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Pattern and frequency of use of complementary and alternative medicine among patients with epilepsy in the midwestern United States

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Abstract

Complementary and alternative medicine (CAM) is recognized to be commonly used by patients, yet there have been few studies regarding the scope of CAM use by patients with epilepsy. This study assessed usage and perceptions of CAM by patients with epilepsy in the midwest of the United States. A 25-item survey was administered to adult patients with epilepsy, and data were collected from 228 patients. The survey collected demographics, specific CAM usage, adverse effects of CAM therapy, and perceptions of the effectiveness of CAM. Thirty-nine percent reported using CAM; 25% reported using CAM specifically for their epilepsy. Prayer/spirituality was the most commonly used form of CAM (46%), followed by "mega" vitamins (25%), chiropractic care (24%), and stress management (16%). CAM use is common among midwestern patients with epilepsy, although the pattern of use may be slightly different than in other regions of the United States and elsewhere.

Keywords: Complementary; Alternative; Medicine, CAM; Epilepsy; Seizures; Midwest; Prayer; Stress management

1. Introduction

Complementary and alternative medicine (CAM) consists of medical treatments and therapies that are not a part of conventional medicine [1]. Worldwide, it is estimated that greater than 80% of the population of developing countries depend on CAM, whereas about 50% of the population in industrialized countries use CAM [2]. More specifically, CAM use is prevalent in 70% of the Canadian population, 48% of the Australian population, and 42% of the US population [3]. In the United States, about 600 million visits are made to CAM practitioners annually, at an estimated cost of $30 billion [3].

Prayer and spirituality are commonly used CAM therapies, as are stress management, herbal remedies, chiropractic, acupuncture, meditative practices, and yoga [4,5]. These therapies appear benign and, in many cases, have been considered extremely useful [6]. However, some negative reactions have been associated with the use of herbals by the elderly, such as dementia and decreased cognitive skills [7]. As a result, seemingly benign supplemental or alternative therapies may have implications that warrant a physician's awareness and involvement.

Moreover, CAM is used by patients for various medical conditions, including epilepsy. A 2003 study reported that 44% of individuals with epilepsy in Arizona had used various CAM treatments for their seizures, with prayer constituting 44% of such CAM use [6]. In a study from the United Kingdom, 11% of epilepsy patients used CAM for their seizures; however, seizure frequency was not reported to be affected. Despite the pervasiveness of CAM use among those with epilepsy, there have been few studies regarding the scope of CAM use within this population. Although

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CAM use has been assessed and reported in the western United States [8], there have been no studies regarding CAM usage and its possible benefits for patients with epilepsy in the midwest. The goals of this study were to assess the extent to which CAM treatments are used for epilepsy and to assess the perceptions of CAM by patients at a midwest comprehensive epilepsy center, Via Christi Comprehensive Epilepsy Center (VCCEC) in Wichita, Kansas.

2. Methods

2.1. Participants and instrument

Patients 18 years and older who were physically able to speak, hear, or read were eligible to participate in the study. Chart review was conducted only for those patients who were solicited by phone or in person. Those not accessible by these methods were sent the survey via mail. There were no identifiers on the mailed survey, so a chart review was not possible. The chart review allowed for inclusion of such variables as the numbers and names of antiepileptic drugs (AEDs) taken and the number of seizures. The data set remained de-identified throughout the research process.

A 25-item survey was designed for this study. The instrument collected demographic data, specific CAM usage (whether or not they used various types of CAM), duration of use of CAM, adverse effects of CAM therapy, and patients' perception of the effectiveness of CAM compared with more conventional treatments.

2.2. Procedure

The Via Christi Regional Medical Center's institutional review board and the University of Kansas School of Medicine's human subjects committee approved this project. Consent forms were completed and signed by patients who were interviewed in person. Consent forms were read to patients interviewed via telephone. Consent forms were not needed for surveys mailed to patients as there were no identifiers.

This study began in June 2005 with five students administering a structured interview via telephone. The duration of the interview was approximately 15 minutes. In-person interviews were conducted throughout July with VCCEC patients coming in for their regularly scheduled appointments. Surveys were completed by the students while they interviewed the patients.

To access additional participants, eligible patients received a letter describing the study and asking for their participation. Patients willing to participate received a survey in June 2005. Only one survey was administered for each patient. Following completion of the survey, data management and analysis were performed using SPSS 14.0 computer software. All data were de-identified to ensure confidentiality throughout the entire research process.

3. Results

Seventy-nine surveys were completed by phone and in person. Additionally, 446 surveys were mailed out to participants, and 149 were completed and returned, a 33% response rate. This produced a total of 228 completed surveys (Table 1). The majority of respondents (85%) were Caucasian. Of those surveyed, 34% reported having a high school education, 46% reported being employed, 35% reported having a household income less than $15,000, and 41% reported being married. Whereas 39% agreed or strongly agreed that they feel/felt separated from family, friends, or others because of their epilepsy; 44% disagreed or strongly disagreed.

When asked if they were currently using complementary and alternative medicine, 9% responded "yes," 29% responded "unsure," and 61% responded "no." However, when later asked in the survey about their use of specific forms of CAM, 39% of patients reported using various forms of CAM. Of all surveyed, 63% did not complete this portion of the survey, 15% did not use CAM (checked no examples of CAM), 14% reported using one type of CAM, and 9% reported using more than one type of CAM (range, 2–16 types).

From a list of 30 CAM therapies (Table 2), prayer/spirituality was the most commonly used (41%), followed by "mega" vitamins (22%), chiropractic care (21%), and stress management (14%). Fifty-seven (25% of all patients) reported using CAM specifically for their epilepsy; 33 using prayer/spirituality, 14 "mega" vitamins, 11 chiropractic care, and 11 stress management. Although relatively uncommon CAM therapies in this study, cranberry juice ($n = 10$), black cohosh ($n = 8$), echinacea ($n = 7$), and melatonin ($n = 6$) were the most frequently used botanicals for all respondents.

Just less than half (47%) of all respondents reported they would consider using CAM for their epilepsy, and 39% reported being unsure. When asked why patients did not use CAM, 79% of all cases reported they did not know enough (Table 3). Although only 11% of cases reported they did not use CAM due to financial restrictions, 58% reported they would be more likely to use CAM if insurance covered the expenses. Still, later in the survey, 46% ($n = 38$) of the valid responses agreed or strongly agreed that CAMs are less expensive than AEDs. Of the valid cases, 56% reported purchasing their CAM from grocery stores, and 18% reported obtaining their CAM from health food stores.

Of all valid responses, 37 (49%) reported their physician was aware of their use of CAM. In fact, of the valid cases, most (29%) stated they learned about CAM from their doctor, and 27% reported learning about CAM from family or friends. Twenty-six reported this had been due to their doctor's recommendation or advice, seven had wanted to know if CAM was safe, and six had been concerned about drug interactions. Although 20 (27%) were unsure, 18 (24%) reported their physician was not aware of their CAM use. Seven reported this was because the doctor never asked about CAM, and another seven reported they did not need to share this with their doctor. Six reported never thinking about informing their doctor, three indicated they thought their doctor would disapprove, and one reported the doctor would not be interested. Regardless, 91% of all cases agreed or strongly agreed they would inform their physician if they were to use CAM.

Perceptions of CAM usage as treatment for epilepsy were also assessed. For each type of CAM, patients were asked if the CAM benefited their epilepsy (Table 4) and to report the side effects associated with the treatment