SDS consists of 20 items that reflect symptoms of depression and uses a four-level scoring method based on frequency:

- (1) none or a little of the time;
- (2) some of the time;
- (3) quite a lot of the time;
- (4) most or all of the time.

Scores on the 20 items were summed to obtain a total score.

The scale has a threshold value of 53 points, scores ≥ 53 indicate depression.

2.5. Data analysis

Quantitative data were expressed as mean \pm standard deviation. Normally distributed data were tested using analysis of variance; non-normally distributed data were tested using the rank sum test. Univariate factors with P -values ≤ 0.10 were included in a multiple linear regression analysis. SPSS 22.0 (SPSS Inc., Chicago, IL, U.S.A.) was used for data analysis; P -values < 0.05 indicated statistical significance.

2.6. Ethical issues

All eligible participants were informed of the study procedures and gave their informed consent. The study was approved by the Office of Research Ethics Committees of West China Second Hospital.

3. Results

3.1. Demographic characteristics of caregivers

Data for the principle caregiver for 319 patients were used; the response rate was 95.2% (319/335).

3.2. Prevalence of depression

The mean SDS score was 36.37 ± 10.178 and 5.3% (17/319) of participants were classified as depressed.

3.3. Factors related to SDS scores

The univariate analysis results showed significant differences between place of residence ($P=.054$), children's medication adherence ($P=.011$), attitude towards seizures ($P=.019$), medical expenses payment (0.025), and SDS scores (Table 1).

The multiple linear regression model included the univariate factors mentioned above with $P \leq 0.10$. Multiple linear regression analysis of factors influencing depression in caregivers of children with epilepsy showed that all four factors were related to depression: place of residence ($B=0.114$; standard error = 0.643; $P=.039$), attitude towards seizures ($B=-0.121$; standard error = 1.215; $P=.029$), medical expenses payment ($B=-0.111$; standard error = 2.002; $P=.044$), and medication adherence ($B=-0.124$; standard error = 0.393; $P=.025$) (Table 2). Caregivers who lived in rural areas, were more afraid of seizures, did not have the ability to pay medical expenses, and whose children had low medication adherence were more likely to have depression.

Table 1
Characteristics of the study population.

Variable	n	Depression score	F/Z/t	P
Gender				
Male	187	36.134 ± 10.193	0.236	.627
Female	132	36.697 ± 10.185		
Age			-1.246	.214
Place of residence				
City	111	34.991 ± 10.476	2.948	.054
Suburb county	77	35.584 ± 8.705		
Rural	131	37.992 ± 10.563		
Newly diagnosed patient				
No	294	36.269 ± 10.171	0.348	.556
Yes	25	37.520 ± 10.397		
Seizure type				
Generalized epilepsy	177	35.763 ± 9.849	1.402	.237
Focal/partial epilepsy	142	37.120 ± 10.560		
Epilepsy type				
Idiopathic	34	38.471 ± 10.827	1.179	.309
Symptomatic	136	36.654 ± 10.618		
Unknown reason	149	35.624 ± 9.588		
Family history of epilepsy				
No	293	36.314 ± 10.149	0.096	.756
Yes	26	36.962 ± 10.679		
Comorbidity				
No	199	35.794 ± 9.741	1.679	.196
Yes	120	37.317 ± 10.838		
Seizure frequency				
No seizure	121	35.479 ± 9.175	1.532	.179
Everyday	37	36.757 ± 9.993		
Every week	11	37.091 ± 9.082		
Every month	52	39.750 ± 11.033		
Every year	80	35.475 ± 10.766		
uncertain	18	35.278 ± 11.549		
Quantity of medication				
1	251	36.335 ± 10.112	0.012	.914
≥2	68	36.485 ± 10.493		
Adverse reactions				
No	286	36.238 ± 10.257	0.443	.506
Yes	33	37.485 ± 9.537		
Time for medication use				
≤6 month	81	37.556 ± 11.307	1.483	.224
>6 month	238	35.962 ± 9.756		
Medication adherence			-2.562	.011
Caregivers				
Parents	296	36.487 ± 10.203	0.567	.452
Non-parents	23	34.826 ± 9.930		
Caregivers' age				
≤30 years	116	37.845 ± 10.506	1.404	.242
31–44 years	167	35.335 ± 9.682		
45–59 years	32	36.500 ± 10.680		
≥60 years	4	35.500 ± 15.438		
Working status				
Employed	208	35.817 ± 10.060	1.746	.187
Unemployed	111	37.396 ± 10.362		
Education level				
High school or below	209	36.713 ± 10.208	0.847	.430
Specialist	58	34.793 ± 9.729		
Bachelor degree or above	52	36.731 ± 10.568		
Attitude towards seizures				
Fear	98	38.561 ± 11.234	2.346	.019
Not fear	221	35.394 ± 9.539		
Total household income				
≥20000	27	34.704 ± 8.619	1.163	.327
10000–20000 RMB	37	34.730 ± 10.126		

(continued)

Table 1
(continued).

Variable	n	Depression score	F/Z/t	P
5000–10000 RMB	83	35.711 ± 10.261		
3000–5000 RMB	112	36.679 ± 9.780		
≤3000 RMB	60	38.450 ± 11.340		
Medical expenses payment				
Difficult to pay	27	40.556 ± 9.799	5.060	.025
Able to pay	292	35.980 ± 10.141		
Parents marital status				
Married	289	36.405 ± 10.183	0.043	.836
Non-married	30	36.000 ± 10.292		

4. Discussion

This was a cross-sectional study to investigate the prevalence and related factors of depression among caregivers of children with epilepsy in southwestern China. The results indicated that the prevalence of depression in caregivers of children with epilepsy was 5.3%, which is lower than that found for similar samples in northern China, Italy, and the United Kingdom.^[8,9] The study conducted in northern China reported that 38.4% of the parents reached depressive state^[9] and the study conducted in the United Kingdom^[8] showed that mothers of children with epilepsy were significantly more likely to score in the at risk range than fathers on depression (55% vs 33%), which were both higher than our results, the reasons may be as follows: (1) the study in northern China was conducted in 2008,^[9] in the past ten years, patients' understanding of epilepsy is becoming more comprehensive and 91.5% (292/319) caregivers in our study thought that they could be able to afford medical expenses, so they are less worried and afraid of this disease; (2) the seizures in nearly half of children with epilepsy in northern China were poorly controlled, so their parents were more likely to be depressed. (3) the study conducted in the United Kingdom only included 47 children with epilepsy, the sample size was relatively small, which contains 7 patients with cerebral palsy,^[8] so the severity of the disease may cause parents to be depressed.

Place of residence, attitude towards seizures, medical expenses payment, and children's medication adherence predicted depression status in caregivers of children with epilepsy. There are several possible reasons for this association.

(1) Fear of seizures was one of the main factors related to caregiver depression. The negative effects of seizures include possible cognitive impairment, injury, and mood disorders.^[12,13] Caregivers also worried that their children would experience discrimination from others when they had seizures; therefore, fear of seizures could easily lead to depression in caregivers.

- (2) Families of children with epilepsy who have low socioeconomic status experience difficulty paying for medical expenses.^[14] Children from such families are less likely to receive good medical services, which has a detrimental effect on caregiver mental health. Therefore, ability to pay medical expenses may predict depression status in caregivers.
- (3) In rural areas, caregivers with less education may have less awareness of epilepsy. As they are of lower socioeconomic status, they may feel ashamed about their children having epilepsy and are more likely to become depressed. In addition, inadequate medical resources in rural areas may also cause depression in caregivers.^[15]
- (4) Regular medication is important to control seizures in children with epilepsy.^[16] Owing to the large number of anti-epileptic drugs, children may forget to take their medications. Low medication adherence can lead to a poor treatment effect, resulting in caregiver depression.^[17]

Owing to its complexity, long-term nature, and considerable comorbidity, providing high-quality epilepsy management is challenging. Therefore, clinical practice measures are needed that address the mental state of caregivers of children with epilepsy.

- (1) Policy development agencies need to ensure adequate monitoring of human and health care system data to assess the management of epilepsy, and provide guidelines for high-quality management of epilepsy and adequate resources to ensure universal health coverage;
- (2) Appropriate training for health care providers is also needed, especially in rural areas, to provide high-quality drug management services for patients with epilepsy;
- (3) Caregivers should ensure that medication is continuously available to avoid medication interruptions and maintain the therapeutic effect.^[5,18,19]

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

Variable	Non-standardized coefficient	Standard error	Standard coefficient	T	P
Constant	45.175	3.535		12.779	.000
Place of residence	1.330	0.643	0.114	2.069	.039
Attitude towards seizures	-2.669	1.215	-0.121	-2.197	.029
Medical expenses payment	-4.054	2.002	-0.111	-2.025	.044
Medication adherence	-0.885	0.393	-0.124	-2.253	.025

There were some study limitations.

- (1) Although the West China Second University Hospital is the largest hospital in western China, this was a single-center study, so the findings are representative only of families in western China;
- (2) The cross-sectional study design does not permit causal inferences;
- (3) The study included patients from February to June 2018; the prevalence of depression may show seasonal differences.
- (4) Self-rating depression scale was used for evaluating depression, and it does not directly provide diagnosis of depression without evaluation by a psychiatrist.
- (5) Due to the limited data, we did not collect the data of intelligence problems of children with epilepsy, which may be related to depression of caregivers.

In future studies, more studies can be carried out to evaluate the relationship between intellectual disability and depression of caregivers. Future research should overcome these limitations.

5. Conclusion

Some caregivers of children with epilepsy in southwestern China experience depression. Health care providers should pay particular attention to caregivers who live in rural areas, who have a fear of seizures, who experience difficulty paying for medical expenses, and who have children with low medication adherence.

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Author contributions

CSY and YT contributed equally to this study; CSY, YT and YFM designed the review, collected data, carried out analysis and interpretation of the data and wrote the review. LZ and LLZ designed the review, collected data, checked the data and wrote the review.

CSY and YT contributed equally to this study

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