



Complementary and integrative medicine in epilepsy: What patients and physicians perceive ☆

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ARTICLE INFO

Article history:

Received 28 May 2019

Revised 27 July 2019

Accepted 3 September 2019

Available online 6 November 2019

Keywords:

Complementary

Epilepsy

Perception

Seizure

ABSTRACT

Purpose: The purpose of the current study was to investigate the extent to which people with epilepsy (PWE) use complementary and integrative medicine (CIM) to treat their illness and to assess their perceptions. We also investigated the perceptions of their treating physicians.

Methods: In this cross-sectional study, all adult patients with epilepsy, who had the illness for at least one year, were recruited at the outpatient epilepsy clinic at Shiraz University of Medical Sciences, from January 2019 until March 2019. A questionnaire was designed for this survey. We also designed a similar questionnaire to investigate perceptions of the physicians in the same region.

Results: One hundred and one patients participated. Seventy-one patients (70%) believed that CIM would be helpful in treating seizures; the most commonly reported CIM therapies were prayers, exercise, and herbs. Sixteen patients (16%) had actually used CIM to treat their seizures, but only one patient perceived that CIM was more effective than antiepileptic drugs to bring her seizures under control. Thirty-one neurologists participated in the study. Seventeen neurologists (55%) believed that CIM would be helpful in treating epileptic seizures. The most commonly reported CIM therapies were meditation, yoga, and exercise.

Conclusion: Complementary and integrative medicine is considered and used by many PWE to treat epileptic seizures. Cultural issues probably play an important role in having faith in CIM. Physicians involved in the care of PWE should provide appropriate information regarding the safety and efficacy of various CIM treatments for PWE.

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1. Introduction

Epilepsy is one of the most common chronic neurological disorders; perhaps seventy million people worldwide suffer from this disorder [1]. The mainstay of treatment is drug therapy. In the past decades, many new antiepileptic drugs (AEDs) have been introduced to the market, so there are now about 30 AEDs available to treat epilepsy [2]. However, about one-third of patients with epilepsy have persistent seizures despite use of appropriate AEDs [3]. Epilepsy surgery is a valuable option for patients with drug-resistant seizures, but it is not an option for every patient with drug-resistant epilepsy and it does not even work well for all who are seemingly good candidates for epilepsy surgery [4]. On the other hand, ongoing epileptic seizures are associated with increased risks of morbidity and mortality [5,6]; therefore, patients with

drug-resistant seizures are often desperate to seek help wherever they can find it, even if it is an unconventional option.

Complementary and integrative medicine (CIM), also called complementary and alternative medicine, is defined as “those healthcare and medical practices not currently an integral part of conventional medicine” [7]. Use of CIM is prevalent worldwide; more than 40% of the populations in most of the Western countries use CIM for various health conditions [8]. In a previous study five years ago [9], we observed that many adult people with epilepsy (PWE) (53%) believed that CIM might be useful in treating seizures. The purpose of the current study was to reinvestigate the extent to which PWE use CIM treatments for their illness and to assess their perceptions about efficacy of CIM to treat their epileptic seizures. We also investigated the perceptions of their treating physicians during the same time period; this has rarely ever been studied before and is complementary to our previously published study [9] and may advance our understanding of the situation. Knowledge of perceptions of the people (both patients and their treating physicians) on application of CIM for the treatment of epilepsy may help authorities, both in the education system and the healthcare

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system, to design appropriate educational programs and guide healthcare professionals and patients alike to improve their knowledge and practices.

2. Material and methods

In this cross-sectional study, all patients above 18 years of age, who had been treated for epilepsy for at least one year, were surveyed at the outpatient epilepsy clinic at Shiraz University of Medical Sciences, which is the only epilepsy clinic in south Iran, from January 2019 until March 2019. All patients had access to healthcare facilities and standard AEDs. The diagnosis of epilepsy was made based on the clinical grounds and electroencephalography (EEG) findings. Patients or their caregivers (when the patient had intellectual disability or was not able to speak, hear, and read), who were physically able to speak, hear, and read, were eligible to participate in the study. A questionnaire was designed for this survey (Appendix 1). The survey anonymously collected some demographic data and also specific data about CIM perceptions and usage (any usage at any time) (self-administered). In this study, we also approached all the neurologists, who practice in Fars province in south Iran, during their scientific meeting that was held in March 2019. An anonymous questionnaire similar to the above was prepared (Appendix 2). There were no exclusion criteria.

This study was conducted with approval by the Shiraz University of Medical Sciences Review Board. The patients were informed about the study, and if agreed, they participated. Demographic variables and relevant clinical variables were summarized descriptively to characterize the study population. We performed univariate analyses using Pearson chi-square and *t*-test. *P* value less than 0.05 was considered as significant.

3. Results

One hundred and one patients (77 people) or their caregivers (24 persons) participated in this study. They included 53 women and 48 men. Age of the interviewees was 34 ± 10 years (range: 19–69 years). Age of the patients was 35 ± 12 years (range: 19–71 years), and duration of their illness was 15 ± 11 years (range: 1–51 years). Level of education of the interviewees was as follows: high school in 52 and college graduate in 46 people (3 missing). All patients were taking AEDs: 44 were on monotherapy and 48 were receiving polytherapy with AEDs (9 missing). Thirty-seven patients did not have any seizures in the past 12 months, and 55 patients experienced one or more seizures during such a period of time (9 were missing). Seventy-one people (70%) believed that CIM (one or more items) would be helpful in treating epileptic seizures; the most commonly reported CIM therapies were as follows: prayers (46%), exercise (28%), and herbs (23%) (Table 1). Such a belief was not associated with their gender (Pearson chi-square test; $p = 0.8$), age (*t*-test; $p = 0.3$), level of education (Pearson chi-square test; $p = 0.08$), AED regimen (Pearson chi-square test; $p = 0.3$), seizure control status (Pearson chi-square test; $p = 0.7$), and duration of illness (*t*-test; $p = 0.5$) (Table 2). Sixteen patients (16%) had actually used CIM to treat their seizures. The CIM therapies that were used by these 16 patients included the following: herbs in six patients; special (traditional) diets by three; and acupuncture, psych reading, prayers, and sports each by one patient (three persons did not provide a response). Only one patient perceived that CIM was more effective than AEDs to bring her seizures under control; she used traditional diet recommendations. Patients, who used CIM, expressed that dissatisfaction with the cost of conventional AEDs (14 patients; 88%), dissatisfaction with the effectiveness of conventional AEDs (10 patients; 63%), and dissatisfaction with the adverse effects of conventional AEDs (9 patients; 57%) were their main motives to use CIM.

In a secondary analysis, we considered the patients (77 people) and the caregivers (24 people) as two different groups. Fifty-two patients (68%) and 19 caregivers (79%) believed that CIM (one or more items) would be helpful in treating epileptic seizures ($p = 0.3$). The most commonly reported CIM therapies were prayers (32 patients and 14 caregivers; $p = 0.1$), exercise (21 patients and seven caregivers; $p = 0.9$), and herbs (17 patients and six caregivers; $p = 0.7$) in both groups, and the differences were not significant.

Thirty-one neurologists (16 women and 15 men; 3 academic-based general neurologists and 28 community-based general neurologists), who participated in the scientific meeting in March 2019 in Shiraz, completed the survey. The total number of the neurologists in the geographical area of this study is 47. Seventeen neurologists (55%) believed that CIM (one or more items) would be helpful in treating epileptic seizures; this rate was not statistically different from that in the patient group (Pearson chi-square test; $p = 0.1$). The most commonly reported CIM therapies were as follows: meditation (39%), yoga (35%), and exercise (29%) (Table 3). Six neurologists (19%) had actually recommended CIM to treat their patients, but only one perceived that CIM was more effective than AEDs; he used traditional diet recommendations.

4. Discussion

In this study, we observed that CIM is an option that is considered by many PWE and also by many physicians involved in the care of PWE in south Iran, despite the lack of enough scientific proof for its efficacy in most instances [8]. In a previous study (only on PWE) five years ago, we had a similar observation [9]. High rates of perception and application of CIM to treat epileptic seizures have also been reported from many other places in the world, even from the Western countries [10,11]. In a previous study from the USA, prayer/spirituality was the most commonly used form of CIM [10], which is similar to our observation.

No randomized, controlled trials have ever evaluated the efficacy of various CIM treatments for epilepsy. This high rate of perception of the efficacy of CIM in treating epileptic seizures in the Iranian society (both in ordinary people and among healthcare professionals) is probably due to the cultural perceptions of the people [9]; when a minority of them used CIM for this purpose, most did not notice any added advantage! Interestingly, having faith in CIM to treat

Table 1

Do you think that any of the following might be helpful to treat seizures (101 patients/caregivers)?

Complementary and integrative medicine modality	Helpful	Not helpful	I do not know
Herbal drugs	23	18	51
Exercise	28	15	50
Yoga	18	31	50
Meditation	10	29	62
Hypnosis	3	33	63
Acupuncture	8	32	61
Chiropractic care	0	28	70
Massage therapy	11	33	57
Reflexology	1	32	67
Aromatherapy	1	34	63
Homeopathy	3	31	64
Biofeedback	3	29	65
Ayurvedic medicine	0	30	66
Psych readers	1	58	37
Exorcism	1	63	33
Pray	46	23	31
Traditional medicine	8	38	45

Some answers were missing.

Table 2Associations between having faith in complementary and integrative medicine (CIM) to treat seizures and some clinical variables.^a

	Patients who believed in CIM (N# 71)	Patients who did not believe in CIM (N# 30)	P value
Gender ratio (female: male)	38:33	16:14	0.8
Level of education (school, diploma, college)	15:16:37	10:11:9	0.08
Antiepileptic drug regimen (polytherapy vs. monotherapy)	32:34	16:10	0.3
Uncontrolled seizures	37	18	0.7
Duration of epilepsy (mean years \pm standard deviation)	15 \pm 12	17 \pm 8	0.5
Age (mean years \pm standard deviation)	34 \pm 11	36 \pm 10	0.3

^a There were some missing data.

chronic medical conditions is not limited to PWE. In a previous study investigating the prevalence of CIM use among dermatology outpatients in Shiraz, Iran, the authors observed that 31% of the patients had used one of CIM methods [12]. The most frequently method used in their study was herbal medicine [12]. In another study investigating CIM use in patients with diabetes mellitus in the same geographical area, the authors observed that 75% of their patients used at least one type of CIM in the last year prior to the interview [13]; most (98%) reported use of herbal preparations [13]. Ironically, the physicians involved in the treatment of PWE, who are supposed to deliver the best evidence-based care to their patients, had a similar perception on CIM efficacy in treating epileptic seizures. This may create a vicious cycle of misconceptions in the society, where patients and physicians add to each other's false beliefs. To the best of our knowledge, no study ever investigated perceptions of patients and physicians in the same region on the efficacy of CIM to treat epileptic seizures. This observation may add to our understanding of why some PWE put faith in CIM to treat their seizures; possibly, by receiving false information or recommendations from their physicians. We have to say that we did not investigate the cause and effect relationship between the perceptions of the patients and those of the neurologists in this study. On the other hand, previous studies have indicated that most patients do not inform their physicians that they are using CIM to treat their seizures [14]; we did not explore this in the current study either. The role(s) that physicians play in the application of CIM by PWE to treat their seizures should be investigated in future studies.

In addition to the above-mentioned hypothetical speculation, there are various other reasons to explain why many PWE use CIM to treat

their seizures [8]; high failure rates of conventional AEDs to treat seizures; comorbidities of epilepsy for which AEDs are of little help; and the perception that CIM is more natural and less toxic than AEDs by PWE [8]. However, there are probably some other reasons for which PWE may make a decision of using an unconventional therapy (i.e., CIM) to treat their seizures. We observed that, high cost of AEDs and their adverse effects were considered as important factors by some patients. In a previous study from Germany [15], the highest observed independent predictive value of CIM use was the occurrence of adverse drug events of AEDs.

We have to say that lack of high quality evidence to support the use of CIM in PWE does not necessarily mean that such therapies are harmful in these patients. As a matter of fact, there are some anecdotal reports of the efficacy of some CIM therapies (e.g., meditation, yoga, nutritional and herbal supplements, acupuncture, etc.) in helping patients with epilepsy [16]. Therefore, it is important to educate both healthcare professionals and the public on the potential advantages and disadvantages of the most commonly used CIM in each society. For example, while the practice of spirituality and religiosity can be a positive coping strategy for PWE, it is necessary to demystify myths and misconceptions about epilepsy treatment and improve the knowledge of professionals, patients, and their caregivers to enable them to explore their full treatment options [17].

In conclusion, CIM is considered and used by many PWE to treat epileptic seizures. Cultural issues probably play an important role in having faith in CIM. Healthcare professionals involved in the care of PWE may play a significant role in creating/correcting conceptions on epilepsy treatment strategies and options. Improving the knowledge of PWE and healthcare professionals about the risks and potential benefits of CIM is very important. Further well-designed clinical trials are required to investigate the precise role of various CIM treatment options in PWE.

This study has some limitations. Its cross-sectional design and the reliance on the self-report are among the limitations. In addition, we did not look at the income of PWE. It might influence whether the patients could afford conventional AEDs or CIM options. We also did not collect the data on the association between the beliefs in CIM and adherence of the patients to their conventional treatment. Finally, it is important to know that who promulgated the concepts of CIM to the patients (e.g., friends, social media, etc.) and this should be investigated in future studies.

Declaration of competing interest

Ali A. Asadi-Pooya, M.D.: Honoraria from Cobel Daruo; Royalty: Oxford University Press (Book publication). Others: none.

Acknowledgment

This study was supported by the Pharmaceutical Sciences Research Center, Shiraz University of Medical Sciences, Shiraz, Iran.

Table 3

Do you think that any of the following might be helpful to treat seizures (31 neurologists)?

Complementary and integrative medicine modality	Helpful	Not helpful	I do not know
Herbal drugs	5	17	6
Exercise	9	16	6
Yoga	11	12	8
Meditation	12	13	6
Hypnosis	3	15	12
Acupuncture	1	20	9
Chiropractic care	0	22	7
Massage therapy	2	23	5
Reflexology	2	18	10
Aromatherapy	3	16	9
Homeopathy	2	20	6
Biofeedback	6	16	7
Ayurvedic medicine	0	14	13
Psych readers	1	14	11
Exorcism	1	16	12
Pray	2	15	11
Traditional medicine	5	18	6

Some answers were missing.

Appendix 1. CAM questionnaire

Dear Patient,

We are conducting a research study to learn about application of alternative medicine to treat seizures in epilepsy.

The survey does not include any information that would reveal your identity and is anonymous. Please do not write your name or any other specific personal information on the questionnaire.

If you agree to participate in this study, please fill out the survey in the following pages as completely as possible. Please read each item and circle either YES, or NO. If any question makes you uncomfortable, you do not have to answer it.

We appreciate your time and your cooperation. Thank you very much.

Application of Alternative Medicine to Treat Seizures in Epilepsy

Who is filling the questionnaire: **self (patient)** **parent** **care-giver**

Your Age:

Your Sex: **Female** **Male**

Level of Education of interviewee: **High school** **Some college** **Graduate**

Age seizures first started in the patient:

Which anti-epileptic drugs are you taking?.....

How often do you have seizures:

- None for at least 1 year
- Less than once per month
- More than once per month

1. Do you think that any of the following might be helpful to treat seizures?

- Herbal drugs:	YES	NO	DO NOT KNOW
- Exercise:	YES	NO	DO NOT KNOW
- Yoga:	YES	NO	DO NOT KNOW
- Meditation:	YES	NO	DO NOT KNOW
- Hypnosis:	YES	NO	DO NOT KNOW
- Acupuncture:	YES	NO	DO NOT KNOW
- Chiropractic care:	YES	NO	DO NOT KNOW
- Massage therapy:	YES	NO	DO NOT KNOW
- Reflexology:	YES	NO	DO NOT KNOW
- Aromatherapy:	YES	NO	DO NOT KNOW
- Homeopathy:	YES	NO	DO NOT KNOW
- Biofeedback:	YES	NO	DO NOT KNOW
- Ayurvedic medicine:	YES	NO	DO NOT KNOW
- Psych readers:	YES	NO	DO NOT KNOW
- Exorcism:	YES	NO	DO NOT KNOW
- Pray to saints or supplication therapy	YES	NO	DO NOT KNOW
- Traditional medicine:	YES	NO	DO NOT KNOW

2. Have you ever **USED** anything other than **conventional antiseizure medicine** to treat your seizures? (such as vitamins, herbs, other supplements, acupuncture, chiropractic manipulation, exercises, or anything mentioned above)?

YES NO

How did its effectiveness compare with the effectiveness of the medicines your doctor prescribed?

Less effective More effective Equally effective

3. If you have used anything other than conventional **antiseizure medicines** to treat your seizures, what are the reasons? (You may choose to select more than one answer)

- Dissatisfaction with the cost of conventional therapy
- Dissatisfaction with the effectiveness of conventional therapy
- Dissatisfaction with the side effects of conventional therapy
- I do not believe conventional therapy works

Appendix 2. Alternative medicine questionnaire**Application of Alternative Medicine to Treat Seizures in Epilepsy**Your Sex: **Female****Male**

1. Do you think that any of the following might be helpful to treat seizures?

- Herbal drugs:	YES	NO	DO NOT KNOW
- Exercise:	YES	NO	DO NOT KNOW
- Yoga:	YES	NO	DO NOT KNOW
- Meditation:	YES	NO	DO NOT KNOW
- Hypnosis:	YES	NO	DO NOT KNOW
- Acupuncture:	YES	NO	DO NOT KNOW
- Chiropractic care:	YES	NO	DO NOT KNOW
- Massage therapy:	YES	NO	DO NOT KNOW
- Reflexology:	YES	NO	DO NOT KNOW
- Aromatherapy:	YES	NO	DO NOT KNOW
- Homeopathy:	YES	NO	DO NOT KNOW
- Biofeedback:	YES	NO	DO NOT KNOW
- Ayurvedic medicine:	YES	NO	DO NOT KNOW
- Psych readers:	YES	NO	DO NOT KNOW
- Exorcism:	YES	NO	DO NOT KNOW
- Pray to saints or supplication therapy	YES	NO	DO NOT KNOW
- Traditional medicine:	YES	NO	DO NOT KNOW

2. Have you ever **USED** anything other than **conventional antiseizure medicine** to treat your patients? YES NO

If yes, name what you have used or tried:

How did its effectiveness compare with the effectiveness of the medicines you prescribed? Less effective More effective Equally effective

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