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Use of computers and the Internet for health information by patients with epilepsy

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Abstract

The purpose of this study was to describe computer and Internet use among an online group and a clinic-based group of people with epilepsy. Greater than 95% of the online group and 60% of the clinic group have access to computers and the Internet. More than 99% of the online group and 57% of the clinic group used the Internet to find health information. A majority of people reported being likely to employ an Internet-based self-management program to control their epilepsy. About 43% reported searching for general information on epilepsy, 30% for medication, 23% for specific types of epilepsy, and 20% for treatment. This study found that people with epilepsy have access to computers and the Internet, desire epilepsy-specific information, and are receptive to online health information on how to manage their epilepsy.

Keywords: Epilepsy; Internet; Web; Computers; Computer literacy; Health information; Patient information; Self care

1. Introduction

More than 2.3 million Americans have epilepsy [1]. People with epilepsy, like others with chronic illness, have extensive needs for information to help them manage their condition and its impact on their lives. According to DiIorio, people with epilepsy are faced with management issues in five broad areas: medication, seizure, safety, information/support, and lifestyle [2]. Together these areas are called epilepsy self-management, and studies have shown that patients who receive more information about self-management demonstrate greater health benefits [3]. The challenge for health professions is how best to deliver useful self-management information in an appealing manner.

One approach that has gained support in recent years is the delivery of health information through Internet sites. According to a recent Pew Internet & American Life Project poll, more than 113 million adults have searched for health information online [4]. It is estimated that 50 to 80% of adults with Internet access use it to locate information about health care [5–7]. People with chronic conditions or those in poorer health are more likely to employ the Internet for medical information seeking [8]. Internet users of health information consider the information useful and believe it improves their knowledge about health care issues [5,9,10].

People with epilepsy are no exception. Of the numerous Web sites for epilepsy information in the United States, the most comprehensive include the Epilepsy Foundation Web site (www.epilepsyfoundation.org) and Epilepsy.com (www.Epilepsy.com). Both sites contain a significant

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amount of information related to medication actions and side effects, seizures, pregnancy, and school issues, to name a few. In addition, the sites include information on research studies, advocacy, resources, answers to common questions, and eCommunities programs, some of which have moderated daily chat sessions. Although investigators have assessed how people in the general population use the Internet to obtain health information, little is known about how people with epilepsy use the computer and Internet to obtain epilepsy-specific information. These data are important to assess the potential impact of computer- and Internet-based tools for epilepsy information and self-care. The purpose of this study was to describe access to and use of computers and the Internet among people with epilepsy, reasons for using the computer, and use of the Internet to search for health and epilepsy information.

2. Methods

2.1. Design and sample

To meet the objectives of the study, we conducted a cross-sectional survey among people living with epilepsy and their caregivers. The survey was administered in two ways. Online surveys were distributed through Survey Monkey for a month, and paper-and-pencil surveys were distributed to people at two epilepsy clinics over 2 to 3 months. Online participants were recruited through an epilepsy LISTSERV, Epilepsy-L, and through Epilepsy.com. People arriving for regularly scheduled appointments at two epilepsy clinics were invited to participate by completing a paper-and-pencil version of the same questionnaire. To be eligible, all participants had to be over the age of 18, able to read and write English, and provide consent. For this study, we focused on responses from patients who reported having epilepsy and excluded surveys completed by others (e.g., caregivers, family members).

2.2. Computer use survey

The 38-item survey included sections on demographics, computer and Internet access, and frequency of computer and Internet use. It also contained questions about participants' purpose for and comfort in using computers, reasons for using the Internet, and use of the Internet to find health information. Participants who had used the Internet to search for information about epilepsy were asked to indicate which epilepsy-related Web sites they had visited. In addition, the survey included an item asking how likely the participants would be to use an online program to help them manage their epilepsy. The online version of the survey contained one item not found in the paper form. The item was an open-ended question asking what participants were looking for when they visited an epilepsy-related Web site. The questionnaire was designed by reviewing other surveys that assessed computer and Internet use [7]. Researchers knowledgeable in the areas of e-health and epilepsy patient care assessed the face validity of the survey items. This study was approved by the institutional review board of the university and medical clinics.

2.3. Statistical analysis

The paper-and-pencil questionnaires were entered into SPSS Version 13 for analysis. The questionnaires collected by Survey Monkey were imported directly into SPSS. Descriptive statistics, primarily frequencies and percentages, were run for all variables. The results were entered into table format based on item content. χ^2, t tests, and Fisher's exact tests were used to compare variables between the online and clinic groups. For the open-ended question regarding the type of epilepsy information participants sought online, we employed common qualitative data analysis methods [11]. A codebook was developed of major response categories by two individuals. Responses were coded by two raters, the codes were categorized into major themes, and exemplar quotes were selected.

3. Results

A total of 183 people with epilepsy completed the survey; 146 completed the online version and 37 completed the paper-and-pencil version at the clinics. The mean age of the sample was 38.2 years (SD = 13.8). Majorities of the sample were white (88.9%) and female (58.1%). Most (82.0%) had completed some college and had a family income of at least $25,000 per year (65.2%). About 37.0% of the sample worked full-time, 20.9% were unable to work due to disability, and 14.9% were students.

Demographic characteristics varied between the online and clinic samples (Table 1). The clinic group had a larger percentage of black/African-American participants ($\chi^2(1) = 61.16$, $P < 0.0001$) and a larger percentage of participants unable to work due to disability ($\chi^2(179) = 28.32$, $P < 0.0001$) than the online group. In addition, the clinic group had a smaller percentage of participants who had completed high school ($\chi^2(179) = 5.34$, $P = 0.02$), but a larger percentage whose household income was more than $50,000 per year ($\chi^2(166) = 4.13$, $P = 0.04$) than the online group.

Table 1
Demographics of people with epilepsy

	Online Survey	Paper Survey
	$n = 146$[a]	$n = 37$[a]
Gender, n (%)		
Male	63 (43.2)	14 (37.8)
Race, n (%)		
White	127 (88.2)	17 (48.6)
Black	2 (1.4)	16 (45.7)
Other	15 (10.4)	2 (5.7)
Household Income ($/yr), n (%)		
⩽20,000	41 (30.6)	17 (50.0)
20,001 – 50,000	36 (26.9)	9 (26.5)
>50,001	57 (42.5)	8 (23.5)
Education Level, n (%)		
Less than grade 12	5 (3.4)	8 (22.8)
Grade 12 or GED	19 (13.0)	10 (28.6)
College 1-3 years	53 (36.3)	8 (22.8)
College 4 years +	69 (47.3)	9 (25.8)
Employment Status, n (%)		
Full-time	56 (38.6)	9 (25.0)
Unable to work due to disability	28 (19.3)	23 (63.9)
Student	23 (15.9)	—
Part-time	11 (7.6)	1 (2.8)
Currently not working	27 (18.6)	3 (8.3)
Mean Age (sd)	38.2 (14.0)	41.0 (10.7)

[a] n varied for questions.