



Self-reported adherence in patients with epilepsy who missed their medications and reasons for nonadherence in China

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ABSTRACT

Objectives: The objectives of this study were: (1) to evaluate self-reported adherence in adult patients with epilepsy in China who had missed taking their antiepileptic drugs (AEDs) at least once and (2) to determine why patients were not adherent to their medication to employ interventions targeted at barriers to adherence. **Methods:** A questionnaire was used to collect the patients' demographic data, disease information, and reasons for why the patients did not take their AEDs. Adherence was also included as measured using a four-item Morisky questionnaire (Morisky-4 questionnaire).

Results: Of the 131 patients, 4.6%, 70.2%, and 25.2% showed high, medium, and low adherence, respectively. The reasons for nonadherence included forgetfulness (54.2%), being seizure-free for a period (48.9%), and fear of adverse drug effects (27.5%).

Conclusions: Medium adherence was the predominant nonadherence pattern, and forgetfulness, being seizure-free for a period, and fear of adverse effects were the primary reasons for nonadherence to AEDs. To overcome barriers to nonadherence, it is essential to use tools that are sensitive to reasons for nonadherence.

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1. Introduction

Epilepsy is one of the most common neurological disorders worldwide, and the majority of people with epilepsy who live in developed countries manage their condition with anti-seizure medication [1]. For those patients who are treated, antiepileptic drugs (AEDs) are the mainstay of treatment [2]; however, many patients are unsuccessful at treating epilepsy with AEDs. Poor adherence to prescribed medication is considered to be the main cause of unsuccessful drug treatment for epilepsy [3,4]. Adherence to AEDs in patients with epilepsy is low and generally ranges from 20% to 80% [4], with nonadherence ranging between 30% and 50% [5]. Antiepileptic drugs nonadherence has been associated with increased resource utilization and costs [6,7]. Thus, nonadherence to AEDs is a critical problem that should be taken seriously, particularly in developing countries such as China, where the number of patients with epilepsy was 9 million in 2007 [8]. In developing countries, few patients with epilepsy receive adequate medical treatment. An estimated 75% to 90% receive no treatment at all; thus, epilepsy treatment in developing countries remains far

from satisfactory [4,9], and adherence is an important problem to be solved.

Several measurements and interventions have been developed to assess and improve adherence. Although adherence in chronic and acute diseases has been reported in many studies [4,7,10–14], little is known regarding the extent of nonadherence [15] and even less is known in the Chinese population. Information about why patients are not taking their prescribed medications is important in designing appropriate interventions. Patient self-reports can simply and effectively measure adherence [10]. Self-report is considered to be the most appropriate method to use to monitor adherence and can distinguish between intentional nonadherence and unintentional nonadherence, which exhibit different underlying causes and may thus require different interventions [16]. Distinguishing between intentional and unintentional nonadherence may help to understand nonadherence so that effective interventions may be developed [17].

Thus, it is important to assess the extent of nonadherence and its underlying causes. To achieve this goal and to provide additional information on adherence in the Chinese population, we surveyed adult patients with epilepsy in China who had missed taking their AEDs at least once to examine the extent and reasons for nonadherence using the four-item Morisky questionnaire (Morisky-4 questionnaire).

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2. Methods

2.1. Participants

Patients were recruited from HuaShan Hospital of Fudan University in Shanghai, China. This study was approved by the Research Ethics Committee of HuaShan Hospital. To achieve our research goal, we selected patients who: (1) were diagnosed with epilepsy, (2) were older than 16 years of age, (3) took AEDs for more than 6 months, (4) had missed taking their AEDs at least once, (5) could complete the questionnaire by himself/herself or understand it after having it explained by others, and (6) visited the outpatient clinic at the Hospital of HuaShan.

The exclusion criteria included: (1) treatment with traditional Chinese medicine (TCM), (2) communication language barriers, and (3) cognitive impairment that caused difficulty in understanding or communicating with the investigators.

In this study, 134 adult patients with epilepsy were eligible on the basis of these criteria, with 3 patients refusing to answer the questionnaire. Thus, a total of 131 questionnaires were obtained.

2.2. Questionnaire

Information was collected using the questionnaire, including the patients' demographic data, disease characteristics, self-reported adherence, and reasons for why the patients had missed taking their AEDs.

Multiple reasons for nonadherence in the questionnaire included: forgetfulness, fear of adverse drug effects, being seizure-free for a period, discomfort after taking the AEDs, belief that the AEDs were ineffective, belief that it's unnecessary to take AEDs, no access to refill medications at nearby hospitals, used-up AEDs, and "others." The term "used-up AEDs" meant that the patients had run out of their AEDs and did not refill their medication despite being able to do so.

2.3. Self-reported adherence

Self-reported adherence was measured by the Morisky-4 questionnaire, which was developed by Donald E. Morisky et al. in 1986. It is the most widely used multi-item questionnaire to measure self-reported adherence. The questionnaire's validity has been previously demonstrated [18,19], and the questionnaire correlates well with the clinical outcomes in various chronically ill populations [15]. All of the items were translated into Chinese and were answered by a "yes" or a "no" response for each item as in the original scale. A lack of a "yes" response represented high adherence, 1–2 "yes" responses represented medium adherence, and 3–4 "yes" responses represented low adherence.

2.4. Statistical analyses

All of the data were analyzed using the IBM SPSS Statistics 19 software program. Descriptive analyses and graphs were used to describe the demographic data, disease characteristics, self-reported adherence, and nonadherence reasons of the patients.

Chi-square tests ($p < 0.05$) were used to assess the differences between categories of gender, age, education, working status, type of seizure, and frequency of seizure.

3. Results

The demographic and disease characteristics of the 131 subjects (age 16–77 years) are summarized in Table 1.

Table 1
Demographic and disease characteristics (n = 131).

Characteristic	Number
Male	72 (55.0%)
Age, mean (SD)	31.2 (12.6)
Education	
Primary school	14 (10.7%)
Junior school	43 (32.8%)
High school	42 (32.1%)
Graduate	32 (24.5%)
Working status	
Student	23 (17.6%)
Full-time employed	57 (43.5%)
Part-time employed	1 (0.8%)
Unemployed	41 (31.3%)
Retired	6 (4.6%)
Housewife	3 (2.3%)
Type of seizure	
Partial seizures	82 (62.6%)
Generalized seizures	49 (37.4%)
Frequency of seizures	
Yearly	73 (55.7%)
Monthly	41 (31.3%)
Weekly	17 (13.0%)

3.1. Patients' self-reported adherence

Adherence, as measured by the Morisky-4 questionnaire, was classified into high, medium, or low levels. Of the 131 nonadherent patients with epilepsy, there were 6 patients with high (4.6%), 92 patients with medium (70.2%), and 33 patients with low (25.2%) adherence. The number and rate of "yes" responses to each item were the following: "Do you ever forget to take your medicine?", 98 (39.7%) patients; "Are you careless at times about taking your medicine?", 34 (13.8%) patients; "When you feel better do you sometimes stop taking your medicine?", 75 (30.4%) patients; and "Sometimes if you feel worse when you take the medicine, do you stop taking it?", 40 (16.2%) patients.

Because there were more than 2 groups in each category, several of the groups had been combined. The "high" adherence group was combined with the "medium" adherence group because it was lower than 5 after being divided into several categories. Importantly, the "high" adherence group was not truly high because some of the patients had missed their medications due to the AEDs being "used up." There were no differences found between all of the categories. Further details are shown in Table 2.

3.2. Reasons for nonadherence

When the patients were asked why they had missed their AEDs, the primary reason reported in the questionnaire was forgetfulness (54.2%) followed by being seizure-free for a period (48.9%) and fear of adverse drug effects (27.5%). The responses for all of the reasons collected in the study are presented in Fig. 1.

Because the additional reasons for nonadherence reported by the patients were different from each other, it was difficult to classify the reasons into separated categories. In addition, some reasons that had been reported by a few patients could not be classified into a category. Thus, these reasons were combined into the category of "others."

The reasons for nonadherence that were reported by the patients for the category "others" (30, 22.9%) included: the use of several new antiepileptic drugs was too expensive (4, 13.3%); stress over the effects of the antiepileptic drugs on marriage or fertility (4, 13.3%); unawareness of taking the medications (3, 10.0%); misunderstandings about the disease (3, 10.0%), such as the needlessness of taking antiepileptic drugs after an operation and the idea that the patient had believed that they were cured; the patient would commonly

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