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# Disease awareness and dietary habits of patients with epilepsy in western China: a cross-sectional study

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## Abstract

**Background:** The optimal management of epilepsy includes engaging patients through education on knowledge of the disease, its treatment and diet control.

**Methods:** This was a cross-sectional survey-based cohort study, aimed to investigate the awareness of epilepsy in Chinese patients and to understand their dietary habits. Participants were consecutively enrolled from epileptic patients treated in a single epilepsy center from October 1, 2019 to February 29, 2020. A self-reported questionnaire (Cronbach's  $\alpha = 0.758$ ) consisting of 3 parts was sent to 407 patients with epilepsy. The questionnaire included items on demographic information, epilepsy features, awareness of epilepsy treatment and dietary habits.

**Results:** About half of the patients (53.8%, 219/407) thought epilepsy was curable and only 80% knew that the first choice of treatment is medication. While 58.6% of the patients with low educational level preferred the use of antiepileptic drugs ( $p = 0.014$ ), 52.7% believed that the medication should not be stopped immediately after seizure control ( $p = 0.026$ ), especially after surgery (40.5%,  $p = 0.011$ ). Patients with lower household monthly incomes had less awareness of the use of antiepileptic drugs than patients with higher incomes: only 39.2 and 49.8% of patients with lower incomes thought that the drugs could be stopped after epilepsy surgery or seizure control, respectively, compared to 51.6 and 66.1% with higher incomes. Alcohol (86.2%), caffeine (56.8%) and strong tea (49.1%) were top three foods considered by the patients to be avoided to prevent seizures. Approximately 30.2% of patients identified at least one food that made them susceptible to seizures.

**Conclusions:** Patient education on epilepsy, antiepileptic drugs and diet for management of seizures should be provided especially to patients with less education, lower income or inaccurate beliefs of epilepsy in Western China.

**Keywords:** Epilepsy, Awareness, Antiepileptic drug, Dietary habit, Epilepsy education, Survey

## Background

Epilepsy affects approximately 65 million people worldwide, making it one of the most common neurological disorders [20, 28]. Compared to healthy individuals,

patients with chronic epilepsy have lower educational levels, lower annual incomes, and worse status of health, posing a great healthcare burden for caregivers [5, 16, 21]. Patient education is an important supplement to therapeutic treatment of epilepsy [32], because it can increase the quality of life and reduce stigma and social fear of patients [27]. Studies conducted in different countries have revealed regional differences in patient knowledge on epilepsy and education [1, 8, 29, 39].

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The optimal treatment plan for epilepsy includes patient sufficient awareness of epilepsy, a proper diet, and proper use of antiepileptic drugs (AEDs) [17, 23]. Diet plays an important role in the management of epilepsy. The US National Health and Nutrition Examination Survey in 2001-2002 has found a high prevalence of nutrient deficiency among patients with epilepsy [35]. Alcohol and coffee [38] can increase the susceptibility to seizures [11, 12, 14, 34]. In traditional Chinese medicine, consumption of certain “stimulating” foods, such as mutton, sow meat, and chicken, can contribute to chronic diseases. Conversely, a diet high in fruit and vegetables can help prevent many chronic diseases [4, 7].

Despite the availability of AEDs, nearly one third of patients are resistant to them [22]. In addition, approximately 40% of patients in China have never received AEDs or they prefer low-dose AEDs, and epilepsy in more than 70% of patients in rural regions of China is uncontrolled [15].

In this study, we conducted a cross-sectional survey in western China, as a first step to strengthen patient awareness of proper diet and AEDs for epilepsy management.

## Methods

### Participants

In this cross-sectional survey-based study, participants were consecutively recruited from patients treated in a single epilepsy center from October 1, 2019 to February 29, 2020. Patients who were older than 14 years and diagnosed with epilepsy at least 1 year before referral from a primary medical center were eligible participants. Patients were excluded if they (1) self-reported seizures within 48 h before completing the questionnaires; (2) had a history of mental retardation, alcohol or drug abuse, or uncontrolled psychosis; (3) had incomplete clinical or demographic data; or (4) were unable to read or understand the questionnaires.

We considered patients to have drug-resistant epilepsy if they had been treated with two or more appropriate AEDs [22]. Seizure freedom was defined as no seizure for at least 12 months or in a period three times the pre-treatment inter-seizure interval, whichever was longer [22].

### Content of questionnaire

The custom-designed questionnaire (Cronbach's  $\alpha = 0.758$ ) consisted of three parts, covering the general information of patients, knowledge about epilepsy treatment, and dietary habits. Part 1 requested demographic characteristics, including age, sex, educational level, household monthly income and source of income. Basic epilepsy clinical feature was also included in this part, such as seizure onset in 30 days. A question “What do

you think epilepsy is?” was also included, to test patients' knowledge on the disease. Candidate answers provided were “a disease”, “possession by ghosts”, “the result of eating wrong food” or “others”.

Part 2 assessed the awareness of epilepsy treatment. Question 1 was “Can epilepsy possibly be cured?” Candidate answers provided were “Yes” (scored as 1 point) or “No” (scored as 0 point). Question 2 was “What's the first choice of treatment for epilepsy?” Respondents answered “therapeutic treatment” (1 point) or “Unknown” or “surgery” (0 point). Question 3 was “What drug treatments are effective against epilepsy?” Candidate answers provided were “AEDs” (1 point) or “Unknown” or “traditional herbal medicine” (0 point). Question 4 was “Would you stop taking AEDs immediately after seizure control?” Respondents might answer “No” (1 point) or “Yes” or “Unknown” (0 point). Question 5 was “Would you take medication immediately after epilepsy surgery?” Respondents might answer “Yes” (1 point) or “No” or “Unknown” (0 point).

Part 3 was to survey the dietary habits. The question was “What foods should be avoided because they can induce seizures?”. The participants could choose up to 14 food items, of which nine are considered “stimulating” by the traditional Chinese medicine: fermented glutinous rice wine, sow meat, rabbit meat, chicken, mutton, beef, eel, coriander and konjak. The remaining items were alcohol, caffeine, strong tea, sparkling water and ice food.

### Statistical analysis

Sociodemographic information and epilepsy-related clinical characteristics at baseline are described in terms of means and standard deviation if the data were continuous, or in terms of frequency if the data were categorical. Differences between groups were assessed using the chi-square test in the case of continuous data, or Fisher's exact test in the case of categorical data. Statistical analysis was made using the SPSS 20.0 software (IBM, Chicago, IL).

## Results

### Patient demographics

Of the 591 patients treated for epilepsy at our center during the recruitment period, 128 were excluded because they were younger than 14 years, 49 refused to participate, and seven had incomplete clinical data. Therefore, 407 patients (206 men, 50.6%) were included in this study, with a mean age of 28.35 (SD 12.72) years (range 14–84) (Table 1). The number of patients with low household monthly incomes (<2500 RMB, approximately 380 USD) was about twice of the number of patients with a household monthly income  $\geq 2500$  RMB. Only 64 (15.7%) of the patients had medical insurance coverage to pay

**Table 1** Characteristics of patients with epilepsy

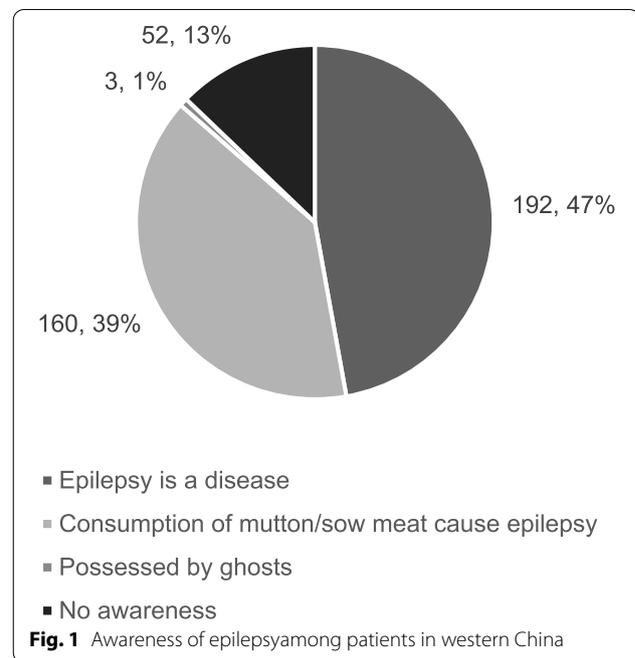
Characteristic	No.	%
<b>Age (years)</b>		
14-25	215	52.8
26-45	143	35.1
46-84	49	12.0
<b>Sex</b>		
Male	206	50.6
Female	201	49.4
<b>Education level</b>		
≤Junior high school	163	40.0
Senior high school	95	23.3
≥University	149	36.7
<b>Monthly household income</b>		
<2500 RMB	283	69.5
≥2500 RMB	134	32.9
<b>Medical insurance</b>		
No	343	84.3
Yes	64	15.7
<b>Seizure within 30 days</b>	138	33.9
<b>Drug resistant epilepsy</b>	126	31.0
<b>Seizure free</b>	68	16.7
<b>Know that epilepsy is a disease</b>	192	47.2

for their epilepsy treatment at our center, and the other patients (343, 84.3%) had out-of-pocket medical burdens. About one third of the patients reported experiencing seizures in the 30 days prior to the survey. Patients with higher educational level had a lower tendency to report such seizures than those with lower educational level.

#### Awareness about epilepsy and AEDs

Less than half of the patients knew that epilepsy is a disorder. Over one third of patients believed that eating “stimulating” food viewed in traditional Chinese medicine might cause epilepsy (Fig. 1). About half of the patients thought epilepsy was curable, while 12.8% believed it was an incurable disease. There was no significant difference in the awareness of epilepsy as a disease between patients who had seizures within 30 days before survey and those who did not have. In contrast, there was a significant difference in the awareness between patients with different household monthly income levels and different educational levels (Table 2).

Nearly 80% of patients knew that pharmacotherapy is a treatment choice for epilepsy. Approximately 76.9% of patients with a university degree or above preferred AEDs for treatment, significantly higher than the 58.6% of patients with lower educational level ( $p=0.014$ ). A significantly higher proportion (69.2%) among patients with a university degree or above believed that AEDs should



not be stopped immediately after seizure control, compared to 52.7% of patients with lower educational level ( $p=0.026$ ). The same result was observed for the question about whether one should stop taking AEDs after epilepsy surgery. Nearly half of patients with low household monthly income believed that one could stop AEDs immediately after seizure control, and only 39.2% knew that they should take the drugs after epilepsy surgery.

#### Dietary habits

The top three foods that patients considered to receive attention were alcohol (86.2%), caffeine (56.8%) and strong tea (49.1%). More than 15% of patients thought that sparkling water (24.3%), mutton (20.9%), konjak (17.2%), fermented glutinous rice, wine and coriander should be avoided (Fig. 2). Nearly one third of patients identified at least one type of “stimulating food” to be treated with caution. The dietary habits did not seem to vary significantly with sex, marital status, education level, monthly household income or seizure onset in 30 days.

#### Discussion

Epilepsy is frequently associated with comorbidities and significant social stigma [24]. Nearly half of the patients in western China in our study showed little awareness of epilepsy, AEDs and the importance of diet. The poor health knowledge has a negative impact on chronic disease management [36]. Our results suggest that more efforts are needed to strength education of patients on

**Table 2** Response about epilepsy treatment between different subgroups

Question	Answered the question correctly		If patients believes epilepsy is a disease		If patients with drug resistant epilepsy		If patients with Seizure freedom		If patients with low family monthly income		If patients experience seizure within 30 days		If patients lower educational level	
	n	%	F value	p value	F value	p value	F value	p value	F value	p value	F value	p value	F value	p value
Q1	219	53.8	11.047	0.001	0.362	0.591	0.413	0.306	8.226	0.003	0.224	0.675	15.037	<0.001
Q2	334	82.1	15.963	<0.001	1.652	0.212	2.112	0.097	1.417	0.263	0.229	0.684	4.250	0.051
Q3	248	60.9	10.613	0.001	0.002	1.000	3.197	0.078	0.577	0.508	0.000	1.000	6.403	0.014
Q4	223	54.8	17.222	<0.001	0.407	0.590	0.216	0.690	9.255	0.002	0.508	0.528	5.018	0.026
Q5	175	43.0	6.230	0.016	0.686	0.449	0.361	0.593	5.401	0.023	1.796	0.205	6.717	0.011

epilepsy, its treatment and diet, especially for patients with lower education levels and lower incomes.

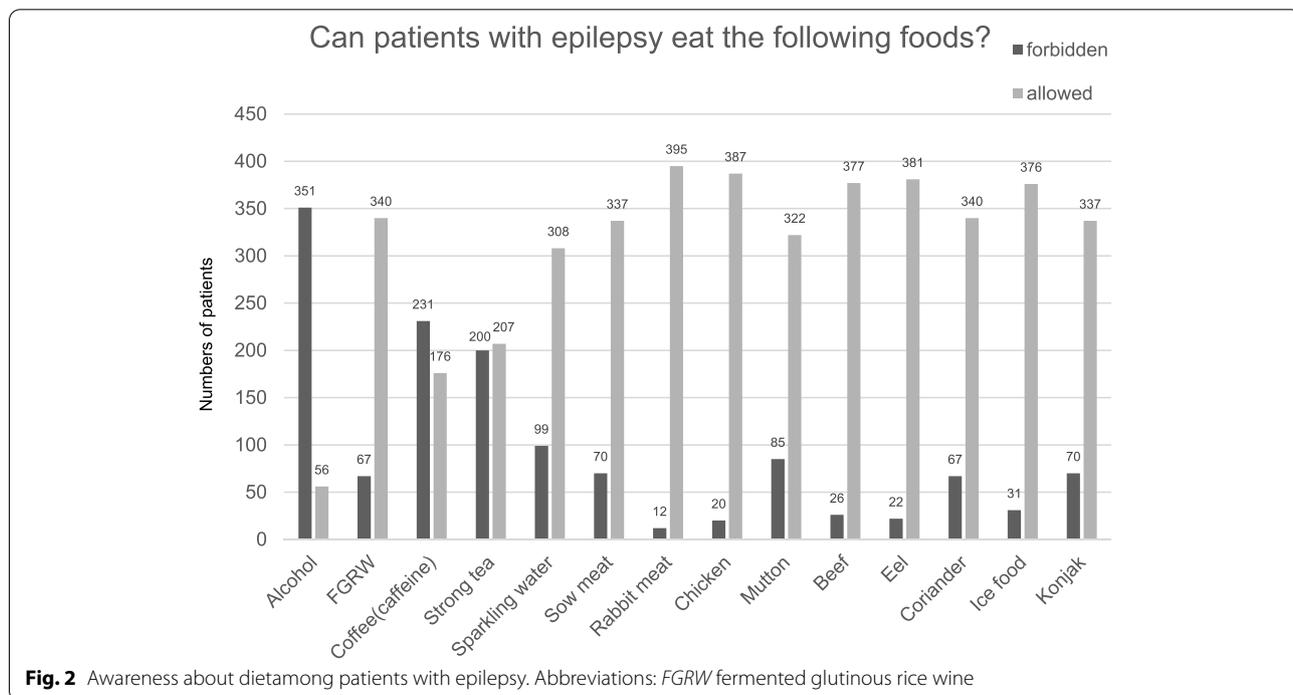
There are regional differences in the awareness and knowledge about epilepsy, possibly due to the differences in study design, the social-cultural differences, and varied access to education. While more than 80% of patients with epilepsy surveyed in Thailand were aware of epilepsy, a study from southern Ethiopia showed that 27% of patients with epilepsy knew nothing about it, and approximately 40% believed that it was a punishment from God [25]. Several studies have associated poor health literacy with lower education and income levels [31, 33]. Indeed, we found that the lower education among our patients was associated with their lack of awareness about AEDs.

The stigma related to epilepsy may help explain why so many respondents in our survey did not think that

epilepsy is a disease. In India, nearly 42.30% of patients with epilepsy and their relatives feel a stigma related to epilepsy [26]. The stigma related to epilepsy can make it difficult for patients to work, start families or obtain driving licenses [6, 37]. Fortunately, such gaps in epilepsy awareness and understanding can be addressed through appropriate education for patients and their families [13, 32].

In this study, we found that the lower educational level was related to a higher risk of seizure onset within 30 days before the survey. However, previous studies have shown that there is no association between seizure severity and health literacy [2]; rather, the seizure severity is affected by multiple pathophysiological factors [2].

In this study, most of the patients believed that alcohol, caffeine and strong tea could induce seizure. In fact,



**Fig. 2** Awareness about diet among patients with epilepsy. Abbreviations: FGRW fermented glutinous rice wine

consumption of alcohol and caffeine has been shown to increase the risk of seizures. For example, alcohol intake on Saturdays tends to cause seizures on Mondays [30]. Caffeine can increase the seizure risk, especially at high doses [34]. In addition, caffeine can antagonize the effects of AEDs in animal models of drug-resistant epilepsy [3, 10]. Conversely, chronic low-dose caffeine exposure has been shown to reduce the number of seizures and the electroencephalographic activity in people with focal seizures, suggesting that low-dose caffeine can help control seizures [19].

While epilepsy patients in China are typically advised to avoid alcohol and caffeine intake, most of our respondents did not link consumption of fermented glutinous rice wine to seizures, which may be because that the Chinese name of this drink does not contain the word “wine”.

In Chinese culture, “stimulating” foods such as mutton and sow meat are thought to be capable of inducing chronic diseases. In this study, the top five “stimulating” foods considered by the patients to be associated with seizures were: sparkling water, mutton, sow meat, konjak, and coriander. Dietary changes are recommended for seizure control in drug-resistant epilepsy [9]. A ketogenic diet based on high fat, low carbohydrate and low protein can help control seizures, but it remains unclear whether certain meats should be avoided. Greater consumption of vegetables is associated with better seizure control [18]. These insights have implications for patient education in many countries, especially in countries where traditional medicine and inaccurate beliefs about disease are prevalent.

### Limitations

Our study has some limitations. First, although our epilepsy center is the largest center in western China, a small sample size (407 patients) was employed in this study, and the patients were from only a single site. Second, the questionnaire survey was carried out in a self-reporting manner, so the results may be subject to bias. The results should be verified and extended in larger studies from additional sites. Third, although we are a single-center study, but data source of patients shows they are from the western typical provinces and cities, including Tibet, Sichuan province, Guizhou province and so on.

### Conclusions

The lack of knowledge on epilepsy, AED medication and dietary interventions is common among patients with epilepsy in western China. Patients with lower educational level and lower household income, especially those who do not believe that epilepsy is a disease, are populations particularly in need of educational interventions.

Dietary interventions should emphasize the importance of a balanced diet and take into account local beliefs about the effects of “stimulating” foods, especially in regions where traditional medicine and inaccurate beliefs about the disease are prevalent.

### Abbreviation

AEDs: Antiepileptic drugs.

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### Authors' contributions

Conception and design of the study: Xiaoting Hao, Dong Zhou. Acquisition of data: Enzhi Li, Qi Zhang, Wenjing Li, Xiao Yang. Analysis and interpretation of data: Nanya Hao, Bo Yan, Qi Zhang. Manuscript drafting: Qi Zhang, Wenjing Li. Revising it critically for important intellectual content: Xiaoting Hao, Dong Zhou. Final approval of the version to be submitted: Xiaoting Hao. The author(s) read and approved the final manuscript.

### Authors' information

Not applicable.

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### Availability of data and materials

All data are available from the corresponding author upon reasonable request.

### Declarations

#### Ethics approval and consent to participate

The study was approved by the Ethics Committee of Sichuan University [No. 2019(508)], and all participants gave informed consent.

#### Consent for publication

All participants gave consent for publication.

#### Competing interests

Author Dong Zhou is the associate editor for *Acta Epileptologica*. Author Dong Zhou was not involved in the journal's review of, or decisions related to this manuscript.

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