



# Epilepsy-related concerns among patients with epilepsy in West China

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## ABSTRACT

**Purpose:** In the present study, we aimed to investigate patient-derived epilepsy-related concerns among Chinese individuals with epilepsy and the impact of seizure control on patient concerns.

**Methods:** All adult patients with epilepsy who had visited the outpatient clinic at West China Hospital between July 2014 and June 2016 were invited to participate in the study. All patients were given a blank sheet of paper and asked to list any concerns they had regarding their disease in order of importance. Demographic and clinical characteristics were also evaluated while regression models were used to examine the impact of seizure control on patient concerns.

**Results:** A total of 1040 patients reported 2202 concerns across 25 distinct categories. The most frequently listed concerns were worries about seizures (55.4%), maintaining a job (17.4%), and the heritability of epilepsy (16.0%). The legal right to drive was listed by only 3.5% of patients who took the survey while seizure recurrence was described by participants as the most important concern (379, 36.4%). Compared with the group with uncontrolled seizures, the group with controlled seizures reported less frequently about “holding down a job” (odds ratio (OR): 0.333 (0.187–0.591)), “fear of being injured during a seizure” (OR: 0.353 (0.183–0.682)), and “leading a normal life” (OR: 0.452 (0.234–0.871)), but they reported more frequently about “having another seizure” (OR: 2.447 (1.614–3.710)), “problems with medication side effects” (OR: 1.733 (1.148–2.616)), and their “legal right or ability to drive” (OR: 2.360 (1.094–5.092)).

**Conclusion:** Our findings indicated that Chinese adults with epilepsy had various concerns, some of which differed from those observed in Western populations. Concerns about heritability of seizures, marriage, and pregnancy were of greater concern to Chinese patients compared with Western patients while the legal right to drive appeared to be less of a concern to Chinese patients. Patients with controlled seizures may still have many concerns. Chinese physicians should monitor patient concerns even among those whose seizures remain controlled to meet their needs. More time and attention should be given to address these issues in clinical practice in the context of Chinese culture.

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## 1. Introduction

Epilepsy exerts a significant impact on a patient's quality of life as seizures can impair an individual's ability to obtain an education, drive, work, and develop/maintain social relationships [1]. In our previous study, we observed that Chinese patients with epilepsy faced higher rates of unemployment, lower income, lower marital satisfaction [2], poorer social support [3], and greater driving restrictions than the general population [4]. Several quantitative tools, such as the Quality of Life in Epilepsy Inventory (QOLIE), have been designed to assist in evaluating the quality of life in people with epilepsy. However, these inventories do not include all domains of patient perspectives regarding epilepsy [5]. Items on the commonly utilized QOLIE-89 were derived by a team of experts in reference to other questionnaires [6], and

previous studies have reported discrepancies between patient concerns regarding epilepsy and the factors considered important by healthcare professionals [7,8]. To address this issue, Gilliam et al. asked their patients to list their concerns in order of importance [9], from which they developed the 20-item Epilepsy Foundation of America (EFA) Concerns Index. Several studies have been conducted using the EFA Concerns Index or by directly asking adults with epilepsy to report their concerns centered around living with epilepsy [10]. Driving, having seizures, employment concerns, and memory problems were the most frequently cited concerns [8,9,11–13]. These studies have also indicated that patients are able to express unambiguous life concerns that are not necessarily included in investigator-developed measures of health-related quality of life (HRQOL) [9].

The concerns of patients with epilepsy vary according to region and country. In one Korean survey, 11.8% of participants listed driving as a main concern while 48%–60% of those with epilepsy in the United States and Australia listed driving as a concern [8,9,14]. However, to the best of

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our knowledge, very few surveys have investigated the concerns of Chinese patients with epilepsy. Thus, we aimed to investigate patient-derived quality-of-life concerns among Chinese individuals with epilepsy. Besides, one of the goals of antiepileptic treatment is to achieve seizure freedom. However, one previous study in Korea revealed that patients with controlled seizures still had many concerns regarding epilepsy [12]. We further investigated the impact of seizure freedom on patient concerns, with the goal of identifying factors that can be used to improve patient well-being and epilepsy care in China.

## 2. Materials and methods

### 2.1. Study setting and procedures

All adult patients with epilepsy treated at the epilepsy clinic of West China Hospital (a tertiary referral center in Chengdu) between July 2014 and June 2016 were invited to participate in the present study. The study was approved by the Ethics Committee of the West China Hospital of Sichuan University, and all patients provided written informed consent prior to their participation in the study.

Patients were excluded upon meeting any of the following criteria: (a) under 18 years old; (b) newly diagnosed with epilepsy; (c) severe coexisting physical or psychiatric illness such as cancer, stroke, dementia, schizophrenia, and mental retardation; and (d) fewer than 6 years of education. Eligible patients were then invited to a quiet room for an interview.

### 2.2. Sociodemographic status, clinical information, and epilepsy-related concerns

Sociodemographic data including age, gender, occupational status, personal income, educational level, marital status, and location (rural/urban) were gathered during the structured interview. Clinical information (e.g., frequency and type of seizures, age at onset, number of antiepileptic drugs (AEDs), and the length of time that patients remained seizure-free) was obtained from the medical records of each patient.

Epilepsy-related concerns were investigated using the survey methods described by Gilliam et al. [9]. Patients were given a blank sheet of paper and asked to list all concerns they had about living with epilepsy in order of importance. After finishing the survey, the concerns listed were tabulated in accordance with the EFA Concerns Index [9], which exhibits an inter-item reliability of 0.94 (Cronbach's  $\alpha$ ) and test-retest reliability of 0.85 [15,16].

Any concerns that did not align with the domains of the EFA Concerns Index were categorized as concerns unique to Chinese adults. This process was conducted by two authors (JC and XT), and ambiguous concerns were categorized based on consensus.

### 2.3. Data analysis

Sociodemographic and clinical variables were analyzed using descriptive statistics. Means and percentages were used to describe the distributions of continuous and categorical variables, respectively. Open-ended responses were grouped according to content and tabulated in accordance with the domains of the EFA Concerns Index. We first determined and ranked the frequency of the most important concerns.

Next, the sample was divided into two groups based on the frequency of seizures: seizure-free for  $\geq 1$  year (group with controlled seizures) and seizure-free for  $< 1$  year (group with uncontrolled seizures). We then compared baseline clinical and sociodemographic characteristics between the two groups. We examined the impact of seizure control on the concerns using regression models. The first model is an unadjusted model. The second model adjusted for clinical factors (seizure type, onset age, number of AEDs) and demographics factors (age, gender, marital status, living location, education, income,

employment status). Factors exhibiting significant differences between two groups, those observed to exert an impact on patient concerns in previous studies [11,12,17], and seizure frequency were entered into a multivariate analysis. In the multivariate model, patient concerns were converted into dichotomous variables (0 = not one of the patient's listed concerns, 1 = one of the patient's concerns). Demographic variables were coded as follows: gender (0 = female, 1 = male), living location (0 = rural, 1 = urban), education (1 = did not complete high school, 2 = high school graduate, 3 = college graduate), marital status (0 = single, 1 = married), monthly income (0 = less than 1500 Yuan, 1 = 1500 Yuan or greater than 1500 Yuan), age at onset (0 = below age 18, 1 = age 18 or over age 18), and seizure(s) in the last 12 months (1 = no, 0 = yes).

All statistical analyses were performed using IBM SPSS Statistics 22.0 (SPSS, Inc., Chicago, Illinois). All p values were two-sided, and the level of statistical significance was set at  $p < 0.05$ .

## 3. Results

### 3.1. Clinical and sociodemographic characteristics

From June 2014 to July 2016, a total of 1218 adults with epilepsy visited our clinic and were invited to participate in this study. Among them, 67 declined to participate. There was no significant difference in demographic or clinical features between patients who had declined and patients who had agreed to participate ( $n = 1151$ ), all of whom had received a validated diagnosis of epilepsy. Among these 1151 patients, 88 had a new diagnosis (diagnosed with epilepsy during the visit when the survey was conducted), five had cancer, four had experienced a stroke, one had dementia, and 13 had fewer than 6 years of educational experience. Following exclusion of these patients, a total of 1040 patients completed the study.

The demographic and clinical characteristics of the 1040 included patients are presented in Table 1. Among these patients, 536 (51.5%) were male while 504 (48.5%) were female. The average patient age was  $30.7 \pm 11.9$  years. The median personal income was 1500 (interquartile range: 1500–3000) Yuan per month. Among all patients, the mean age at the time of seizure onset was  $20.3 \pm 12.8$  years. Seventy patients (6.7%) experienced simple partial seizures, 296 (28.5%) experienced complex partial seizures, 648 (62.3%) experienced convulsive seizures, and 26 (2.5%) experienced other types of seizures. Seventy-two patients (6.9%) experienced seizures on a daily basis, 54 (5.2%) experienced seizures on a weekly basis, 351 (33.8%) experienced seizures on a monthly basis, 373 (35.9%) experienced seizures on a yearly basis, and 190 (18.3%) had not experienced a seizure during the past year.

### 3.2. Epilepsy-related concerns among patients with epilepsy

The 1040 patients of the present study reported 2202 epilepsy-related concerns. In our study, the most frequently listed concern was seizure recurrence (571, 55.4%) (Table 2). In particular, 145 (13.9%) patients expressed concerns about having another seizure while 431 (41.4%) patients expressed concern that their condition could not be cured. Other concerns described by at least 10% of patients included the following: holding down a job (181, 17.4%), seizures being hereditary (166, 16.0%), medication side effects (165, 15.9%), fear of getting injured during a seizure (153, 14.7%), the financial burden of epilepsy medications (145, 13.9%), and concerns about pregnancy (139, 13.4%), marriage (121, 11.6%), and leading a normal life (121, 11.6%). Concerns listed by less than 10% of patients included the following: problems thinking or remembering (69, 6.6%), not being able to do things alone (54, 4.9%), and concerns about legal rights or being allowed to drive (36, 3.5%). All 20 concerns outlined in the domains of the EFA Concerns Index were mentioned by patients of the present study. However, patients expressed five additional concerns not listed in the EFA

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