



Illness perception in Chinese adults with epilepsy



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ARTICLE INFO

Article history:

Received 14 June 2016

Received in revised form 10 October 2016

Accepted 25 October 2016

Available online 31 October 2016

Keywords:

Illness perception

Epilepsy

Social support

Coping style

ABSTRACT

Background: Epilepsy is among the most common neurological disorders worldwide. Understanding the patient's subjective experience plays an important role in the treatment and rehabilitation of the patient. However, few studies are concerned about the illness perception of Chinese adults with epilepsy.

Methods: 117 Chinese adults with epilepsy and 87 Chinese adults with chronic liver disease completed the Chinese version of the Revised Illness Perception Questionnaire (CIPQ-R). The Chinese epilepsy patients also completed the Social Support Rating Scale (SSRS) and Simplified Coping Style Questionnaire (SCSQ). A comparison about CIPQ-R score between the epilepsy group and chronic liver group was conducted using the independent sample *t* test. Partial correlation coefficients were calculated among the eight subscales of the CIPQ-R and its associated factors.

Results: Results for the CIPQ-R indicated that both the epilepsy patients and the chronic liver disease patients had a moderate belief in their personal control and treatment control over their disorder. Consistent with our hypothesis, patients with epilepsy and those with chronic liver disease perceived their respective disease similarly in terms of timeline and illness coherence. However, epilepsy patients had a higher negative emotional representations level than that we expected when compared to those of the patients suffering from chronic liver disease. Partial correlation analysis in Chinese epilepsy patients showed that the timeline acute/chronic dimension and emotional representations dimension were closely related to the other dimensions of illness perception. Moreover, the illness perception of the patients was significantly associated with social support, coping style, duration of epilepsy, seizure frequency, and the number of antiepileptic drugs.

Conclusion: Chinese patients with epilepsy had limited understanding of the illness, and poor belief in personal control and treatment control. They had a negative emotional response to their illness, and feared of the effects on the patient or patient's family. Social support, coping style, duration of epilepsy, seizure frequency, and the number of antiepileptic drugs could affect the illness perception of these patients. Further studies should focus on how to improve patients' attitudes towards their disease.

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1. Introduction

Epilepsy is one of the most common neurological disorders in the world, and about 90 percent of these patients live in developing countries (Ngugi et al., 2010). The prevalence of epilepsy in China,

the largest developing country, is 5.0 per 1000 people (Chang and Wang, 2012). Epilepsy is a chronic disease that causes bodily harm to patients and results in a significant burden to their families and society (Beghi, 2016; Keezer et al., 2016). The primary treatment for epilepsy is still the long-term administration of antiepileptic drugs (Gurumurthy et al., 2016). Fortunately, about 70% of patients have their seizures controlled with drugs, but the remainder continues to have seizures and their physical health, quality of life, and mental health are suffering from negative effects (Elger and Schmidt, 2008). Since the introduction of Engel's Biopsychosocial Model, the emotions, cognition, and behaviors are increasingly accepted as important factors related to health (Alonso, 2004). Understanding

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the patient's subjective experience plays an important role in the treatment and rehabilitation of disease (Borrell-Carrio et al., 2004).

The self-regulatory model (SRM) (Leventhal et al., 1992) posits that a causal relationship exists between illness-related behaviors and their cognitive and emotional representations of illness. Beliefs about illness, or illness perceptions, are central to the SRM, and these illness representations are derived from a variety of sources, including patients' social circles, their subjective experience of the illness, views on the illness presented in the media, and cultural and folk beliefs (Hagger and Orbell, 2003; Vollmann et al., 2010). The SRM also indicates that illness perceptions are represented in five key dimensions (Leventhal et al., 1992): (1) causal—causal factors of the illness, (2) identity—the illness's label and symptoms, (3) timeline—chronic or acute, or cyclical in nature, (4) cure/control—the feasibility of the control or cure of the illness, and (5) consequences—possible outcomes of the illness on an individual's life. The Illness Perception Questionnaire (IPQ) (Weinman et al., 1996) was developed as a quantitative measure of the five dimensions of the SRM.

Despite the usefulness and wide application of the IPQ, a revised version of the questionnaire was constructed after only a few years: the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002). In the IPQ-R, some dimensions were restructured and new dimensions were added. The timeline dimension was separated into acute/chronic and cyclical dimensions, and control was divided into the personal control and treatment control dimensions. In addition, two new dimensions, the emotional representations (one's emotional response to the illness) and illness coherence (the sense of having a comprehensive understanding of the illness), were introduced (Moss-Morris et al., 2002). The nine subscales (identity, timeline acute/chronic, timeline cyclical, personal control, treatment control, illness coherence, consequences, emotional representations, and causes) comprise the Revised Illness Perception Questionnaire (IPQ-R).

The IPQ and IPQ-R have been used extensively in studies on physical health and shown to be valid and reliable measures of patients' illness representations (Moss-Morris et al., 2002); they have also been found to be widely applicable in research on patients with various diseases, such as diabetes mellitus, coronary heart disease, and systemic lupus erythematosus (Abubakari et al., 2012; Barbasio et al., 2015; Mosleh and Almalik, 2014). Numerous studies have indicated that significant correlations between treatment, rehabilitation, quality of life, and illness perception (Have et al., 2013; Lo et al., 2016; Natalie et al., 2014; Velez-Velez and Bosch, 2016). For instance, Velez-Velez investigated the relationship between adherence and illness perceptions in patients with chronic kidney disease and highlighted the importance of patients' personal control to improve their adherence to treatment (Velez-Velez and Bosch, 2016).

Despite the evidence that patients' illness perceptions can influence treatment efficacy and recovery from the disease, little is known about Chinese patients' illness perceptions of epilepsy. Some studies came from Europe have showed that patients with epilepsy had formed a cognitive model of their disease, viewed the illness as a serious condition, had a poor belief in disease control (Goldstein et al., 2005; Whitehead et al., 2013). And the illness perception in epilepsy will affect the patient's quality of life (Shallcross et al., 2015). But previous studies have only studied the illness perception of the disease without disease control group (Goldstein et al., 2005; Shallcross et al., 2015), or compared illness perception between epilepsy patients and neurologists (Whitehead et al., 2013), or studied the differences in illness perceptions between patients with non-epileptic seizures and functional limb weakness (Ludwig et al., 2015). At the same time, the research samples are all taken from the European. So far, there is no report about Asian people's illness perception in epilepsy. So the primary objec-

tive of our study was to investigate the cognitive representation of illness in Chinese patients with epilepsy and compare it with the patients who suffer from chronic liver disease, in order to learn about the perceptions of these epilepsy patients. The results of our study illuminated the illness perceptions of these patients and their relationship with the illness's dimensions. Patients with chronic liver disease were recruited for comparison because they share similar chronic disease patterns to those who suffer from epilepsy (Erlangsen et al., 2015; Sleeth et al., 2016; Yang et al., 2016). However, chronic liver disease is a much greater threat to life than epilepsy. The comparison of the illness perceptions between patients with epilepsy and those with chronic liver disease allows us to clearly evaluate the differences in illness perceptions between the two patient groups. We expect that epilepsy patients and chronic liver disease patients would not differ in the timeline acute/chronic and timeline cyclical dimensions because both illnesses are chronic and require a longer timeline of treatment. Due to the life-threatening nature of their disease, chronic liver disease patients may experience greater consequences and emotional representations and have lower perceived control over their illness than epilepsy patients do.

The second objective of this study was to investigate a potential association between the social support, coping style, clinical characteristics, and illness perception in Chinese patients. Before our research, some studies have proved that social support is believed to influence the patient's illness perception (Graça et al., 2016; Grewal et al., 2010; Hoseini et al., 2016). Some researches reported that people with lower levels of social support were less likely to believe they have personal control over their illness (Grewal et al., 2010). Hoseini et al. further evidenced that social support had direct effects on illness perception (Hoseini et al., 2016). Similarly, illness perception and coping styles were also found to be related to each other (Baiardini et al., 2012; Lin et al., 2013a; Rexhaj et al., 2012). A previous study has found that changing patient's illness representations can be an approach to improve coping behavior (Lin et al., 2013a). Baiardini and his partner also showed that one person would have a good use of coping strategies if he reached well-being in illness perception (Baiardini et al., 2012). Therefore, if we can understand the relationship between the illness perception, social support, and coping style, then application in disease management, the improvement of well-being and minimize suffering may be expected. The other objective of our current study is to identify a potential association among coping style, illness perceptions and social support in epilepsy patients. Our study offers some preliminary data on this relationship and provides a more balanced and comprehensive understanding of the role of illness perception in the adjustment of patients to epilepsy.

2. Methodology

2.1. Participants

The sample consisted of 117 Chinese epilepsy patients, 56 males and 61 females, by convenient sampling from the epilepsy neurology clinic of the First Affiliated Hospital of Anhui Medical University, Anhui, China. To be included, patients from the outpatient department had to meet the following criteria: (a) were age 18 or older; (b) obtained a diagnosis of epilepsy made by neurologists according to the criteria of the 2001 International Classification of Epilepsies and Epileptic Syndromes (ILAE) (Engel, 2001); (c) had no history of cranial trauma and craniotomy; (d) had no other demonstrable disease (e.g., kidney disease, tumors, or heart disease); (e) had no history of psychiatric disorders (e.g., schizophrenia); and (f) had the ability to read and understand the questions. The study was approved by the local Ethics Committee of the First Affiliated Hos-

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