

ORIGINAL ARTICLE

Cognitive deficiency, parental relationship, and coping strategies are related with anxiety and depression among parents of children with epilepsy

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Abstract

Background: The diagnosis of epilepsy in a child often and understandably causes psychological adjustment difficulties in the parents. To help parents of children with epilepsy cope with stress, it is important to understand how parents cope with the sickness of their child. The objective of this study was to assess factors related to the state of anxiety and depression among parents of children with epilepsy.

Methods: The present study was a cross-sectional study, and the data were collected through an anonymous, Internet-based survey platform between October 2018 and October 2019 from 250 participants aged 22–65 years. Participants were invited to fill questionnaires include socioeconomic questionnaire, anxiety, depression, and coping strategies scale.

Result: Among the parents of children with epilepsy, 48.8% (122/250) had depressive symptoms (Patient Health Questionnaire-9 [PHQ-9] score >4) and 46.4% (116/250) had anxiety symptoms (7-item Generalized Anxiety Disorder [GAD-7] score >5). Depression among parents of children with epilepsy was significantly associated with comorbidity (odds ratio [OR] = 0.392, 95% CI = 0.182–0.846), a poor parental relationship (OR = 0.283, 95% CI = 0.130–0.614), positive coping (OR = 0.947, 95% CI = 0.903–0.992), and negative coping (OR = 1.287, 95% CI = 1.179–1.405). Anxiety among parents of children with epilepsy was significantly associated with a poor parental relationship (OR = 0.416, 95% CI = 0.207–0.835) and negative coping (OR = 1.155, 95% CI = 1.087–1.228).

Conclusions: The present study indicates the importance of couple support and providing effective coping to make parents of children with epilepsy more resilient in the presence of negative life events, especially for parents of children with comorbidity with cognitive deficiency.

KEYWORDS

combability, coping strategies, couple relationship, epilepsy, parents

Highlights

- Parents of children with epilepsy are at high risk of experiencing anxiety and depression.

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- Negative coping strategies are related to higher self-reported depression symptoms and positive coping strategies are related to lower self-reported anxiety symptoms among parents of children with epilepsy.
- Negative coping strategies are related to higher self-reported anxiety symptoms among parents of children with epilepsy.
- Comorbidity of cognitive deficiency and changes in the couple relationship are significantly associated with depression among parents of children with epilepsy.

1 | INTRODUCTION

It has been demonstrated that a child's health status, measured by childhood chronic illnesses such as diabetes and epilepsy, is an important factor that influences parents' emotional distress.¹ Like other childhood chronic illnesses, given the burden of daily treatment tasks, reports from different nations show that epilepsy is not only an individual problem but is also a family problem. The diagnosis of epilepsy in a child often and understandably causes psychological adjustment difficulties in the parents.^{2,3} First, the daily care of a child with epilepsy is usually resource demanding, which implies that parents need tremendous psychosocial support. Unfortunately, many parents report limited coping resources and less social support after their child's diagnosis.^{4,5} Ferro and colleagues claimed that psychosocial disturbances among parents of children with neurological disorders are related to worse family functioning and limited family resources.⁶ Second, the psychological disturbance of parents is associated with the years with epilepsy of the patients, severity of the child's seizure and comorbidity with.⁷ Parents' emotional distress in the chronic course of a child's epilepsy has been reported to be associated with fear of learning difficulties and other psychosocial/functional difficulties, and these concerns may continue to be demonstrated several years after diagnosis.⁸

Previous researchers found that 50.0% and 25.7% of caregivers of patient with epilepsy experience depressive and anxious states, respectively.^{9,10} Compared to families of healthy children, families of a child with epilepsy have been found to experience significantly more stress, anxiety, depression, withdrawal from social relationships, social isolation, low quality of life, and restrictions in family life.¹¹⁻¹⁵ Multiple researchers have acknowledged the importance of paying attention to anxious and depressive states among caregivers of children with epilepsy because the mental health status of caregivers of children with epilepsy also affects the treatment outcome and the psychosocial well-being of children with epilepsy.^{16,17}

A child's diagnosis of epilepsy represents a substantial stressor that requires a process of coping. Studies have demonstrated that coping strategies significantly

impact the experience of psychological disturbances among different populations.⁵ For example, adaptive coping styles toward stress are associated with increased psychological well-being, whereas maladaptive coping styles are associated with increased distress.¹⁸ To help parents of children with epilepsy cope with stress, it is important to understand how parents cope with the sickness of their child. In general, coping strategies can be categorized into positive strategies and negative strategies. However, studies have found that the use of avoidance strategies, higher levels of escape-avoidance strategies, and other negative coping strategies among parents of children with various neurological disorders predicted increases in negative affect.^{18,19} Furthermore, individuals' use of lower levels of escape-avoidance strategies, more problem-focused strategies, emotion-focused strategies, and other positive coping strategies predicted increases in positive affect.^{5,20} Studies have shown that individuals' use of positive coping strategies is related to less distress than is found among those who use negative coping strategies.¹⁸

Cognitive deficiency comorbidities, also called intellectual disability or deficits in intellectual functioning, are often seen in children with epilepsy. Comorbidity with cognitive deficiency is associated with worse quality of life, increased behavioral problems, learning difficulties, poor academic outcome, worse social skills, all of which adversely affect long-term psychosocial functioning, and unfortunate worse prognosis.²¹ These will undoubtedly increase the burden of caregivers and affect the mental health well-being of caregivers owing to the demands of caregiving. More and more studies claimed that comorbidity with cognitive deficiency has been reported to be associated with psychological disturbance of the caregiver.^{22,23}

Meanwhile, having a family member with epilepsy had a significant impact on family functioning such as relationship of the caregiver. One study stated that the burden of caregiving of children with epilepsy impacts negatively on family functioning.²⁴ In children with chronic illness, family communication difficulties can significantly impact the child's and parents' psychosocial well-being.²⁵ However, little is known about parental relationship impact parents' psychosocial well-being in the context of epilepsy of their children.

The purpose of the present study was to examine the relationship among demographic information, comorbidity with cognitive deficiency, changes in couple relationships after a child's diagnosis, and coping strategies with the anxiety and depression symptoms of parents of children with epilepsy.

2 | METHODS

2.1 | Participants and procedure

This study was a cross-sectional study, and the participants were 22- to 65-year-old parents of children with epilepsy. A more detailed description of the demographic data is presented in Table 1. This study was conducted in two cities in the Chongqing and Chengdu areas by three research assistants.

2.2 | Sample and setting

The data were collected through an anonymous, Internet-based survey platform between October 2018 and October 2019 from 250 participants aged 22–65 years. The researchers posted a description of the study's objectives and benefits, a confidentiality guarantee, the consent form, and contact information. Individuals who self-identified as parents of children with epilepsy were recruited for the current research and were provided informed consent material, including the topics of the survey and their rights as potential participants. To protect their confidentiality, the participants agreed to participate in the research via a typed response rather than typing their name on the online consent form. The online questionnaire was posted at two hospitals. The average time to complete the questionnaire was

TABLE 1 Characteristics of the study population

Variables	Depression		χ^2/Z	<i>p</i>	Anxiety		χ^2/Z	<i>p</i>
	No	Yes			No	Yes		
Marriage								
Married	125	117	0.626	0.429	130	112	0.043	0.836
Divorced	3	5	-	-	4	4	-	-
Gender								
Male	42	28	3.013	0.083	42	28	1.601	0.206
Female	86	94	-	-	92	88	-	-
Ethnicity								
Han nationality	125	111	5.261	0.022	130	106	3.735	0.053
Other	3	11	-	-	4	10	-	-
Religion								
Nonbeliever	118	110	0.319	0.572	122	106	0.009	0.926
Believer	10	12	-	-	12	10	-	-
Family structure								
Lineal family	62	48	2.651	0.266	65	45	2.452	0.294
Nuclear family	62	67	-	-	64	65	-	-
One-parent family	4	7	-	-	5	6	-	-
Medical decision maker								
Doctors	89	85	0.001	0.981	93	81	0.005	0.942
Parents	39	37	-	-	41	35	-	-
Place of residence								
Rural	46	59	4.019	0.134	50	55	2.714	0.257
Suburban county	25	18	-	-	24	19	-	-
City	57	45	-	-	60	42	-	-

(Continues)

TABLE 1 (Continued)

Variables	Depression		χ^2/Z	<i>p</i>	Anxiety		χ^2/Z	<i>p</i>
	No	Yes			No	Yes		
Medical expenses payment								
Self-funded	102	89	1.572	0.210	109	82	3.914	0.048
Rural cooperative medical care	26	33	-	-	25	34	-	-
Father's education level								
High school or below	74	77	0.969	0.616	79	72	0.260	0.878
University specialist	23	17	-	-	22	18	-	-
Undergraduate	31	28	-	-	33	26	-	-
Mother's education level								
High school or below	72	78	1.538	0.463	78	72	0.387	0.824
University specialist	24	19	-	-	24	19	-	-
Undergraduate	32	25	-	-	32	25	-	-
Comorbidity with cognitive								
No	113	88	10.339	0.001	116	85	6.970	0.008
Yes	15	34	-	-	18	31	-	-
Parental relationship								
No change	115	85	15.885	0.000	117	83	9.654	0.002
Deteriorating	13	37	-	-	17	33	-	-
Coping								
Positive coping	13.77 ± 9.748	16.25 ± 5.644	-2.652	0.008	14.43 ± 9.469	15.62 ± 6.109	-1.040	0.298
Negative coping	5.08 ± 4.992	9.14 ± 4.082	-7.416	0.000	5.538 ± 5.103	8.83 ± 4.245	-5.992	0.000

approximately 5 min. The participants in this study were parents of children with epilepsy who were Chinese citizens ($N = 250$). Seventy participants were male. A total of 105 respondents lived in villages, 43 respondents lived in towns, and 102 respondents lived in cities. The other baseline characteristics of the cohort are presented in Table 1.

2.3 | Assessments and measurement

2.3.1 | Sociodemographic characteristics

The sociodemographic questions sought information regarding age, sex, education, religion, and ethnicity.

2.3.2 | Couple relationship

One variable tested was the respondents' perceived sense of their couple relationship after their child's diagnosis. Each subject self-rated this relationship as worse or remaining the same.

2.3.3 | Seven-item Generalized Anxiety Disorder (GAD-7)

The GAD-7 scale was used to measure generalized anxiety symptoms in the past 2 weeks on a 4-point scale from 0 (not at all) to 3 (nearly every day).²⁶ The scores on the GAD-7 range from 0 to 21; scores of 5, 10, and 15 represent mild, moderate, and severe anxiety symptoms, respectively. Higher scores indicate more symptoms. The measure has previously been validated in a Chinese sample of hospital patients²⁷ and a sample of Chinese individuals with epilepsy.²⁸ The measure demonstrated adequate internal consistency with Cronbach's $\alpha = 0.95$. The current study defined parents whose score was above 5 as having anxiety symptoms (GAD-7 score >5).

2.3.4 | Patient Health Questionnaire-9 (PHQ-9)

Depression was assessed with the PHQ-9. The PHQ-9 yields a continuous measure of the frequency of

symptoms of depression in the past 2 weeks.²⁹ Each of the nine items was rated on a scale from 0 (not at all) to 3 (nearly every day). The PHQ-9 total score ranges from 0 to 27 with five severity categories: minimal (0–4), mild (5–9), moderate (10–14), moderately severe (15–19), and severe (20–27). The validity and reliability of the PHQ-9 have consistently been verified to assess depressive experiences in patients with psoriasis vulgaris, Chinese outpatients, and general populations in China.^{30,31} In the current study, the Cronbach's α of the scale was 0.95. The current study defined parents whose score was above 4 as having depressive symptoms (PHQ-9 score >4).

2.3.5 | Simplified Coping Style Questionnaire (SCSQ)

The SCSQ is a self-report questionnaire that has proven to be a reliable and valid instrument.³² The SCSQ was used to assess the parent's coping style. This 20-item scale has two dimensions: "active coping" (12 items) and "passive coping" (8 items).³² Responses are given on a 4-point Likert scale (0 = never; 3 = very often). Active coping emphasizes positive coping characteristics, such as "handling the distressing emotions caused by the problem." Passive coping emphasizes the characteristics of negative coping, such as "escaping troubles by drinking and smoking."³² The SCSQ has consistently been verified to assess coping strategies in patients with depression and the general population.^{33,34} The scores for the active coping items are added together to represent the overall positive coping score, with higher scores indicating higher frequent use of the positive coping style. The scores for the passive coping items are added together to represent the overall negative coping score, with higher scores indicating higher frequent use of the negative coping style. The internal consistency of the SCSQ by Cronbach's α was 0.91. The Cronbach's α was 0.90 for the active coping subscale and 0.83 for the passive coping subscale.

2.4 | Statistical analyses

We used the χ^2 or Fisher's exact test to investigate group differences for the categorical variables and variance analysis for the quantitative variables.

First, we conducted univariate analysis and included factors with univariate $p \leq 0.10$ in the multivariate logistic regression model. Multivariate analysis was performed to examine the relative contribution of potential predictors of depression or anxiety using binary logistic regression. A $p \leq 0.05$ was assumed to be statistically significant. Data

analyses were performed using SPSS version 22.0 (SPSS Inc.).

3 | RESULT

3.1 | Basic characteristics

Of the 250 participants who were included, 28% (70/250) were male, 94.4% (236/250) were of Han nationality, and the majority (91.2%, 228/250) had no religious beliefs. With regard to family structure, the participants had a lineal family which means a family includes mothers, fathers, daughters, sons, grandparents, grandchildren, and so forth (44%, 110/250), nuclear family (husband, wife, and unmarried children) (51.6%, 129/250), or one-parent family (4.4%, 11/250).

The medical decision-makers were doctors (69.6%, 174/250) and parents (30.4%, 76/250). The locations of the participants were rural areas (42%, 105/250), suburban counties (17.2%, 43/250), and cities (40.8%, 102/250). The characteristics of the included patients are summarized in Table 1.

3.2 | The prevalence of depression or anxiety

Overall, 48.8% (122/250) of the parents of patients showed symptoms of depression, and 46.4% (116/250) showed symptoms of anxiety.

3.3 | Factors associated with depression or anxiety (Tables 2 and 3)

In the univariate analysis, gender, ethnicity, comorbidity with cognitive deficiency, parental relationship, positive coping, and negative coping were significantly associated with depression. These six factors with univariate $p \leq 0.10$ were included in the multivariate regression model. The multivariate analysis results showed that comorbidity with cognitive deficiency (odds ratio [OR] = 0.392, 95% CI = 0.182–0.846), parental relationship (OR = 0.283, 95% CI = 0.130–0.614), positive coping (OR = 0.947, 95% CI = 0.903–0.992), and negative coping (OR = 1.287, 95% CI = 1.179–1.405) were associated with depression.

In the univariate analysis, ethnicity, medical expenses payment, comorbidity with cognitive deficiency, parental relationship, and negative coping were significantly associated with anxiety. These five factors with univariate $p \leq 0.10$ were included in the multivariate regression model. The multivariate analysis results showed that parental relationship (OR = 0.416, 95% CI = 0.207–0.835) and negative coping (OR = 1.155, 95% CI = 1.087–1.228) were associated with anxiety.

TABLE 2 Logistic regression analysis of influencing factors for depression

Variables	<i>B</i>	SE	Wald	<i>p</i>	OR	95% CI
Gender						
Male	-0.443	0.344	1.656	0.198	0.642	0.327-1.261
Female	Reference					
Ethnicity						
Han nationality	-1.028	0.720	2.035	0.154	0.358	0.087-1.468
Other	Reference					
Comorbidity with cognitive deficiency						
No	-0.936	0.392	5.695	0.017	0.392	0.182-0.846
Yes	Reference					
Parental relationship						
No change	-1.264	0.396	10.169	0.001	0.283	0.130-0.614
Deteriorating	Reference					
Positive coping	-0.055	0.024	5.257	0.022	0.947	0.903-0.992
Negative coping	0.252	0.045	31.983	0.000	1.287	1.179-1.405

Abbreviations: *B*, regression coefficient; CI, confidence interval; OR, odds ratio; SE, standard error.

TABLE 3 Logistic regression analysis of influencing factors for anxiety

Variables	<i>B</i>	SE	Wald	<i>p</i>	OR	95% CI
Ethnicity						
Han nationality	-0.572	0.655	0.763	0.382	0.564	0.156-2.037
Other	Reference					
Medical expenses payment						
Self-funded	-0.487	0.339	2.058	0.151	0.614	0.316-1.195
Rural cooperative medical care	Reference					
Comorbidity with cognitive deficiency						
No	-0.592	0.358	2.738	0.098	0.553	0.275-1.115
Yes	Reference					
Parental relationship						
No change	-0.878	0.356	6.090	0.014	0.416	0.207-0.835
Deteriorating	Reference					
Negative coping	0.145	0.031	21.615	0.000	1.155	1.087-1.228

Abbreviations: *B*, regression coefficient; CI, confidence interval; OR, odds ratio; SE, standard error.

4 | DISCUSSION

The present study investigated the factors related to the mental health well-being of parents of children with epilepsy. Although it has been acknowledged that many factors play important roles in the relationship between stress and emotional problems in parents of children

with epilepsy, very little research has focused on coping strategies, the severity of the disease, and couple relationships in this regard.

The current research found that parents who reported worse couple relationships had significantly more depressive and anxiety symptoms. This finding suggests that parents of children with epilepsy who have

a poor couple relationship are more vulnerable to psychological disturbance in the face of adverse life events than parents with more supportive relationships. This is in line with findings showing that poor social support seems to increase the likelihood of developing difficulties in the presence of stressful events.³⁵ Trute and Hauch found a strong correlation between family cohesion and mental health well-being such that a better couple relationship could help each partner cope with stressors, leading to better mental health well-being.³⁶ A recent literature review claimed that the quality of life of parents of children with epilepsy is not related to seizure control but is more closely related to the impact of the family environment, such as the couple relationship.¹² The interrelationship among psychological symptoms and couple relationships is potentially bidirectional and perhaps a sort of vicious circle, which implies that worse couple relationships can contribute to poor parental mental health and vice versa.

As hypothesized, the present study suggests that coping strategies seem to play an important role in parents of children with epilepsy. In line with other studies, this study found that parents of children with epilepsy who had more depressive symptoms reported using self-blame, rumination, catastrophizing thinking, and other negative coping strategies to a significantly higher extent and positive coping strategies to a significantly lower extent.^{37,38} In addition, a stronger relationship between coping strategies and anxiety symptoms was found for those who used negative coping strategies to a higher extent than for those who did not. These findings indicate that different coping styles determine psychological well-being after the experience of stressful events. These findings support those of other studies that have emphasized the importance of active coping strategies in reducing stress for parents of children with epilepsy and many other diseases.^{5,12} This study identified the need for coping strategies involving the maintenance of mental health well-being in times of crisis.

Previous studies have found that the severity of life stressors is highly correlated with parental stress and mental health.^{14,39} Of particular significance is the finding that depressive symptoms are associated with comorbidity with other diseases, such as cognitive dysfunction, which suggests that parents of children with epilepsy who have severe manifestations of comorbidity experience a particular reduction of their psychological well-being.⁴⁰ However, it should be noted that these parents may experience more cumulative stressors than parents of children with epilepsy without comorbidity with cognitive deficiency. A higher level of depressive symptoms was significantly associated with comorbidity with cognitive deficiency, which implies that increased stress was associated with higher psychological disturbance scores. It is obvious that

when children develop epilepsy and comorbidities, they may have more difficulty with treatment and a worse prognosis. It is also possible that these parents have more difficulty caring for children with epilepsy and its complications.

The present study has several limitations. First, the current study is a cross-sectional investigation, so no causal inference can be made. In the future study design, cohort study can be considered. Second, this study adopts voluntary anonymous participation and self-report instruments, which may have sample selection bias and recall bias. Third, this study adopts the strategy of quantitative research, and the subjective experience of many subjects may not be well understood. Future research can consider the combination of quantitative and qualitative research to explore the experiences of parents of children with epilepsy.

5 | CONCLUSIONS

The current study sought to understand the factors that influence psychological distress in the parents of children with epilepsy. The present study found that couple relationships, disease severity, and coping strategies play a critical role in the occurrence of anxiety and depressive symptoms in parents of children with epilepsy. The current study highlights the need for effective support to be provided to families in need, such as those families whose children with epilepsy who have severe manifestations of comorbidity. Second, a supportive relationship between a husband and wife is associated with better care for their child with epilepsy, and vice versa. Parents of children with epilepsy need to be helped to effectively deal with the problems existing in the couple relationship and improve the quality of the couple relationship. A positive couple relationship is not only conducive to the mental health of the couple, but also can provide a more supportive environment for the children. Most importantly, parents of children with epilepsy need to be helped to develop more effective coping styles, improve their ability to cope with everyday dilemmas, help them adopt more effective adaptive coping styles, and reduce ineffective and destructive coping styles. Based on the results of the present study, future clinical studies need to design intervention strategies that focus on improving couples' relationship and promoting effective coping styles and evaluate the effect of such intervention strategies on the mental health improvement of parents of children with epilepsy.

AUTHOR CONTRIBUTIONS

Zhengjia Ren and Dan Yu conceptualized and designed the study. All authors participated in investigation. Chunsong Yang wrote the statistical analysis plan.

Chunsong Yang analyzed the data. Zhengjia Ren drafted the first version of the manuscript. All authors read and edited the manuscript.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data from the current study are available from the first author upon reasonable request.

ETHICS STATEMENT

This cross-sectional study was approved by the Clinical Research Ethics Committee of the West China Secondary Hospital (2019-007). All procedures of the study were performed in accordance with the 1964 Declaration of Helsinki.

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