



Clinical Research

Caregiver-reported religious beliefs and complementary and alternative medicine use among children admitted to an epilepsy monitoring unit



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ARTICLE INFO

Article history:

Received 1 November 2016

Revised 26 January 2017

Accepted 26 January 2017

Available online 14 March 2017

Keywords:

Epilepsy

Complementary and alternative medicine

Epilepsy monitoring unit

Children

ABSTRACT

Complementary and alternative medicine (CAM) includes a wide range of practices and products that are generally outside the use of conventional medicine as practiced in Western cultures. Use of CAM in persons with epilepsy is high, even compared to individuals with other chronic health conditions. In this study, we surveyed caregivers of children admitted to a regional epilepsy monitoring unit (EMU) in the southeast United States to assess CAM use among patients ($N = 225$). Thirteen percent of respondents indicated current use of CAM by their child, 16% reported past use, and 43% reported interest in future use, most commonly in marijuana as a potential treatment (23%). Over 25% of respondents expressed interest in CAM use related to side effects of anti-epileptic medications. Regarding prayer as a form of CAM, a large majority of respondents in this sample identified as Christian and actively prayed for their child's illness, revealing a high prevalence of spiritual practices in this population. Eighty-one percent of respondents reported that they had not discussed CAM use with their doctor. Discussing CAM use with a health care provider was significantly related to past CAM use ($p < .02$), but not current use or willingness to try CAM in the future ($p > .05$). These results have important implications for future practice and support increased communication and patient education, as many anti-epileptic medications interact with certain herbs and supplements, posing a potential health risk and treatment barrier in this population.

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1. Introduction

Complementary and alternative medicine (CAM) is defined as practices and products within a diverse medical and health care system that are generally outside the use of conventional medicine as practiced in Western cultures (e.g., the United States). Classic domains of CAM include mind–body medicine, biologically-based practices, manipulative and body-based practices, and energy medicine [1–5]. Although CAM use is common in the United States (i.e., 34% of adults) [6], individuals with chronic health conditions are more likely to use CAM when compared to the general population [7–9]. Furthermore, the use of CAM in patient populations differs widely based on disease characteristics (e.g., diagnosis, duration of symptoms) and patient demographics (i.e., age, gender, ethnicity, geographic location, socioeconomic status, and education level) [2,8–17]. Individuals who use CAM often do so in an attempt to improve their overall health, increase quality of life,

and/or decrease negative symptoms of health conditions or their treatments (e.g., medication side effects) [4,16,18,19].

In individuals with epilepsy, examination of CAM use is indicated due to the incidence of medication side effects [4,9,20–22], lowered quality of life [4,23–27], psychiatric comorbidity [23,24,28–30], and continued seizures following pharmacotherapy [4,31,32]. Previous research finds high rates of CAM use among adults with epilepsy [33, 34], potentially due to the high rate of individuals with medication-resistant seizures [1,13].

Research suggests that rates of CAM use differ between children and adults in the United States (12% of children ages 4–17) [6,35]. Furthermore, parents may be more conservative in choice of CAM for their children [36]; however, parental CAM use is a positive predictor of CAM use in children [2,9,13]. Thus, although parents' use is influential, decision-making varies between the two groups. The use of CAM may be higher in children with epilepsy, even when compared to children with other chronic health conditions (62% in children with epilepsy, 59% for childhood cancer, 51% for asthma, and 47% for sickle cell disease in the Midwestern U.S.) [13].

Although the use of CAM is influenced by a belief in the safety of its use [11], many studies find that less than half of families using CAM discuss their use with a doctor [2,4,10,33,37]. While certain types of CAM have little interference with standard medical treatment and few or no side effects (e.g., yoga, manual therapies, osteopathy) [2,33,38,39], certain

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biologically-based practices can interfere with medication regimens, particularly anti-epileptic drugs (AEDs), making communication about CAM use between health care providers and patients of primary importance.

Specifically, herbal supplement use is common among individuals taking prescription medications (16%) [40]. This is particularly problematic in individuals with epilepsy, as some herbal supplements may have pro-convulsant effects (e.g., borage oil) [41,42], while others lower the bioavailability or efficacy of AEDs (e.g., Shankpushpi decreasing efficacy of phenytoin) [43,44]. St. John's wort and *Ginkgo biloba* are used with the intention of alleviating depressive symptoms commonly associated with epilepsy; however, these supplements increase the risk of seizures, potentially by reducing seizure threshold [33,44]. Although some herbal/dietary supplements are reported as positive additions to a patient's treatment plan, evidence of success from herbal remedies are often not reported in controlled clinical trials. Additionally, side effects of biologically-based approaches are rarely reported. This may contribute to a biased view of herbal remedies [44].

The present study was intended to contribute to the existing literature by investigating the use of CAM as well as the influence of religious beliefs in children admitted to a regional epilepsy monitoring unit in the southeast region of the United States.

2. Material and methods

2.1. Sampling methodology

Between 2014 and 2016, caregivers of children admitted to the EMU at Children's of Alabama were asked to complete a questionnaire on the day of admission. The sample consisted largely of children with medication-resistant epilepsy. In total, 225 families completed the survey and were included in final analyses. Patients with repeat admissions to the EMU were asked to complete the questionnaire only once. This research was approved by the Institutional Review Board at our institution.

2.2. Questionnaire

A 5- to 10-min questionnaire, developed by clinicians in pediatric neurology and neuropsychology at our institution, was intended to be brief for accessibility to a large sample. A large majority of questions were presented in multiple-choice format. The questionnaire included patient demographics (i.e., age, gender, race, and seizure duration), information on religious beliefs and practices, and a survey of CAM use. See Appendix A for a copy of the questionnaire. Although debated for use in overall prevalence rates [45], many researchers classify prayer as a type of mind-body intervention and thus, broadly a form of CAM [6,33,46], particularly when prayer or other religious practices prevent parents from consenting to conventional medical treatment for their children with epilepsy. Therefore we also explored how prayer and religious healing fit into the pattern of CAM use in our cohort. Identifying patient information (e.g., name, date of birth, medical record number), was excluded from the survey in order to protect patient confidentiality.

2.3. Data analysis

Data were analyzed using descriptive statistics to determine frequency and prevalence and are reported as percentages. Additionally, chi-square analyses and independent t-tests were used to examine associations between variables of interest.

3. Results

3.1. Sample demographics

Average age of children in the study was 9.09 years ($SD = 5.27$, range: 0–21 years). Fifty-three percent of patients in the sample were male and 47% were female. Seventy percent of individuals identified

their race as Caucasian, 23% as African American, 3% as Hispanic, <1% as Asian, and <1% as other. Three percent did not report their race. Forty-four percent of children had experienced seizures for less than 2 years, 26% for 2–5 years, and 31% for longer than 5 years. Eighty-six percent of survey respondents were mothers of children in the EMU, 7% were fathers, 4% were grandmothers, 1% were step-parents, and 2% reported another caregiver role.

3.2. Prevalence of CAM use

Thirteen percent of caregivers reported that their child was currently using some form of CAM. Sixteen percent had used CAM in the past and 43% reported interest in future use. Current CAM use ranged from 0% (herbs, hypnosis, magnetic therapy, and oxygen therapy) to 5% (massage, vitamins/supplements). Similarly, report of past CAM use ranged from 0% (acupuncture, hypnosis, and marijuana) to 6% (vitamins/supplements). Caregivers were most interested in trying marijuana (23%), music therapy (20%), massage (19%), and vitamins or supplements (16%) for their child in the future. No respondent reported that their child was currently using herbs, 1% reported previous use for their child, and 9% reported interest in future use (see Fig. 1).

3.3. Motivation for using CAM

Twenty-seven percent of respondents were motivated to try other treatments not prescribed to help with seizure reduction, 5% because they believed that prescribed medications were harmful, 14% because of medication inefficacy, 2% because the alternative therapies were more consistent with their beliefs, 9% because CAM methods had worked for others, and 10% for an unlisted reason. Fifty-three percent reported that they would try anything that might help. Seizure duration and patient age were not significantly related to CAM use ($p > .05$).

3.4. Spiritual beliefs

A large majority of participants were Christian (85%). Less than 1% of respondents were Jehovah's Witness and Buddhist. Four percent reported no religious affiliation, and 8% marked "other" or preferred not to report their religion.

Eighty-eight percent of respondents had prayed for their child's illness. Of those, 72% reported praying for their child's illness daily, 12% weekly, and 13% occasionally. Additionally, of those who reported praying for their child's illness, 78% reported great benefit, 10% reported some benefit, and 11% unknown benefit. No respondent who prayed for their child's illness indicated no benefit.

Fifteen percent of respondents reported that they had held a religious ceremony for healing of their child's illness. Of those who held a religious ceremony, 48% reported great benefit, 27% reported some benefit, 6% reported no benefit, and 18% were unsure.

3.5. Doctor-patient communication

A majority (68%) reported that their doctor or nurse had never asked about their CAM use. A minority (17%) recalled an occasional inquiry about alternative therapies by their doctor or nurse. Only 10% were asked about CAM use at every clinic visit. Eighty-one percent of respondents reported that they had not discussed CAM use with their health care provider. One-tailed chi-square analyses revealed that discussion of CAM use with a health care provider was significantly related to past CAM use ($p = .01$), but not current use ($p = .33$) or willingness to try CAM in the future ($p = .21$).

4. Discussion

Our survey revealed several findings in a large pediatric EMU sample regarding prevalence of CAM use, religious beliefs and practices, and

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