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# Development and validation of the Chinese Version of the Adult Epilepsy Self-Management Scale (C-ESMS) in Western China

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ABSTRACT

*Purpose:* To develop and validate the Epilepsy Self-Management Scale (ESMS) for Chinese persons with epilepsy (PWE).

*Methods:* On the basis of ESMS, the standard translation procedure was used to set up the Chinese version of the ESMS (C-ESMS). A consecutive cohort of PWE admitted in Sichuan Provincial People's Hospital were recruited randomly from May 2017 to December 2017 and required to complete the C-ESMS. Project analysis was employed to test the homogeneity of each dimension. Content validity was evaluated by experts. Exploratory factor analysis and confirmatory factor analysis (CFA) were applied to assess the validity. Cronbach's alpha was used to evaluate the reliability.

*Results:* Of the 400 completed C-ESMS forms, only 394 (98.5%) were suitable for analysis. The C-ESMS included 34 items and five dimensions, after removing four and modifying three items. The correlation coefficient of all 34 items was greater than 0.4. Each item level (I-CVI) and scale level CVI (S-CVI) was equal to 1. Five factors were extracted and together they explained 51.24% of the data's variance. The factor load of each item was 0.446–0.843. The CFA showed that CMIN/DF was 1.325, goodness of fit was 0.835, comparative fit index was 0.921, and root mean square error of approximation was 0.041. The total Cronbach's alpha of the scale was 0.848, and Cronbach's alpha in each dimension was 0.784–0.845.

*Conclusion:* The C-ESMS exhibited good reliability and validity for adult PWE in western China.

## 1. Introduction

Epilepsy, a common chronic disease of the nervous system, affects about 50 million people worldwide and has been listed as a key neuropsychiatric disorder by the World Health Organization (Murray et al., 2012). Good control of seizures is the main goal of epilepsy treatment (Murray et al., 2012). Patients with epilepsy (PWE) with poorly controlled seizures have high risks of comorbidity and accidental mortality; their social activities, such as, marriage, employment, and education, are considerably hampered (Capovilla et al., 2016; Chen et al., 2016; Si et al., 2016; Perzynski et al., 2017; Oh et al., 2017). To date, drug treatment is the preferred initial treatment for PWE (Murray et al., 2012). In addition, lifestyle modification, which has long been promoted by the academic community, is used as a supplementary treatment (Kotwas et al., 2016). The frequency of seizures is closely related to living habits, medical compliance, emotion, and other factors (Bradley et al., 2016; Smith et al., 2017). Self-management of epilepsy refers in a broad sense to the adaptive behavior that patients take to control or reduce seizure occurrence. Self-management covers a wide range of aspects, including drug adherence, access to disease information and feedback, personal lifestyle management (Legion, 1991), self-regulation of emotions, alcohol avoidance, reducing exposure to fluorescent stimuli, and avoidance of triggering factors, all of which ultimately improve the quality of life of PWE (Chen et al., 2016;

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Yadegary et al., 2015; Kotwas et al., 2017). Systematic and comprehensive assessment of self-management level and measures is important to the popularization and optimization of self-management strategies and clinical treatment for PWE (Legion, 1991; Helmers et al., 2017). The Epilepsy Self-Management Scale (ESMS), developed by Colleen Dilorio et al. is an accurate assessment tool in standardizing self-management strategies for PWE (DiIorio et al., 1994). The scale has been extended from the original version with 26 items to the current version with 38 items. The scale has five areas, including medication (items 4, 8, 9, 16, 21, 24, 25, 27, 28, and 30), information (items 1, 3, 5, 7, 20, 35, 37, and 38), safety (items 6, 17, 23, 26, 29, 31, 34, and 36), seizures (items 10, 11, 12, 15, 19, and 32), and lifestyle (items 2, 13, 14, 18, 22, and 33). Each item in the scale is graded on a five-point Likert scale, ranging from "1 = never" to "5 = always.". The total possible score of the ESMS ranges from 38 to 190, and a high score suggests good self-management (DiIorio et al., 1994). The English version of the ESMS has been translated into other languages and is widely used (Dehghan Nayeri et al., 2013; Hixson et al., 2015). However, no such tool about the self-management of epilepsy is available in China. Thus, the translation and application of the ESMS are important considering the heavy economic burden of epilepsy in Chinese patients (Liu et al., 2013a).

## 2. Methods

### 2.1. Participants and study areas

PWE were randomly recruited from the Epilepsy Center of Sichuan Provincial People's Hospital (a tertiary hospital in western China) from May 2017 to December 2017. The statistically required sample size was five-times the number of items (38 × 5). The inclusion criteria were as follows: (1) PWE aged between 16 and 60 years and diagnosed in accordance with the ILAE criteria; (2) PWE of Chinese Han ethnicity; (3) PWE with active epilepsy and undergoing antiepileptic drug therapy during the study period for at least one year prior to enrollment (according to the scale); and (4) PWE who provided written informed consent and understood the research protocol. Patients suffering from other serious neurological or mental diseases (such as major depression, schizophrenia, severe cognitive dysfunction and so forth) which might potentially hamper the completion of the scales were excluded. Research protocols and informed consent were approved by the local ethics committee (Sichuan Academy of Medical Science and Sichuan Provincial People's Hospital).

### 2.2. Procedures

#### 2.2.1. Translation of the ESEM

First, two native Chinese neurologists who are proficient in English independently translated the original scale into Chinese. The neurologists then discussed their outputs to reach a consensus on the first draft of the Chinese ESEM. Afterwards, the Chinese ESEM was back-translated into English by another two Chinese neurologists who are proficient in English and not familiar with the ESMS. Finally, the original English and the back-translated versions were compared by another two English-speaking neurologists to check the consistency. Twenty PWE who met the inclusion criteria were recruited randomly from outpatient clinics for the pilot language and reading tests. The Chinese ESMS (C-ESMS) was further developed during the usage process after repeated discussions and modifications.

#### 2.2.2. Collection of basic information (demographic and clinical characteristics)

Basic demographic and disease information was collected by the researchers in a face-to-face interview. The collected information included age, gender, employment status, educational level, residency, marital status, seizure onset, seizure type, seizure frequency (within the year), and antiepileptic drugs taken. The C-ESMS was independently completed by each patient in a separate quiet space after a detailed explanation of the instructions.

### 2.3. Statistical analysis

The basic demographic and disease characteristics of the study population were provided by standard descriptive statistics. All the completed scales were randomly divided into odd and even groups. The odd-numbered groups were designated for project analysis, content validation, exploratory factor analysis (EFA), and reliability testing. The even-numbered groups were designated for confirmatory factor analysis (CFA). Considering the matured dimension of this scale, project analysis was employed to test the homogeneity of each dimension. If the correlation coefficient between the item and total scores of the associated dimension is less than 0.4, then the item will be considered for deletion or modification. Content validity was evaluated by five experts from the department of neurology. For good content validity, each item level (I-CVI) should be equal to 1 and the scale level CVI (S-CVI) should be $> 0.8$. The construct validity was tested using EFA and CFA. Principal axis factoring and varimax rotation were used in EFA. A Kaiser–Meyer–Olkin (KMO) value $> 0.6$ and Bartlett sphericity test at $p < 0.01$ indicated that the data met the criteria for factor analysis. A load factor of at least 0.3 and commonalities of at least 0.2 were considered for item analysis. Eigenvalue $> 1$ and scree plot were used for calculating the component rotation. The CMIN/DF, comparative fit index (CFI), goodness of fit (GFI), and root mean square error of approximation (RMSEA) were used in CFA to compute the scale model fitness. Cronbach's alpha was used to analyze the internal reliability of the scale. An alpha value of at least 0.7 on each dimension and a total scale of at least 0.8 were considered acceptable.

## 3. Results

In this study, a total of 400 scales were collected. Six scales had identically scored items or had a completion time of less than 5 min, suggesting poor patient cooperation, and hence were excluded from this study. A total of 394 scales were used for analysis.

### 3.1. Demographic and clinical characteristics

The baseline information of 394 PWE is shown in Table 1. A total of 209 participants were male, 111 participants received education at or below middle school, 76.7% lived in urban areas, 48.4% were married, 39.8% had seizure frequency between once a year and once a month, and 59.1% were currently on monotherapy.

### 3.2. Project analysis

Project analysis was conducted in the odd group. The correlation coefficient between the item score and the corresponding total score of each dimension was calculated in the five dimensions separately. The correlation coefficient of all items was greater than 0.4, except for items 26, 35, and 37. The correlation coefficient of item 26 from the safety management dimension was 0.32 ($p < 0.01$). For items 35 and 37 from the information management dimension, the correlation coefficients were 0.19 and 0.35 ($p < 0.01$), respectively.

### 3.3. Validity

#### 3.3.1. Content validity

An item-level CVI (I-CVI) = 1 and a scale-level content-validity index (S-CVI) = 1 indicated that the scale had good content validity.

#### 3.3.2. EFA

After the removal of items 26, 35, and 37, the KMO test and