Epilepsy & Behavior 64 (2016) 224–232

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Social support for people with epilepsy in China

Xin Tong [a,1], Jiani Chen [a,1], Sung-Pa Park [c], Xi Wang [b], Chiyi Wang [b], Minglian Su [b], Dong Zhou [a,*]

[a] *Department of Neurology, West China Hospital, Sichuan University, Chengdu, Sichuan, PR China*
[b] *West China School of Medicine, Sichuan University, Chengdu, Sichuan, PR China*
[c] *Department of Neurology, School of Medicine, Kyungpook National University, Daegu, Republic of Korea*

ARTICLE INFO

Article history:
Received 26 March 2016
Revised 8 August 2016
Accepted 9 August 2016
Available online 17 October 2016

Keywords:
Epilepsy
Social support
Onset age
Depression
China

ABSTRACT

The aim of this study was to better understand social support in adult people with epilepsy (PWE) in China and to explore the factors related to weaker or stronger social support in PWE when compared with a group of matching healthy controls. Consecutively, we recruited PWE from the epilepsy outpatient clinic of the West China Hospital and healthy controls from nearby urban and rural areas. People with epilepsy and healthy controls were gender- and age-matched. Each participant was interviewed and completed the following instruments: the Social Support Rating Scale (SSRS) and the Hospital Anxiety and Depression Scale (HADS). In addition, we measured quality of life (QoL) in PWE using the Quality of Life in Epilepsy Inventory (QOLIE-31). We compared the SSRS scores between PWE and healthy controls and searched for relevant factors using correlation and regression analyses. The results showed that PWE scored lower on the SSRS than healthy controls. For PWE, early onset and depression were related to weaker social support. In healthy controls, being married and being psychiatrically healthy (i.e., scored lower on the HADS) were related to stronger support. Family members, especially parents and spouses, were the most powerful supporters for PWE and healthy people, but PWE relied on their families to a greater extent. Early intervention and psychiatric treatment are important to address and improve social support for PWE.

1. Introduction

Dealing with epilepsy, just like other chronic conditions [1], often means changing one's lifestyle rather than simply controlling seizures [2]. This new lifestyle can include a variety of adjustments, management skills, and practices [3–5], impacting not only people with epilepsy (PWE) themselves but also the environments in which they live, especially their families [6].

Epilepsy is often a socially underappreciated health problem in Asia [7,8]. As for China, misconceptions and negative attitudes toward epilepsy are often held by many Chinese people, either domestically [9] or overseas [10]. Such situations are even worse for people from rural areas with a lower educational and socioeconomic status [9,11]. When it comes to life satisfaction, compromised social interaction is one of the most common complaints of PWE [12]. It has also been revealed that PWE were more likely to experience frustration in social interactions; therefore, the social factor should be considered more when it comes to life satisfaction and quality of life (QoL) in PWE [12].

Among all of the social factors, social support is a key mechanism in chronic condition management [13,14] and plays a significant role in the management of epilepsy. Cohen defined social support as "a social network's provision of psychological and material resources intended to benefit an individual's ability to cope with stress" [15]. Thoits identified perceived support availability as one of the seven possible mechanisms through which social relationships and social support can improve a person's physical and psychological wellbeing [16].

The importance of social support for PWE has been increasingly recognized in recent research. Social support influences self-management in PWE and improves their QoL by providing informational, instrumental, and emotional resources [17,18]. A few studies have focused on the kind and level of support PWE actually receive and the relationship between social support and self-management [18,19]. In China, there have been analogous studies as well. They mostly emphasized the relationship between marriage and social support [5,20] and found that, in China, PWE encountered more marital discord that was associated with poor social support. What is known about the social support in Chinese PWE is far from sufficient. Perhaps this is because the health burden of China is extremely heavy with a population as large as 1.36 billion [21] and with 4.6/1000 of the people having active epilepsy [22]. The aim of this study was to better understand social support and to explore the relevant factors associated with social support in adult PWE in China.

---

[*] Corresponding author at: Department of Neurology, West China Hospital, Sichuan University, No. 37 Guoxue Road, Chengdu, Sichuan 610041, PR China.
E-mail address: zhoudong66@yahoo.de (D. Zhou).

[1] These two authors contributed equally to this work.

http://dx.doi.org/10.1016/j.yebeh.2016.08.010
1525-5050/

2. Methods

2.1. Participants

From October 2014 to February 2015, we consecutively recruited 296 PWE from the epilepsy outpatient clinic of the West China Hospital, a large tertiary care hospital in Chengdu City, West China. A total of 271 healthy controls were recruited in urban neighborhoods around the hospital and a rural community near the city of Chengdu. All of the controls volunteered after seeing our recruitment poster. According to medical history checks (i.e., reports from the subjects themselves and their relatives and available hospital documents), healthy controls had never experienced any epileptic seizures or seizures due to an acute health condition (e.g., fever or encephalitis). Each PWE was matched with a control according to gender and age (±2 years). If a subject had multiple suitable matches in the other group, the matching pair was decided randomly. Participants who did not have suitable matches were excluded from the data analysis.

To ensure valid communication, each participant was required to be an adult (18 years or older) who had completed at least primary education. Exclusion criteria for both groups included any known conditions that might significantly affect their social and mental status or hamper the appropriate understanding and completion of the interview. Such conditions included stroke, cancer, physical disability, and serious neurological/psychiatric disorders (e.g., cognitive deficits or schizophrenia). These exclusion conditions were determined by medical history checks (including self-reported and available hospital-recorded medical histories) and brief physical examinations.

2.2. Study design

The protocol and informed consent of this study were approved by the Ethics Committee of West China Hospital, Sichuan University. Every participant was fully informed of the study's purpose and content; afterwards, each participant provided a written informed consent stating his/her willingness to participate. Epilepsy diagnoses were made according to the International League Against Epilepsy (ILAE) criteria [23] by qualified neurologists. To confirm the diagnosis, all of the PWE underwent EEG tests, and four-fifths of them underwent brain MRI scans, as well. The controls did not undergo these tests, and the diagnosis of nonepilepsy was established by medical history checks.

All of the participants had face-to-face interviews with trained neurologists. During the interview, demographic, socioeconomic, and clinical (related to epilepsy) information was collected for PWE. For healthy controls, only demographic and socioeconomic information was collected. The demographic variables included gender, age, domicile (urban versus rural), and education (in years). The socioeconomic variables included employment status (employed versus unemployed), family income (Chinese yuan/month), and marital status (married versus not married). Since only four participants were divorced, they were classified as not married. The clinical variables included onset age, duration of epilepsy (in years), seizure type (partial versus generalized), etiology (idiopathic versus cryptogenic or symptomatic), seizure frequency (daily, weekly, monthly, yearly, or no seizure in the last year), antiepileptic drug (AED) therapy regimen (none, monotherapy, or polytherapy [i.e., ≥2 AEDs]), and duration of AED intake (in years). After this information was collected, both groups were asked to describe their general feelings about their social environment, as well as whom the most important supporters were in their daily lives. Lastly, eligible PWE completed three questionnaires: the Social Support Rating Scale (SSRS), the Hospital Anxiety and Depression Scale (HADS), and the Quality of Life in Epilepsy Inventory (QOLIE-31). Meanwhile, the controls completed only the first two questionnaires because the QOLIE-31 was specially designed for PWE. The questionnaires were completed in a separate room with interviewers absent. If the participants needed instructions, they could ask the interviewers next door. Only the technical questions related to answering methods could be answered, and the reviewers were forbidden to give personal opinions. For example, in one section of the SSRS, interviewees were asked to rate the degree of support they received from different family members including spouse, parents, offspring, and brothers or sisters. The participants without children might ask which option they should take under the column of offspring. Then, the reviewers would tell them to take the first option, i.e., "no support".

2.3. Questionnaires

2.3.1. The Social Support Rating Scale (SSRS)

Originally developed in Chinese by Xiao, the SSRS is a self-rated scale, with a good 2-month test–retest reliability of 0.92 [24]. It has already been widely used in different Chinese communities and shown to be valid and reliable [25–27]. It contains 10 items and evaluates social support in the following three domains: objective support (three items), subjective support (four items), and support usage (three items). Objective support reflects the degree of actual support received in the past. Subjective support reflects the perceived interpersonal network that an individual can count on. Support usage refers to the pattern of behavior that an individual utilizes when seeking social support [27]. The total score of the SSRS ranges from 12 to 66, with an objective support domain ranging from 1 to 22, a subjective support domain ranging from 8 to 32, and a support usage domain ranging from 3 to 12. Higher scores indicate stronger social support.

2.3.2. The Hospital Anxiety and Depression Scale (HADS)

The HADS is a self-rated scale and consists of 14 items, in which seven items are for anxiety (HADS-A) and seven items are for depression (HADS-D), with a 4-point scale (ranging from 0 = not at all to 3 = very much indeed). Both the HADS-A and HADS-D scores range from 0 to 21. It is a reliable instrument for detecting states of depression and anxiety in general hospitals, and it is also a valid measure of the severity of emotional disorder [28]. For the diagnosis of current major depression disorder in PWE, the HADS-D (≥8) had a specificity of 80.2% and a sensitivity of 85.7%. To identify DSM-IV-defined anxiety disorders among PWE, the HADS-A (≥ 8) showed a specificity of 75%, while its sensitivity of 61% was relatively poor [29]. The validity of the HADS has been established in the Chinese population [30]. A cutoff subscale score of eight (≥8) was used in this study to index clinically significant anxiety or depression for both PWE and healthy controls.

2.3.3. The Quality of Life in Epilepsy Inventory (QOLIE-31)

Developed to assess QoL in PWE, the QOLIE-31 comprises seven subscales covering general and epilepsy-specific domains [31]. It has been translated into multiple languages and used worldwide. The Chinese version of the QOLIE-31 has been previously established and shown to have satisfactory reliability and validity. For each subscale, the 3-month test–retest reliability (Pearson's correlation coefficient) ranged from 0.725 to 0.912 ($P < 0.001$), and the Cronbach's alpha coefficient ranged from 0.627 to 0.898. The alpha between the subscales was 0.912 [32]. Because this instrument is specially designed for PWE, healthy controls did not undergo this part in our study.

2.4. Statistical analysis

First, descriptive statistics were conducted for the demographic and socioeconomic characteristics of both groups and the clinical characteristics of PWE. Quantitative data were expressed as the mean ± standard deviation (SD), and qualitative data were summarized as proportions. Second, we compared PWE and healthy controls on demographic and socioeconomic factors and on the scale scores of the HADS and the SSRS. Because the control group lacked clinical features and the QOLIE-31 score, the comparisons of those aspects were not included. Paired-sample *t*-tests or Wilcoxon tests were used for the continuous