



## Internet usage for health information by patients with epilepsy in China



Jianming Liu<sup>a</sup>, Zhiliang Liu<sup>a,\*</sup>, Zhong Zhang<sup>b</sup>, Sheng Dong<sup>c</sup>, Zhe Zhen<sup>d</sup>,  
Li Man<sup>a</sup>, Ruxiang Xu<sup>a</sup>

<sup>a</sup> Bayi Brain Hospital, The Military General Hospital of Beijing People's Liberation Army, No. 5, Nan Men Cang, Beijing 100700, China

<sup>b</sup> Department of Neurosurgery, Inner Mongolia People's Hospital, Mongolia, China

<sup>c</sup> Department of Functional Neurosurgery, Xuan Wu Hospital, Beijing, China

<sup>d</sup> Department of Neurosurgery, Second Affiliated Hospital, School of Medicine, Zhejiang University, Zhejiang, China

### ARTICLE INFO

#### Article history:

Received 21 April 2013

Received in revised form 14 June 2013

Accepted 15 June 2013

#### Keywords:

Epilepsy

Self-management

Internet

Health information

### ABSTRACT

**Purpose:** Most patients with epilepsy report a desire for more information on the disease and possible treatments than provided by clinicians. In the past two decades, many have turned to the internet for information, but this information is of variable accuracy and objectivity. We assessed the prevalence of internet use for gathering information about epilepsy and patient satisfaction in a sample of epilepsy patients in China.

**Methods:** A cross-sectional multicenter study was conducted using a standard anonymous questionnaire that gathered demographic information and information on internet use. The reasons for using the internet, the sites visited, general satisfaction with the information provided, and impact on self-management were investigated.

**Results:** Of the 780 patients studied, 288 (36.9%) had internet access and 73% of these participants reported searching for general information on epilepsy, 64% for treatment information, 30% to prepare for actual hospital visits, 12% to communicate with other patients, 5% for purchasing products for epilepsy management, and 6% for other reasons. All of the participants used search engines. However, only 6% browsed websites recommended by their doctors and 96.8% thought the information gathered from other sites was inadequate.

**Conclusion:** The internet holds great potential for informing epileptic patients about their disease and to seek social support. Governments, hospitals, doctors, and internet service providers must collaborate to ensure that this information is reliable and beneficial.

© 2013 British Epilepsy Association. Published by Elsevier Ltd. All rights reserved.

## 1. Introduction

Epilepsy is a neurological disorder afflicting people of all ages and socioeconomic classes. The worldwide prevalence is estimated at 50 million,<sup>1</sup> of which 85% live in developing countries.<sup>2</sup> There are currently about 9 million people with epilepsy in China, 6 million with active epilepsy, and 0.4 million new cases reported each year.<sup>3,4</sup>

In chronic diseases such as epilepsy, information and counseling are essential for self-management,<sup>5</sup> which may enhance quality of life and possibly reduce disease-related morbidity and mortality.<sup>6,7</sup> According to Dilorio, people with epilepsy are faced with management issues in five broad areas: medication, coping with seizures, safety, information/support,

and lifestyle issues.<sup>8</sup> However, clinicians in tertiary centers and epilepsy clinics have a limited capacity to provide sufficient information and counseling due to time constraints and other barriers,<sup>9,10</sup> leading patients to rely on other, possibly less reliable, information sources.<sup>11–13</sup>

Health literacy is a barrier to optimal health communication.<sup>14</sup> In response to the need for theory-based self-management programs easily accessible by patients, the WebEase web site was created and tested for feasibility, acceptability, and usability. It plays an important role in eliminating barriers to information access. Patients with epilepsy and their families are increasingly turning to the internet for answers on all aspects of living with epilepsy. In developed countries, the internet has become an important source of information for patient self-management.<sup>15–17</sup> In developing countries like China, however, internet penetration is low. We wanted to know if and how the internet is used by Chinese epilepsy patients, but no such studies have been reported. We conducted a cross-sectional multicenter survey to examine

\* Corresponding author. Tel.: +86 15810294115.

E-mail address: [sxljm10282@163.com](mailto:sxljm10282@163.com) (Z. Liu).

internet access, what types of information are accessed, and patient satisfaction.

## 2. Methods

### 2.1. Study design and patient sample

This cross-sectional study was conducted at four centers: Military General Hospital of Beijing People's Liberation Army, Inner Mongolia People's Hospital, Beijing Xuan Wu Hospital, and Second Affiliated Hospital, School of Medicine, Zhejiang University. This study included all willing participants (a convenience sample) diagnosed at these centers from October 2009 to January 2012. For this study, we focused on the influence of the internet on self-management, so the patients' family members were included in the survey. In our result we defined participant as the patient and their family members.

### 2.2. Internet use survey

We used an anonymous questionnaire designed to assess the reasons for using the internet to acquire information on epilepsy and patient satisfaction with the information provided. The participants were asked to complete the questionnaire in pencil. No compensation was provided to respondents. The survey included sections on demographics, such as age, sex, and access to the internet, as well as items on epilepsy characteristics including age at diagnosis and disease duration. Participants who had used the internet to search for information on epilepsy were asked to indicate how they find epilepsy-related information and which epilepsy-related websites they had visited. In this survey, we divided participants into urban dwellers and rural dwellers as this may have a significant influence on internet access. The urban dwellers were defined as those participants living in a town or city for more than 3 years. All others were defined as rural dwellers.

### 2.3. Statistical analysis

The completed questionnaires were entered into SPSS Version 13 for analysis. Descriptive statistics, primarily frequencies, and percentages were calculated.

## 3. Results

Patients for this study were selected by convenience sampling. Of the 904 patients with epilepsy invited to participate, 124 refused and 780 agreed (59% male), for a response rate of 86.3%. Patients came from all the provinces of mainland China. Mean age ( $\pm$ SD) was 35.3 ( $\pm$ 11.7) years (range, 2 years to 75 years), age at onset ranged from the first month of life to 70 years (mean, 15.1  $\pm$  10.7 years) and mean duration was 8.8 years.

In total, 288 of all the 780 participants (36.9%) had internet access, of which 263 (91.3%) had access to the internet at home and (or) on a mobile phone and 25 (8.7%) had regular access at a location outside their home. The majority of those with internet access (242/288, 84.2%) had searched for information on epilepsy and 18 (6.3%) began to search for information before diagnosis. Of the total sample, however, only 31% (242/780) had ever used the internet to access information on epilepsy.

A slim majority of patients (56.9%) were residing in rural locations, and so may be less likely to have internet access. We therefore examined these two subpopulations separately. Only 83 of 444 rural dwellers (18.6%) had internet access compared to 55.3% of urban dwellers. For rural dwells with access, however, 83.6% (70 of 83) had searched for information on epilepsy, comparable to the 85.3% of urban dwellers. Thus, lack of internet

access is a major barrier regardless of region. Moreover, internet use by rural dwells appears to be limited only by access.

We also probed the reasons for not searching for information about epilepsy on the internet. The most common reasons reported were (1) do not know how to access or find information on the internet (83.2%), (2) do not trust the internet (8.9%), (3) no access to the internet 3.7%, and (4) other reasons 4.2%.

Participants who used the internet to find information on epilepsy were asked to describe what types of information they sought. The major reasons were to find (1) general information on etiological factors for different types of epilepsy and the role of heredity (73%), (2) treatment information (64%), (3) supplementary information for hospital visits such as online registration and information from visiting experts (30%), (4) other patients (12%), (5) sources to buy antiepileptic drugs or other epilepsy-related products (5%), and (6) information on social support, living with epilepsy, women's health, and so on (6%).

All of the participants (288) who had searched for epilepsy-related information on the internet used search engines such as <http://www.baidu.com> or <http://www.google.com>. The most common search words were "epilepsy", "treatment", "new progress", and "traditional Chinese drug". Only 6% browsed websites recommended by doctors.

Most of the participants just wanted information on epilepsy, and the vast majority of the 288 participants who searched for information on epilepsy (96.8%) reported that the information was inadequate. A significant minority, 71 of 288 participants (24.7%), purchased drugs or received treatment through the internet, and 19 had received alternative treatment after they followed advertised links on a website or communication group.

## 4. Conclusion

This is the first study to explore how epilepsy patients in China use the internet to acquire information on the disease and potential treatments. While physicians may do their best to care for and treat patients, there is limited time for patient education. In the clinical setting, 90% of patients surveyed indicated that they wanted more information about epilepsy<sup>18</sup> but often felt embarrassed to ask their busy healthcare provider. Therefore, epilepsy patients are often in need of more information and counseling,<sup>7,10,19</sup> two key components for successful self-management.<sup>7</sup>

One approach that has gained support in recent years is the delivery of health information through internet sites. The advantage of the internet is that it offers a convenient, widely accessible source of disease management and health education tools.<sup>20</sup> Another advantage is the privacy of a computer desktop, allowing a safe, confidential way to get answers to many difficult questions. Many patients also want to connect with other epilepsy patients because many have mobility issues, such as an inability to drive, and feel isolated from others.<sup>21,22</sup> Moreover, many patients are hesitant to ask for assistance because they do not want others to know about their condition. The internet can remove these barriers and facilitate communication with distant support networks.

In January 15, 2013, the China Internet Network Information Center reported an internet penetration rate of 42.1%, slightly higher than the 36.9% found in our sample. Epidemiological studies have demonstrated that persons with epilepsy have significantly lower educational attainment and lower incomes, placing them at risk for low health literacy and limited internet access.<sup>14</sup> We did not analyze educational background of the participants. Rather, we focused on the influence of the internet on patients and their families. In a previous study, we found that epilepsy places a heavy economic burden on patients, families, and the national health care

Download English Version:

<https://daneshyari.com/en/article/10309738>

Download Persian Version:

<https://daneshyari.com/article/10309738>

[Daneshyari.com](https://daneshyari.com)