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Social support for and features of Chinese adults with epilepsy

Rui Zhong, Hanyu Zhang, Yujuan Han, Xin Guo and Weihong Lin*

Abstract

Background: The lack of social support for adults with epilepsy (AWEs) is receiving increased attention, as it may result in low quality of life. This study was aimed to confirm the demographic characteristics of and clinical factors associated with social support for AWEs.

Methods: AWEs were consecutively recruited from our hospital. The 10-term Social Support Rating Scale (SSRS) was used to measure social support. A linear regression analysis with stepwise selection was performed to analyze the independent variables associated with social support for AWEs.

Results: In total, 165 AWEs were consecutively included in the present study. Linear regression analysis showed that the marital status (t=-3.550, $\beta=-0.272$, P=0.001), the age at onset (t=2.545, $\beta=0.192$, P=0.012), and the QOLIE-31 score (t=3.144, $\beta=0.221$, P=0.002) were independent variables associated with social support for AWEs.

Conclusions: Our findings suggest that the poor social support is associated with childhood onset of epilepsy and the unmarried status. This study also confirmed a negative influence of low social support on quality of life in AWEs.

Keywords: Epilepsy, Marital status, Childhood-onset epilepsy, Social support, Quality of life

Background

Epilepsy is a highly prevalent and serious neurological disorder that affects over 70 million people worldwide [1, 2]. Epilepsy has been reported to be related to various poor social outcomes, such as social skill deficits, decreased social competence, poor social cognition, and social anxiety [3–7]. In recent years, the lack of social support for adults with epilepsy (AWEs) is receiving increased attention, as it may result in low quality of life [8, 9]. Establishing and maintaining supportive personal relationships may be a new way to improve the quality of life in AWEs.

Previous investigations on different cultural backgrounds have reported stigma and negative attitudes toward individuals with epilepsy [10–13]. AWEs are less likely to be married than the general population, and

son with epilepsy [14, 15]. Additionally, AWEs may face additional employment barriers, especially for those with lower education levels, compared with controls [16, 17]. These social disadvantages prevent AWEs from receiving necessary social support to confront this chronic condition and lead to social isolation. Social support is the capacity of a social network to provide psychological and material resources that are intended to improve an individual's ability to cope with stress [18]. Zhou and his colleagues recently reported that AWEs had a significantly lower social support score than the healthy controls, and social support was negatively related to depressive symptoms [8]. An adult with epilepsy receiving poor social support also reports lower levels of life satisfaction [19].

parents always object to their children marrying a per-

So far, data on the social support for AWEs are limited in Northeast China. Thus, there is a need for research on the factors affecting social support in Chinese AWEs. In this study, we set out to investigate potential variables associated with social support for AWEs, and identify

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the relationships between social support and psychiatric symptoms (including anxiety and depressive symptoms), perceived stigma, as well as quality of life.

Methods

Participants

This cross-sectional study was conducted among AWEs attending the Neurology Department of The First Hospital of Jilin University, consecutively recruited from May to July 2021. The inclusion criteria included a definite diagnosis of epilepsy based on the International League Against Epilepsy (ILAE) criteria [20]; an age of 18 years or older; willingness to participate in this study; and having sufficient language skills and mental ability to complete the questionnaires thoroughly. The epilepsy patients were excluded if they had any known disease that may influence their social status. The exclusion criteria consisted of (1) a serious brain disorder except for epilepsy (e.g., Alzheimer's disease); (2) a serious brain injury, even if the patient had an ability to complete the questionnaires and interview appropriately; (3) a severe physical illness (e.g., cancer and cardiac disease); and (4) psychiatric diseases (e.g., chronic depression). This study was approved by the Ethics Committee of First Hospital of Jilin University, and all patients provided written informed consent.

Data collection

Demographic and clinical data were collected through a structured face-to-face interview. Medical records were reviewed for additional information when necessary. The demographic information included age, sex, education level, residence, marital status, occupation, and monthly household income per capita. Clinical information included age at epilepsy onset, duration of epilepsy, seizure type, seizure frequency over the last year, and antiseizure medication (ASM) treatment regimen. The types of seizure were grouped as generalized, focal, and unclassified seizures. Social support, depression, anxiety, stigma, and quality of life were evaluated using the 10-item Social Support Rating Scale (SSRS), the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E), the Generalized Anxiety Disorder-7 (GAD-7), the Kilifi Stigma Scale of Epilepsy (KSSE), and the Quality of Life in Epilepsy Inventory (QOLIE-31), respectively, during the interview.

Questionnaire

The 10-item SSRS [21] assesses social support with three self-reported subcomponents, subjective support (4 questions), objective support (3 questions) and support use (3 questions). The total score of the SSRS ranged from 12 to 66, with lower scores indicating weaker social support. The 10-item SSRS has been widely used in the

mainland of China [22–24] and is a reliable scale in people with epilepsy (PWE) [25, 26].

The NDDI-E scale was employed to evaluate depressive symptoms in AWEs [27, 28]. It contained 6 items, and each item had 4 response options scored between 1 and 4 points. The total score ranged between 6 and 24 points, with a lower score suggesting a lower degree of depressive symptoms.

The GAD-7 scale was used to screen for AWEs with anxiety symptoms [29, 30]. This scale had a total of 7 self-reported questions, each rated on a 4-point scale from 0 to 3. The total score ranged between 0 and 21, with a higher score indicating more severe anxiety symptoms.

The KSSE was used to measure the perceived stigma of AWEs [31, 32]. The total KSSE score varied from 0 to 30, by summing 15 items. A higher KSSE score suggested a higher degree of perceived stigma.

The QOLIE-31 inventory was used to measure the quality of life [33]. The questionnaire contained 31 items and a total of 7 subscales. The total score ranged between 0 and 100, with lower scores suggesting a poorer quality of life.

Statistical analysis

Data analysis was performed with the SPSS version 19.0 software. Continuous variables are presented as the mean \pm standard deviation (SD), and categorical variables as proportions. Variables such as age, age at onset, and disease duration were converted from continuous variables into categorical variables. Univariate analyses were conducted to identify factors associated with the level of social support. Associations of the demographic and clinical variables with the SSRS score were tested using the Mann–Whitney U test or the Kruskal–Wallis H(K) test. Spearman correlation analysis was employed to evaluate the relationships between the continuous variables that were not normally distributed. The variables with P < 0.05in the univariate analyses were then included in a multiple linear regression analysis with stepwise selection. A two-sided P < 0.05 was considered significant.

Results

Demographics and clinical characteristics

During May and July 2021, 196 AWEs attended the Neurology Department, of whom 165 agreed to be interviewed, completed the questionnaires and were included in this study. The participants included 81 (49.1%) males and 84 (50.9%) females. The demographic and clinical characteristics are described in Table 1. About 51.5% of the patients had a college level of education or above. Eighty (48.5%) participants were married, and 55 (33.3%) were unemployed. Focal seizures were more frequently observed than other seizure types (83.0%). Approximately

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Table 1 Demographics and clinical characteristics of participants

Variable	n (%) or mean \pm SD	SSRS score		
		mean ± SD	P value	
Age (years)				
18–35	96 (58.2)	36.34 ± 7.46	< 0.001	
35-50	44 (26.7)	41.86 ± 8.52		
≥ 50	25 (15.1)	42.08 ± 6.54		
Sex				
Male	81 (49.1)	38.96 ± 7.93	0.565	
Female	84 (50.9)	38.42 ± 8.25		
Educational level				
University and above	85 (51.5)	38.96 ± 8.27	0.47	
Middle school	68 (41.2)	38.84 ± 7.98		
Primary school and below	12 (7.3)	35.83 ± 7.18		
Residence				
Rural	53 (32.1)	38.25 ± 6.33	0.711	
Urban	112 (67.9)	38.89 ± 8.8		
Marital status				
Married	80 (48.5)	42.29 ± 7.35	< 0.001	
Single	78 (47.3)	35.12±7.03		
Divorced or bereaved	7 (4.2)	37.29 ± 9.76		
Occupation				
Student	41 (24.8)	35.27 ± 7.72	< 0.001	
Employed	69 (41.8)	41.29±7.69		
Unemployed	55 (33.3)	37.96 ± 7.82		
Monthly family income per cap		37.30 17.02		
< 1000	40 (24.2)	38.53 ± 7.64	0.096	
1000–5000	101 (61.2)	37.92±7.96	0.050	
> 5000	24 (14.5)	42.17±8.68		
Age at onset (years)	21(11.3)	12.17 ± 0.00		
18	65 (39.4)	35.49±6.84	< 0.001	
> 18	100 (60.6)	40.76±8.17	₹0.001	
Disease duration (years)	100 (00.0)	40.70 ± 0.17		
<5	69 (41.8)	38.77 ± 7.9	0.738	
5–10		39.02 ± 8.12	0.736	
	44 (26.7)	39.02 ± 6.12 38.29 ± 8.4		
≥ 10	52 (31.5)	30.29 ± 0.4		
Seizure type	127 (02.0)	20.07 0.15	0.224	
Focal onset	137 (83.0)	39.07 ± 8.15	0.324	
Generalized onset	13 (7.9)	36.85 ± 5.87		
Unclassified onset	15 (9.1)	36.80 ± 8.94		
Seizure frequency over the last	•	30.44 0.40	0.413	
Seizure-free	36 (21.8)	39.44±8.49	0.413	
< 1/ month	89 (53.9)	39.1 ± 7.67		
≥ 1/ month	40 (24.2)	37.08 ± 8.55		
ASM therapy regimen				
Monotherapy	115 (69.7)	39.18 ± 7.8	0.232	
Polytherapy	50 (30.3)	37.54 ± 8.62		
GAD-7 score	5.7±5.59	-	-	
NDDI-E score	9.53 ± 3.94	-	-	
KSSE score	6.35 ± 7.15	-	-	
QOLIE-31 score	49.92 ± 11.02	-	-	
SSRS score	38.68 ± 8.073	-	-	

PWE people with epilepsy, ASM antiseizure medication, GAD-7 Generalized Anxiety Disorder-7, NDDI-E Neurological Disorders Depression Inventory for Epilepsy, KSSE Kilifi Stigma Scale of Epilepsy, QOLIE-31 Quality of Life in Epilepsy Inventory, SSRS Social Support Rating Scale

one-fifth of the patients (21.8%) reported to be seizure-free, and some patients (30.3%) received polytherapy. The mean SSRS total score was 38.68 (SD, 8.073).

Associations of demographic and clinical characteristics with SSRS score

Results of the Mann-Whitney U test and Kruskal-Wallis H(K) test showed that factors significantly associated with social support scores were age (P<0.001), marital status (P < 0.001), occupation (P < 0.001), and age at onset (P<0.001). Patients who were married had higher SSRS scores (42.29 ± 7.35) than those who were single (35.12 ± 7.03) or divorced or bereaved (37.29 ± 9.76) . AWEs who were employed (41.29 ± 7.69) reported higher SSRS scores than students (35.27 ± 7.72) and the unemployed (37.96 \pm 7.82). Individuals with monthly family income per capita > 5000 Yuan (42.17 \pm 8.68) had higher SSRS scores than those with lower income levels (37.92 ± 7.96) , but the difference was not significant (P=0.096). No significant associations were found for other demographic and clinical variables with social support.

Correlation between SSRS score and NDDI-E, GAD-7, KSSE, and OOLIE-31 scores

The SSRS score was negatively correlated with NDDI-E (r=-0.294, P<0.001), GAD-7 (r=-0.248, P=0.001), and KSSE scores (r=-0.32, P<0.001). The SSRS score also had significant positive correlations with the QOLIE-31 score in AWEs (r=0.264, P=0.001). Additionally, depression, anxiety, stigma, and quality of life scores were significantly correlated with each other (Table 2).

Linear regression analysis of the independent associated factors with SSRS score

To better explain the independent associations with the total SSRS score in AWEs, we performed a multiple linear regression analysis with stepwise selection. Age, marital status, occupation, age at onset, NDDI-E, GAD-7, KSSE, and QOLIE-31 scores were included in the regression model, with the SSRS score as the dependent variable. Results showed that the marital status (t=-3.550, β =-0.272, P=0.001), age at onset (t=2.545, β =0.192, P=0.012), and QOLIE-31 score (t=3.144, β =0.221, P=0.002) were independent factors associated with social support (Table 3). The model explained 21.6% of the variance of the social support score.

Discussion

Insufficient social support has recently become a topic of discussion in PWE [8, 9, 19, 34]. In this study, we aimed to better understand the social support for AWEs in Northeast China. Two main findings were reported. First,

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Table 2 Correlation between SSRS score and NDDI-E, GAD-7, KSSE, and QOLIE-31 score

	GAD-7 score	C-NDDI-E score	KSSE score	QOLIE-31 score	SSRS score
CAD 7	18			`	
GAD-7 score	l a				
C-NDDI-E score	0.717 (< 0.001)	1			
KSSE score	0.654 (< 0.001)	0.698 (< 0.001)	1		
QOLIE-31 score	-0.776 (< 0.001)	-0.747 (< 0.001)	-0.677 (< 0.001)	1	
SSRS score	-0.248 (0.001)	-0.294 (< 0.001)	-0.32 (< 0.001)	0.264 (0.001)	1

GAD-7 Generalized Anxiety Disorder-7, NDDI-E Neurological Disorders Depression Inventory for Epilepsy, KSSE Kilifi Stigma Scale of Epilepsy, QOLIE-31 Quality of Life in Epilepsy Inventory, SSRS Social Support Rating Scale

Table 3 Linear regression analysis of associated factors with the SSRS score

Variable	beta	SE	t	P value	Adjusted R ²
SSRS score					0.216
Marital status	- 0.272	1.071	- 3.550	0.001	
Age at onset	0.192	1.245	2.545	0.012	
QOLIE-31 score	0.221	0.051	3.144	0.002	

QOLIE-31 Quality of Life in Epilepsy Inventory, SSRS Social Support Rating Scale

AWEs who were married were more likely to have better social support, and individuals with childhood- and adolescent-onset epilepsy had inadequate social support compared to those with adult-onset epilepsy. Second, a low social support score could independently and negatively influence the quality of life in AWEs.

PWE appear to have insufficient social support, and are hugely influenced by the limited social support [19]. Marriage and intimate relationships are an important source of social support. Here we found that the married adults with epilepsy reported higher levels of social support than those who were single or divorced or bereaved. Social support satisfaction has also been identified as a significant predictor of marital adjustment of AWEs [35]. Korean AWEs always have a lower marriage rate and a higher divorce rate than the general population [36]. Similarly, Zhou and his colleagues also reported lower marriage rates in PWE than in the general Chinese population [37]. Many patients who were single or divorced attributed their undesirable marital status to epilepsy [36]. In addition, 18% of families object to their children marrying a person with epilepsy, due to the social discrimination and the negative attitude toward epilepsy in the public [38]. The undesirable marital status may partly explain the lack of social support for AWEs. Another explanation may be that it is not easy for unhealthy people to establish and maintain social ties that contribute to marriage [39]. We also found that AWEs having a job received more social support than the unemployed AWEs. According to the literature, PWE may experience employment obstacles, which lead to a low employment rate in this group [40].

This study suggested that childhood- and adolescentonset epilepsy (onset age ≤ 18 years) was another risk factor for poor social support. A recent study in West China reported similar findings that individuals with childhood-onset epilepsy had weaker social support than those with adult-onset epilepsy [25]. One possible reason for this is that children are vulnerable, and children with epilepsy might be overprotected by their families [41]. This may cause a deficiency in independent social functioning and a lack of social support in their later life. Childhood is a critical phase in the development of social function. Children with epilepsy are always reported with an increased risk of social cognitive deficits [42], behavioral problems [43], social difficulties [44], and impaired social function [45], which may have a negative impact on the perceived social support for patients in the long term. Additionally, adults with childhood-onset epilepsy are less likely to be married, which may prevent them from receiving support from intimate partners [46]. In contrast, we found that adults with new-onset epilepsy had better social support, which was consistent with the finding by Zhou et al. [25]. This may be because that the adults have established an adequate number of social connections and are less influenced by new-onset epilepsy. In a previous study, the age of epilepsy onset was only associated with subjective support but not to objective support in AWEs [25].

A study in the USA has found that PWE with poor social support are more likely to have poor life satisfaction than those with strong social support [19]. Similarly, PWE who reported a lack of affectionate support are more likely to report poor quality of life [9]. Our findings are consistent with these reports. The current study suggested that a low social support score is an important factor in predicting poor quality of life. Evidence has shown positive impacts of good social relationships on health by providing greater economic resources or promoting healthy behaviors [39]. A study in China utilizing

^a (r) Spearman Rho correlation coefficient

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the Hospital Anxiety and Depression Scale showed that the depressive symptoms are related to weaker social support [25]. It is therefore necessary to further study the role of anxiety and depression in a full social context [47]. In this study, the levels of social support had a negative correlation with depressive and anxiety symptoms; however, this significant relationship disappeared in multiple regression analysis. The discrepancy from previous studies may be partly explained by the differences in assessment methods and the sample size. The social support offered by families, friends and significant others could lead to better mental health and life satisfaction [19, 34]. PWE are encouraged to participate in support groups for the benefit of mental health [48].

Some limitations should be noted. First, as the demographic and clinical data were gathered via selfreported methods, a reporting bias may exist. Second, all patients were Chinese AWEs and recruited from a single center, which might lead to a selection bias. Additionally, the SSRS was originally developed in China and is mainly used in the mainland of China. Thus, these findings could not be generalized to all patient groups. Third, the regression model of AWEs explained only 21.6% of the variance in the SSRS score. Several variables that might be related to social support were not included in the current study, such as the severity of seizures. Finally, our study employed a cross-sectional design, which might have limited its ability to evaluate the causal relationship between these variables and social support.

Conclusions

In this study, we found that the childhood onset of epilepsy and the unmarried status were associated with poor social support, and confirmed the negative influence of low social support on quality of life among AWEs. The results suggest that clinicians should focus on patients' social interactions and encourage them to establish and maintain supportive personal relationships.

Abbreviations

AWEs: Adults With Epilepsy; PWE: People With Epilepsy; SSRS: Social Support Rating Scale; ILAE: International League Against Epilepsy; NDDI-E: Neurological Disorders Depression Inventory for Epilepsy; GAD-7: Generalized Anxiety Disorder-7; KSSE: Kilifi Stigma Scale of Epilepsy; QOLIE-31: Quality of Life in Epilepsy Inventory.

Acknowledgements

The authors thank all patients for their participation in this study.

Authors' contributions

RZ and WL conceived of and designed the study. RZ, HZ, XG and YH were involved in data acquisition. RZ analyzed the data and wrote the manuscript. All authors contributed to the article and approved the submitted version. All author(s) read and approved the final manuscript.

Funding

The present study was funded by the Jilin University First Hospital Clinical Cultivation Fund Program (LCPYJJ2017006).

Declarations

Ethics approval and consent to participate

This study was approved by the Ethics Committee of the First Hospital of Jilin University (2017–326), and all patients provided written informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no conflicts of interest.

Received: 2 December 2021 Accepted: 3 March 2022 Published online: 01 July 2022

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