Perception and Use of Complementary and Alternative Medicine among Children and Adults with Epilepsy: The Importance of the Decision Makers

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Received: 12 Nov. 2012; Accepted: 26 Apr. 2013

Abstract- The aim of the current study was to assess the extent to which complementary and alternative medicine (CAM) has been used in children and adults to treat seizures and to compare the perceptions and usage of CAM between adult patients who decides for themselves and adults who decide for their sick children.In this cross-sectional study, patients who have been treated for epilepsy for at least one year at the outpatient epilepsy clinic at the Shiraz University of Medical Sciences were interviewed from January 2012 through March 2012. The questionnaire collected specific information of CAM perceptions and usage among patients. Pearson Chi-Square and Student's t- test were used to compare variables among children group with adults group. Ninety-eight children (their caregivers) and 158 adults (themselves) participated. Adult patients (53%) more frequently believed that CAM might be useful in treating seizures than adults with sick kids (35%) (P = 0.0004). Herbal drugs, traditional medicine and exercise were more often considered as being helpful in treating seizures among adult patients compared to adults with sick children. CAM usage was not different among adult patients compared to adults with sick kids (P = 0.3). CAM is an option considered by many people with epilepsy to treat seizures. The individual who makes the decision as to use any of these unconventional treatment options is probably not different when it comes to self (the patient himself) vs. non-self (the parents / care-givers), despite the observed difference that adult patients more frequently believed that CAM might be useful in treating seizures than adults with sick kids.

Acta Medica Iranica, 2014;52(2):153-157.

Keywords: Complementary and alternative medicine; Epilepsy; Children; Adults

Introduction

Complementary and alternative medicine (CAM) is defined as ''those healthcare and medical practices not currently an integral part of conventional medicine.'' (1). It is estimated that more than 80% of the population in developing countries and more than 40% of the population in most Western countries use CAM for various health conditions, including epilepsy (2,3). CAM is a treatment option for epilepsy considered by many patients and / or their caregivers, despite the lack of enough scientific proof for its efficacy (3). The aim of the current study was to assess the extent to which complementary and alternative medicine (CAM) has been used in children and adults to treat seizures and to compare the perceptions and usage of CAM between adult patients who decides for themselves and adults who decide for their sick children to explore any possible differences among self vs. non-self decision-makers.

Materials and Methods

In this cross-sectional study, all patients who have been treated for epilepsy for at least one year were recruited at the outpatient epilepsy clinic at the Shiraz University of Medical Sciences, from January 2012 through March 2012. All the patients had access to healthcare facilities. The diagnosis of epilepsy was made based on the clinical grounds and EEG findings. Patients (if older than 18 years of age) or their caregivers (if the patient was younger than 18 years) who were physically able to speak, hear, and read were eligible to participate in the study. A questionnaire was designed for this study

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(Appendix 1). The questionnaire collected some demographic data on the person who was filling it (either the patients if older than 18 years or their caregivers if the patient was younger than 18 years), some demographic and clinical data about the patient, and also specific data about CAM perceptions and usage.

This survey was conducted with the approval by the Shiraz University of Medical Sciences Review Board. However, the Ethics committee did not allow us to include two questions in the survey: the questions on "Pray to saints or Holy places" and "Supplication therapy (verses from Holy books or Saints)". The patients were informed about the study and if agreed, participated. Pearson Chi-Square and Student's t-test were used to compare variables among children group with adults group. Then, all independent variables in each group (children and adults) were correlated with the dependent variable: the perception about CAM. The X2 test and Student's t- test were used for univariate analyses. Subsequently, multivariate analysis using logistic regression was performed on variables that were significant ($P < 0.05$) in univariate analysis.

Result

The caregivers of 98 children with epilepsy and 158 adults with epilepsy (themselves) participated in this study. The characteristics of the participants are summarized in table 1. Perception of usefulness of complementary and alternative medicine among adults with sick children and adult patients with epilepsy are summarized in table 2.

Table 1. The characteristics of the participants*

	Caregivers (of patients below 18 years of age)	Patients (older than 18 years of age)	P value
Sex ratio of the interviewee (Male / Female)	33 / 65	81 / 77	0.006
Education of the interviewee (under diploma, diploma, university)	34 / 31 / 30	35 / 58 / 65	0.056
Age of the interviewee (mean ± standard deviation)	34.6 ± 6.8	28.5 ± 7.6	0.001
Duration of epilepsy (in the patient)	5 ± 3.6	11.3 ± 8.7	0.001
Anti-epileptic drugs in the patient (monotherapy vs polytherapy)	47 / 44	84 / 69	0.6
Uncontrolled seizures in the patient (having any seizure in the past year)	71	92	0.08
Having comorbidity in the patient	27	35	0.3

* Some data are missing in each cell

Table 2. Perception of helpfulness of complementary and alternative medicine: adults with sick children compared to adults with epilepsy

Method	Yes (Caregivers / Patients)*	No (Caregivers / Patients)	Do Not Know (Caregivers / Patients)	P value
Herbal drugs	16 / 37	21 / 13	60 / 107	0.007
Traditional Medicine	1 / 16	27 / 33	70 / 106	0.01
Exercise	17 / 55	15 / 21	65 / 82	0.01
Yoga	7 / 24	9 / 19	82 / 113	0.08
Meditation	2 / 10	8 / 18	88 / 129	0.1
Tai chi	0 / 3	8 / 15	90 / 140	0.3
Hypnosis	2 / 6	10 / 19	86 / 133	0.6
Acupuncture	0 / 8	11 / 20	87 / 130	0.06
Chiropractic care	0 / 0	8 / 17	90 / 140	0.4
Massage therapy	8 / 11	13 / 21	77 / 126	0.9
Reflexology	0 / 3	9 / 15	89 / 140	0.3
Aromatherapy	0 / 4	12 / 14	86 / 140	0.2
Homeopathy	1 / 2	9 / 15	88 / 141	0.9
Biofeedback	0 / 1	8 / 14	90 / 143	0.7
Ayurvedic medicine	0 / 0	7 / 12	91 / 145	0.8
Psych readers	0 / 1	49 / 77	46 / 80	0.6
Exorcism	2 / 1	52 / 78	44 / 79	0.4
Total persons who answered YES to any question	Caregivers: 34 (35%) / Patients: 84 (53%)			0.004

* Caregivers: adults taking care of children with epilepsy
Patients: adults with epilepsy

Adult patients more frequently believed that CAM might be useful in treating seizures than adults with sick

kids. Herbal drugs, traditional medicine and exercise were more often considered as being helpful in treating seizures among adult patients compared to adults with sick children. Complementary and alternative medicine usage among children and adults with epilepsy is shown in table 3. Reasons for using CAM (table 4) and reasons for not using CAM (table 5) were not different among adult patients compared to adults with sick kids.

Table 3. Complementary and alternative medicine usage: adults with sick children compared to adults with epilepsy

CAM* used by the patient	Caregivers (of patients below 18 years of age)	Patients (older than 18 years of age)	P value
Herbal and traditional medicine	6 (6%)	18 (11%)	0.16
Exorcism	0	1	-
Yoga	0	1	-
Massage therapy	1	0	-
Homeopathy	1	0	-
Relaxation techniques	1	0	-
Others (not specified)	1	3	-
Total persons used CAM [N (%)]	10 (10%)	23 (14.5%)	0.3

* CAM: Complementary and alternative medicine

Table 4. Reasons for using complementary and alternative medicine: adults with sick children compared to adults with epilepsy *

Reason	Caregivers [N (%)]	Patients [N (%)]	P value
High cost of AEDs**	0	5 (22)	0.16
Low AED efficacy	4 (40)	11 (48)	0.34
AED adverse effects	2 (20)	8 (35)	0.22
Do not believe in AEDs	1 (10)	1 (4)	1.00
Others	6 (60)	11 (48)	0.8

*participants could select more than one answer
** AED: antiepileptic drug

Table 5. Reasons for not using complementary and alternative medicine: adults with sick children compared to adults with epilepsy *

Reason	Caregivers [N (%)]	Patients [N (%)]	P value
Lack of enough information about CAM**	61 (69%)	98 (73%)	0.25
Fear of medical interactions	25 (28%)	35 (26%)	0.53
Fear of adverse effects of CAM	25 (28%)	33 (24%)	0.39
High cost of CAM	4 (5%)	9 (7%)	0.56
Others	9 (10%)	12 (9%)	0.65

* Participants could select more than one answer.
* * CAM: Complementary and alternative medicine

Among children, five patients used CAM for less than six months, and five of them used CAM for longer periods of time. Among adults, 10 patients used CAM for less than six months, and 13 persons used it for longer periods of time. The difference was not significant (P = 0.5). Effectiveness of the CAM used by the patients compared to their AEDs was described as less effective in six patients (60%) in kids and10 (43%) in adults; more effective in three people (30%) in kids and six (26%) in adults; not different in one (10%) kid and 7 (30%) adults; the differences were not significant (P > 0.1).

Thirty-four patients (35%) in kids group and 84 people (53%) in the adults group thought that at least one of the items questioned might be helpful to treat seizures and answered "YES" to at least one question (Table 2). Comparisons of the people who said, "YES" to any question with the others in the kids group did not show any significant differences with regards to the sex (P = 0.2), education (P = 0.2), degree of seizure control (P = 0.7), duration of the disease (P = 0.052), age of the patient (their kid) (P = 0.7), age of the interviewee (P = 0.2), and having comorbidity (P = 0.5). Therefore, we did not do multivariate analysis (logistic regression) in this group. Comparisons of the people who said, "YES" to any question with the others in the adults group did not show any significant differences with regards to the sex (P = 0.7), degree of seizure control (P = 0.2), age of the interviewee (the patient himself) (P = 0.8), and having comorbidity (P = 0.5). However, education (P =

0.006) and duration of the disease (P = 0.01) were significantly different between those who thought CAM is useful and non-believers. Among patients who said CAM might be helpful, 13 (15%) had high school education (10 years or less of education), 27 (32%) had diploma (11 or 12 years of education), and 44 (53%) had university education. Among non-believers these figures were 22 (30%), 31 (42%), and 21 (28%), respectively. Duration of epilepsy among believers was 12.8 ± 9.5 and in non-believers was 9.5 ± 7.5 years. In adults group, the full model containing both predictors was statistically significant (X2 = 18.64; P = 0.0001), indicating that the model was able to distinguish between CAM believers and the others. The model correctly classified 65% of the interviewees. Within the model the following results were observed: high school educational level (P = 0.15, Odds Ratio = 0.5, 95% confidence interval = 0.2 – 1.26), university educational level (P = 0.024, Odds Ratio = 2.4, 95% confidence interval = 1.12 – 5.06), duration of the disease (P = 0.008, Odds Ratio = 1.06, 95% confidence interval = 1.01 – 1.1).

Note: The numbers of CAM users were small in both groups; therefore, we did not perform the above procedure for the people who have actually tried CAM for their illness

Discussion

Epilepsy ranks among the most common chronic neurological disorders. The prevalence of epilepsy ranges between 0.6% and 1% and perhaps fifty million worldwide suffer from this condition (4). On the other hand, more than 30% of individuals with epilepsy have persistent seizures despite use of appropriate anti-epileptic drugs (5). Once two drugs have failed, other treatment options should be considered to treat the seizures (4). Complementary and alternative medicine is an option considered by many people with epilepsy, despite the lack of enough scientific proof for its efficacy (3, 6). In a previous Western study (7), it was observed that 39% of the participants reported using CAM; 25% reported using CAM specifically for their epilepsy. However, in that study, prayer/spirituality was the most commonly used form of CAM (46%), followed by ‘‘mega’’ vitamins (25%), chiropractic care (24%), and stress management (16%). Due to the fact that our Ethics committee did not allow questions related to prayer/spirituality to be included in the survey, we cannot provide a valid comparison with other studies with regards to the frequency of CAM application in treating seizures.

In our study, 35% of adults with sick children and 53% of adult patients thought that at least one of the items questioned might be helpful to treat seizures (P = 0.004). The difference was particularly obvious with more interventional CAM options (e.g., herbal medicine), while more conservative options (e.g., yoga, meditation, and massage therapy) were similarly believed among the two groups. This difference is probably due to the fact that parents are often more careful and considerate when deciding to treat their sick child with an unconventional treatment option that is not recommended by their physician, while adults, who are probably tired of their disease and its conventional treatments, more likely look for other treatment options. However, using CAM to treat seizures was similarly reported by adults with sick children and adult patients themselves. Besides, reasons for either using or not using complementary and alternative medicine among adults with sick children compared with adults with epilepsy were more or less similar; this makes the situation more complicated. In answer to the question that “Why do people use complementary and alternative medicine to treat seizures?” Sirven has mentioned three possible theories. First, high failure rates of conventional therapies; second, the comorbidities of epilepsy; and finally, the perception that CAM may be more natural and less toxic than traditional therapies (3). Most probably, all these theories are valid and contribute to the use of CAM by people with epilepsy to some extent. However, there are probably more factors involved in making such a decision. In a previous study (8), it was observed that CAM use in the past was independently related to gender, economic status, and a belief in the safety of CAM, while their use in the near future was independently associated with the experience with CAM use in the past and a belief in the safety of it.

In this study, we could not find a model to predict who thinks that CAM is effective in treating seizures in the kids group. However, we found a model among adult patients. The model correctly classified most of the interviewees. Within this model, educational level (having university education) made a significant contribution. In other words, people with epilepsy who have university education more likely believe and think that CAM could be helpful to treat their seizures. In a previous study, similar result was observed (9). This is probably due to the fact that people with higher education more often have access to available resources of information (e.g., internet) and is able to look for other therapeutic options for their problem.

Limitations of the study

1. The restriction applied by the Ethics committee on two questions (the questions on "Pray to saints or Holy places" and "Supplication therapy (verses from Holy books or Saints)".) did not allow us to compare these data with other studies.

2. The two groups were not completely matched with regards to the age and duration of their illness. However, they were all adults, and they have been challenging with epilepsy for at least one year.

3. We did not look at income. It might influence whether the patients could afford CAM options or not.

Complementary and alternative medicine is an option considered by many people with epilepsy to treat seizures. The individual who makes the decision as to use any of these unconventional treatment options is probably not important when it comes to self (the patient himself) vs. non-self (the parents / care-givers), despite the observed difference that adult patients more frequently believed that CAM might be useful in treating seizures than adults with sick children. Educational level might influence these perceptions, but further investigation is necessary to clarify the factors involved in making the perceptions of CAM by people with epilepsy and the rationale as to why they choose these therapies.

Acknowledgment

We would like to appreciate Dr. Michael Sperling for his thoughtful comments and the Research Center for Traditional Medicine and History of Medicine, Shiraz University of Medical Sciences, Shiraz, Iran for financially supporting this study.

References

1. Eisenberg DM, Davis RB, Ettner SL, et al. Trends in alternative medicine use in the United States, 1990 - 1997: results of a follow-up national survey. JAMA 1998;280(18):1569-75.
2. Shaikh BT, Hatcher J. Complementary and alternative medicine in Pakistan: Prospects and limitations. Evid Based Complement Alternat Med 2005;2(2):139-42.
3. Sirven JI. Alternative therapies for seizures: Promises and dangers. Semin Neurol 2007;27(4):325-30.
4. Asadi-Pooya AA, Sperling M, editors. Antiepileptic Drugs: A Clinician's Manual. 1st ed. Oxford: Oxford University Press; 2009.
5. Kwan P, Brodie MJ. Early identification of refractory epilepsy. N Engl J Med 2000;342(5):314-9.
6. Schachter SC. Complementary and alternative medical therapies. Curr Opin Neurol 2008;21(2):184-9.
7. Liow K, Ablah E, Nguyen JC, et al. Pattern and frequency of use of complementary and alternative medicine among patients with epilepsy in the Midwestern United States. Epilepsy Behav 2007;10(4):576-82.
8. Kim IJ, Kang JK, Lee SA. Factors contributing to the use of complementary and alternative medicine by people with epilepsy. Epilepsy Behav 2006;8(3):620-4.
9. Easterford K, Clough P, Comish S, et al. The use of complementary medicines and alternative practitioners in a cohort of patients with epilepsy. Epilepsy Behav 2005;6(1):59-62.