

Chinese Internet Searches Provide Inaccurate and Misleading Information to Epilepsy Patients

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Abstract

Background: Most patients with epilepsy want to learn as much as possible about the disease, and many have turned to the internet for information. Patients are likely to use information obtained from the internet to control their epilepsy, but little is known about the accuracy of this information. In this survey, we have assessed the feasibility and usability of internet-based interventions for the treatment of epilepsy.

Methods: Data were collected from an internet search. Different search terms were used to obtain general information on epilepsy together with information about medication, types of epilepsy, treatment, women's health, and other information. The accuracy of the information was evaluated by a group of experts.

Results: A total of 1320 web pages were assessed. The majority were websites related to health. A large number (80.2%) of web pages contained content related to the search term. A significant number of web pages 450/1058 (42.5%) claimed to provide information from a credible source; however, only 206/1058 (19.5%) of the information was accurate and complete; 326/1058 (30.8%) was accurate but incomplete; 328/1058 (31.0%) was correct but nonstandard, and 198/1058 (18.8%) was inaccurate. The authenticity of the information was not significantly different between the two search engines ($\chi^2 = 0.009$, $P = 0.924$). No significant difference was observed in the information obtained from a specialist or nonspecialist source ($\chi^2 = 7.538$, $P = 0.057$). There was also no correlation between the quality of the information and the priority ($\chi^2 = 6.880$, $P = 0.076$).

Conclusions: Searching for information about epilepsy on the internet is convenient, but the information provided is not reliable. Too much information is inaccurate or for advertisement purposes, and it is difficult for patients to find the useful information. Turning to the internet for medical knowledge may be harmful. Physicians should be aware that their patients may search for information on the internet and guide them to safe, reputable websites.

Key words: Epilepsy; Health Information; Internet; Self-management

INTRODUCTION

Epilepsy is a common and widespread neurological disorder.^[1] In chronic diseases such as epilepsy, information and counseling are essential for self-management, which might enhance the quality of life and possibly reduce disease-related morbidity and mortality.^[2,3] Despite this, patients with epilepsy are often ill-informed about the management of their disorder.^[4] In the clinical setting, 90% of patients surveyed reported that they wanted more information about epilepsy.^[5] Clinicians in tertiary centers and epilepsy clinics have a limited capability for providing sufficient information and counseling,^[6,7] leading patients to rely on other sources of information.^[8-10]

Low health literacy is a barrier to optimal health communication.^[11] Nowadays, the internet has become an important source of information on disease factors, self-management, and adjuvant therapies,^[12,13] especially for patients with chronic conditions or those in poor health.^[14]

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In developed countries, the internet has been an important channel through which patients have self-managed their conditions;^[15-17] 57% of Americans^[18] and 84.4% of Koreans^[19] with epilepsy have used the internet to find information. Of the world's 50 million people with epilepsy, 85% live in developing countries.^[20] In countries like China, the percentage of people with internet access is low, but 84.2% of Chinese epilepsy patients with internet access have used the internet to obtain information.^[21] The number of patients using the internet will continue to increase as information technology becomes more available.

Reliable information is available from many professional websites, but it is difficult for patients to find through search engines. People with epilepsy, family members, and healthcare professionals increasingly rely on search engines to retrieve medical information.^[22] However, the full power of the internet for health education and support has not been fully exploited.^[23] Additionally, the use of the internet might not be beneficial; one study demonstrated that epilepsy patients in an online group showed poorer general health, increased anxiety and depression, and a lower quality of life and satisfaction level than patients in an offline group.^[19]

The majority of patients have reported the desire to employ an internet-based self-management program to control their epilepsy,^[18] but little is known about the nature of the information that can be obtained from the internet. In China, some patients have followed informal treatment programs recommended on websites;^[21] because network and medical standards are low in China, we wanted to determine whether this information was reliable. To address this, we gathered data on internet usage and assessed the accuracy and reliability of internet-based interventions in China.

METHODS

Staff at the Affiliated Bayi Brain Hospital (Bayi Clinical College, Southern Medical University, China), collected information from the internet between October 2014 and December 2014. The evaluation group contained four experts – two neurologists (Prof. Ru-Xiang Xu, Affiliated Bayi Brain Hospital, Bayi Clinical College, Southern Medical University, and Prof. Lian-Kun Ren, China-Japan Friendship Hospital) and two neurosurgeons (Prof. Hui Qiao, Beijing Tiantan Hospital and Prof. Yong-Sheng Hu, Beijing Xuanwu Hospital) – who were responsible for assessing the authenticity of the information obtained from search results.

Information was obtained from the two most commonly used search engines in China, Baidu search (<http://www.baidu.com>) and 360 search (<http://www.so.com>). Google (<http://www.google.com>) is the most commonly used search engine in countries other than China but is not used by the Chinese.

The most common epilepsy topics searched for on the internet include general information, medication, types of epilepsy, treatment, new information, social support, other information, and women's health.^[18,21] Some topics such as new information and social support had no fixed search

terms and did not produce standard results; therefore, it was difficult to assess the feasibility and usability of this information. The other topics were all included in this survey.

The Chinese translation of epilepsy is “Dian Xian” and in Chinese proverbs, epilepsy was also called “Yang Gao Feng.” These two names were both used when searching for information. The search terms used are shown in Table 1.

All web pages that could not be opened were excluded. For each search term, information was collected from the first 30 web pages that could be opened. First, we judged the information source of each web page – whether from a specialist, nonspecialist, or not mentioned. Second, we judged the authenticity of the content, which was divided into four categories according to the evaluation group's criteria: Correct and full; correct and incomplete; correct and nonstandard; and wrong. Correct and standard information came from Chinese medical school textbooks while nonstandard and inaccurate information came from expert group discussion forums. For example, the correct and full information regarding the recommended diet for epilepsy patients is a normal, regular diet with diverse varieties of food including steamed rice, pasta, lean meat, egg, milk, fruit, vegetables, fish, and shrimps. It is also recommended not to over-feed or starve oneself. Drinks containing sugar or caffeine can induce seizures and should be avoided. The

Table 1: Search term of epilepsy information online

Search topic	Search term in Chinese	English translation
General information	DianXian zhengzhuang	Epilepsy symptom
	Yang gao feng zhengzhuang	
	Yang gao feng biaoXian	What's epilepsy
	DianXian biaoXian	
Medication	DianXian yin shi	Epilepsy diet
	Yang gao feng yin shi	
	DianXian yao wu zhi liao yuan ze	Epilepsy drug treatment principle
Type of epilepsy	Yang gao feng yao wu zhi liao yuan ze	
	DianXian fenlei	Epilepsy classification
Treatment	Yang gao feng fenlei	
	DianXian zhi liao fang shi	Epilepsy treatment way
	Yang gao feng zhi liao fang shi	
	DianXian shou shu shi ying zheng	Epilepsy operation indication
	Yang gao feng shou shu shi ying zheng	
	DianXian/Yang gao feng shou shu xiao guo	Epilepsy operation effect
Women's health	Yang gao feng shou shu xiao guo	
	DianXian shou shu feng xian	Epilepsy operation risk
	Yang gao feng shou shu feng xian	
	DianXian huai yun	Epilepsy pregnancy
	Yang gao feng huai yun	
	DianXian yi chuan	Epilepsy heredity
	Yang gao feng yi chuan	

intake of spicy food should be reduced, and smoking and drinking should be avoided. Some research has shown that a lack of Vitamin B6 and Vitamin D can promote epileptic seizures in rare cases. If only part of this information was mentioned, then this was considered correct but incomplete. Information stating that avoiding food is taboo was classified as correct and nonstandard. Information stating that normal food should be avoided (e.g., avoid eating beef or mutton) was classified as wrong.

Data were statistically analyzed using SPSS version 13 software (SPSS Inc., USA). Descriptive statistics, primarily frequencies, and percentages were performed for all variables. The Chi-squared test was used to compare variables between the different groups.

RESULTS

A total of 1320 web pages were assessed. The majority of web pages were health websites, followed by net friends, medical institutions, others, network operators, and personal websites. The proportion of each source is shown in Table 2. A large number (1058/1320 [80.2%]) of web pages contained content related to the search term. Information on epilepsy diet was the easiest to find (95% of all pages), followed by epilepsy operation indication (88.3%), epilepsy operation risk (88.3%),

epilepsy classification (86.7%), epilepsy pregnancy (86.7%), epilepsy heredity (86.7%), epilepsy symptoms (80.8%), epilepsy treatments method (75.0%), epilepsy drug treatment principle (73.3%), and epilepsy operation effect (30.0%).

A proportion 450/1058 (42.5%) of web pages claimed to provide information from a credible source (35.2% from specialists, 7.4% from general doctors) while 57.5% did not mention the source of information.

Only 206/1058 (19.5%) of the accessed information was correct and complete; 326/1058 (30.8%) was correct and incomplete; 328/1058 (31.0%) was correct and nonstandard, and 198/1058 (18.8%) was wrong. There were differences between the proportion of each topic and types of website [Tables 3 and 4]. The authenticity was not significantly different between the two search engines ($\chi^2 = 0.009, P = 0.924$). There was also no correlation between the quality of the information and the priority given to the site by search engine listings ($\chi^2 = 6.880, P = 0.076$).

35.2% of information came from specialists, and the authenticity of this information was separately analyzed; 106/272 (28.5%) of this information was correct and full; 116/372 (31.2%) was correct and incomplete; 106/372 (28.5%) was correct and nonstandard, and 44/372 (11.8%) was wrong. These errors can seriously

Table 2: Source of online epilepsy information

Search topic	Network operators	Personal websites	Health websites	Net friends	Medical institutions	Others
Epilepsy symptom	8	2	64	8	26	12
What's epilepsy	26	0	42	30	22	0
Epilepsy diet	16	2	24	28	26	24
Epilepsy drug treatment principle	18	0	76	4	6	16
Epilepsy classification	40	12	46	16	6	0
Epilepsy treatment way	6	2	40	14	32	26
Epilepsy operation indication	4	16	38	20	18	24
Epilepsy operation effect	0	18	44	30	18	10
Epilepsy operation risk	10	0	30	54	10	16
Epilepsy pregnancy	4	14	30	54	8	10
Epilepsy heredity	7	12	29	55	10	7
Total, n (%)	139 (10.5)	78 (5.9)	463 (35.1)	313 (23.7)	182 (13.8)	145 (11.0)

Table 3: Authenticity of epilepsy information searched online

Search topic	Correct and full	Correct and incomplete	Correct and nonstandard	Wrong	Total
Epilepsy symptom, n (%)	18 (20.0)	38 (42.2)	26 (28.9)	8 (10.0)	90 (100.0)
What's epilepsy, n (%)	14 (13.5)	34 (32.7)	28 (26.9)	28 (26.9)	104 (100.0)
Epilepsy diet, n (%)	18 (15.8)	20 (17.5)	36 (31.6)	40 (35.1)	114 (100.0)
Epilepsy drug treatment principle, n (%)	20 (22.7)	48 (54.5)	18 (20.5)	2 (2.3)	88 (100.0)
Epilepsy classification, n (%)	26 (25.0)	44 (42.3)	24 (23.1)	10 (9.6)	104 (100.0)
Epilepsy treatment way, n (%)	8 (7.8)	30 (29.4)	24 (23.5)	40 (39.2)	102 (100.0)
Epilepsy operation indication, n (%)	16 (15.1)	30 (28.3)	46 (43.4)	14 (13.2)	106 (100.0)
Epilepsy operation effect, n (%)	4 (11.1)	4 (11.1)	20 (55.6)	8 (22.2)	36 (100.0)
Epilepsy operation risk, n (%)	34 (32.1)	18 (17.0)	44 (41.5)	10 (9.4)	106 (100.0)
Epilepsy pregnancy, n (%)	26 (25.0)	44 (42.3)	24 (23.1)	10 (9.6)	104 (100.0)
Epilepsy heredity, n (%)	22 (21.2)	16 (15.4)	38 (36.5)	28 (26.9)	104 (100.0)

Table 4: Authenticity of epilepsy information among different type of website

Search topic	Correct and full	Correct and incomplete	Correct and nonstandard	Wrong	Total
Network operators, <i>n</i> (%)	51 (41.5)	30 (24.4)	26 (21.2)	16 (13.0)	123 (100)
Personal website, <i>n</i> (%)	21 (28.8)	30 (41.1)	19 (26.0)	3 (4.1)	73 (100)
Health websites, <i>n</i> (%)	70 (16.3)	168 (39.1)	125 (29.1)	67 (15.6)	430 (100)
Net friends, <i>n</i> (%)	37 (14.2)	57 (21.9)	96 (36.9)	70 (26.9)	260 (100)
Medical institutions, <i>n</i> (%)	17 (13.4)	32 (25.2)	46 (36.2)	32 (25.2)	127 (100)
Others, <i>n</i> (%)	10 (22.2)	9 (20.0)	16 (35.6)	10 (22.2)	45 (100)

impact the patient's treatment and life; for example some "specialist" web pages mentioned that epilepsy is hereditary, that patients cannot get married or eat beef and mutton, that traditional Chinese medicine is a better treatment than antiepileptic drugs, and that epilepsy can be cured by subcutaneously implanting magnets.

The authenticity of the information did not differ significantly between specialist or nonspecialist sources ($\chi^2 = 7.538$, $P = 0.057$). Advertisements were present in 58.3% of all web pages, which contained pop-up boxes and advertisement insertions.

DISCUSSION

Epilepsy is a condition that has been plagued by misinformation and misconception over the centuries. Patients need to be informed in a timely manner and the privacy of a computer desktop provides a safe and confidential way to access information. This study assessed the accuracy of information and the feasibility of internet-based interventions in Chinese epilepsy patients.

We found that around 80% of web pages actually contained information related to the search term. While searching for information about epilepsy on the internet is convenient, we observed that the information provided is not balanced, and some information (such as the effects of surgical treatment) can be difficult to find. It has been reported that 96.8% of epilepsy patients find information obtained from the internet inadequate and unsatisfactory.^[21]

Internet users have reported that they consider the general health information they obtained from the internet useful and believe it improved their knowledge about healthcare issues.^[24,25] For the internet to be useful in this manner, large scale internet access is required, but it is also important that the health information available on the internet is reliable.^[5] Many health websites do not have acceptable standards and may contain inaccurate information.^[26] This is supported by our findings that around 30% of information was nonstandard, and around 18% was actually wrong.

Inaccurate information can be obtained from the internet. By following these guidelines for self-management, epilepsy patients would suffer a lower quality of life. It has been reported that 6% of patients have followed ineffective treatments based on advice received from websites.^[21] These treatments increased the economic and psychological burden of patients and caused physical harm.

Many websites claimed to provide reliable information but failed to ensure the information came from a credible source. According to our survey around 35% of web pages claimed to provide information from a credible source; although the information on these sites was significantly more correct and complete compared to others, about 11% of the information was still wrong. Surprisingly, the rate of correct and complete information was lowest on websites of medical institutions, and 25% of information provided on these sites was inaccurate. Accuracy of information was also not significantly higher when coming from a specialist source. Therefore, how genuine the claimed specialist backgrounds are on the internet, are questionable.

In our survey, the amount of information coming from medical institutions was low and not entirely credible. In China, there are many professional websites including <http://www.caae.org.cn/>, which was created by the China Association Against Epilepsy (CAAE), a member of the International League Against Epilepsy and International Bureau For Epilepsy. The CAAE is a national, nongovernmental, and nonprofit organization. These websites are targeted more at professionals and are difficult to find through search engines.

More than half of the web pages contained advertisements. Most of these advertised the services of private or alternative hospitals and provided easy links to their own websites. These advertisements may exaggerate the effectiveness of treatments or even provide false information. Internet investors expect a high financial return and site owners can now make their website more accessible by buying specific keywords. Therefore, it is not difficult to understand why search results contain so much false information.

Internet use continues to increase among the general population and patients will continue to search for information this way. The internet offers an efficient and low-cost approach toward improving patient clinician communication in the management of chronic conditions.^[27] The epilepsy program of the Center for Disease Control and Prevention in America has supported the development of e-Tools as one of the several approaches toward improving the availability of tools for the self-management of epilepsy and overcoming barriers to treatment that are faced by epilepsy patients.^[28]

The explosion in the number of websites and search engines has made the wealth of available information difficult to comprehend. Searching for medical information on the

internet without appropriate guidance from healthcare experts to the most reliable websites may be harmful.^[27,29] Patients might be more likely to trust the internet as a source of health information if guided to reliable websites by a physician.^[18,30,31]

We have not analyzed an exhaustive number of search terms in our study, and similar problems may exist for other topics or other diseases. These will require further investigation. Connecting the internet with health and medicine involves all levels of society, including individuals, health care providers, professional organizations, communities, and local and federal governments.^[29] Everyone must cooperate to create convenient, reliable internet platforms for patients and more importantly, physicians must be aware that their patients are using the internet as a source of information and guide them to safe, reliable websites.

There is a limitation to this study; we only used two search engines to evaluate the information on Chinese web pages; therefore, these results may not be representative of other search engines and other languages.

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Conflicts of interest

There are no conflicts of interest.

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