# Association between complementary and alternative medicines (CAM) usage and self-perceived cognitive impairment among epilepsy patients

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## Abstract

**Context:** Patients with epilepsy may experience a broad range of cognitive impairments. Self-reporting of symptoms may be confounded by the limited insight of cognitive problems, anxiety, concerns about the safety of AEDs and cultural norms which may lead to reliance on other therapies. **Aims:** This study aimed to evaluate self-perceived cognitive impairment and its association with CAM usage among epilepsy patients. **Settings and Design:** A cross-sectional survey was performed in 100 patients diagnosed with epilepsy at the Neurology clinic. Patients aged 18 years or older, without documented physical or psychiatric illness such as schizophrenia and major depression, were included. **Methods:** Self-administered questionnaire was used to assess CAM usage. An established questionnaire was used to determine subjective cognitive impairment. **Statistical Analysis Used:** Data were analyzed using descriptive and inferential analysis. **Results:** Prevalence of self-perceived cognitive impairment was found to be at 31%. More than half of patients reported moderate/severe problems in fatigue, slowing, and memory categories. The prevalence of CAM usage was found to be at 58%. CAM use was more frequent in males (32%) as compared to females (26%; p = 0.609). The most commonly used CAM included vitamins and minerals (36%), ginseng (16%), antioxidants (15%), and acupuncture (12%). The reasons for CAM usage were cheaper price, easier availability, and inadequate seizure control by AEDs. A significant association was found between subjective cognitive impairment and CAM usage (p<0.01). **Conclusions:** A high prevalence of CAM usage among epilepsy patients was identified. There was a significant association between CAM usage and patient self-perceived cognitive impairment.

Keywords: Epilepsy, Complementary and Alternative Medicine, CAM, Cognitive status

#### INTRODUCTION

Epilepsy patients experience a broad range of subjective cognitive impairments.<sup>[1]</sup> Self-reporting of symptoms may be confounded by limited insight into their cognitive problems, concerns about the safety of AEDs, and cultural norms which may lead to reliance on other therapies.<sup>[2,3]</sup> CAM is taken by epilepsy patients as an alternative treatment option even though its effectiveness has not been established.<sup>[4]</sup> The type of CAM used may vary due to differences in cultural norms and healthcare settings.<sup>[5]</sup> Data on CAM usage and subjective cognitive impairment among epilepsy patients in Malaysia is limited. This study aimed to explore the prevalence of subjective cognitive impairment and its association with CAM usage among epilepsy patients.

# METHODS

#### Study Design

We conducted a cross-sectional survey of 100 epilepsy patients diagnosed at UKMMC. The study was conducted from March 2017 to November 2018.

## Study Population and Sampling Method

Epilepsy patients attending the neurology clinic at the Universiti Kebangsaan Malaysia Medical Center. The patients were recruited from the neurology clinic at the Hospital Universiti Kebangsaan Malaysia. Data was collected using convenient sampling. A list of patients was obtained from the clinical appointment record and the patients were

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randomly called in the physicians' room. Patients were recruited based on the following criteria.

#### Inclusion criteria

Epilepsy patients attending the neurology clinic at the Hospital Universiti Kebangsaan Malaysia, who were 18 years or older, taking AEDs for at-least 6 months were included.

## **Exclusion criteria**

Patients with a physical or psychiatric illness such as schizophrenia and major depression, critically ill patients, and those who refused to participate in this study and patients not fit to be interviewed determined by the physicians were excluded.

## Survey items

The questionnaires comprised of seven main sections which were adapted from previous studies.<sup>[6,7]</sup> Section A captured basic socio-demographic data, including age, gender, religion, marital status, level of education, monthly income, number of comorbidities, and number of medications. Section consists of the ABNAS В questionnaire (A-B Neuropsychological Assessment Schedule) which was used to measure subjective cognitive performance. It comprises of 24 statements across five domains: fatigue, slowing, memory, concentration, and motor coordination and language, with an overall score from 0 (no symptoms) to 72 (severe symptoms). A cut-off score of above 15 ("high") has been previously established to identify those with significant subjective symptoms. Section C of the survey covered the types of CAM used.

## Translation

The forward and backward translation of the questionnaire was performed by a registered proof-reading company. The translated version of the form was then reviewed by two academicians and one practicing pharmacist who are well familiar with Malay and English languages.

#### **Ethical Considerations**

Ethical approval was obtained from the UKMMC human ethics committee and the reference number was UKM PPI/111/8/JEP-2017-138. Informed consent was obtained from all patients before participation in the study.

## **Data Collection**

The patients were approached in the physician's room after they completed the doctor's consultation. They were informed about the purpose of the research and invited to participate in the study. Written informed consent was taken from those patients who agreed to fill the self-administered questionnaires. When appropriate, the nurses also assisted the patients in filling the questionnaires.

## **Data Analysis**

Statistical analyses were performed using the IBM SPSS Statistics Version 23. Data were analyzed using descriptive

and inferential analysis. For categorical variables, frequencies and percentages were used, while for continuous variables describing the study population, descriptive statistics, which included mean and standard deviation (SD), were used.

# **R**ESULTS:

In total, 47 females and 53 males between the ages of 18 and 79 years were recruited in the study. The mean age was 40.18 (SD 17.9) years. Majority of the patients were Malay (n = 51), and Chinese (n = 36), and the remaining patients were Indian (n = 13). Patients represented a variety of education levels from no formal education to post-graduation. The number of comorbidities varied among patients (range between 0 to 4) with a mean of 1.87 (SD 1.01). Thirty-one percent (31%) of patients showed evidence for subjective cognitive impairment (ABNAS score >15). ABNAS scores were significantly higher among the Indian race and Hindu religion (p<0.01). The socio-demographic characteristics of patients, self-perceived cognitive impairment, and CAM usage are presented in Table 1.

Thirty-one (31%) patients scored themselves as 'high' on the ABNAS indicating self-perceived cognitive impairment. More than half of the patients reported moderate/severe problems in fatigue, slowing, and memory categories. The percentage of patients reporting problems in each of the ABNAS domains is shown in Table 2.

The prevalence of CAM use was found to be at 58% among the studied population. CAM use was more frequent in males (32%) as compared to females (26%). Seventy-nine percent of patients reported that they have heard of CAM. The primary sources of information on CAM were friends (39%), family (27%), internet (19%) and doctor (15%). The most commonly used CAM included vitamins and minerals (36%), ginseng (16%), antioxidants (15%), and acupuncture (12%). The majority (68.1%) of the patients reported that CAM is effective. The main reasons for using CAM were cheaper price, easy availability, and inadequate seizure control by AEDs. The type and distribution of CAM used are summarized in Table 3. There was a significant association between CAM usage and subjective cognitive status. The relationship between CAM usage and self-perceived cognitive impairment is shown in Table 4.

# DISCUSSION

Epilepsy is a stigmatizing neurological disorder that often results in a significant physical, psychological, and financial burden on individuals and families.<sup>[8]</sup> Problems associated with epilepsy are further aggravated when patients neglect the antiepileptic drug (AED) therapy due to limited insight into their cognitive problems, anxiety, concerns about the safety of AEDs, and cultural norms and begin depending on other options of treatments.<sup>[9,10]</sup> The goal of this study was to evaluate patient's self-perceived cognitive impairment and its association with CAM usage among epilepsy patients.

More than half of the patients reported moderate/severe problems in fatigue, slowing, and memory categories of ABNAS. Similar results for fatigue, memory, and motor symptoms were reported by patients in the previous study except for slowing which was higher in this study. <sup>[11]</sup> Concentration and language problems were less reported in this study. The perception of impaired cognition was more prevalent among the Indian race and Hindu religion. Race, religion, and cultural influence may affect the medicationtaking behavior. A study done in India showed that although patients were convinced of the necessity of AED, some doubted their personal need for AED. More than half reported strong concerns about the potential negative effects of AED. <sup>[12]</sup> However, studies were done in the UK and South Africa, patients reported high necessity and low concerns about AED side effects. <sup>[13,14]</sup> This shows that patients with different cultural and racial backgrounds will have different medication seeking behavior.

The findings revealed a high prevalence of CAM usage among epilepsy patients. The global prevalence of CAM use reported in previous studies was between 7.5% and 73.3%. The statistics also showed that CAM was more abundantly used in developed countries compared to that in the developing countries.<sup>[4]</sup> Although Malaysia is a developing country, the higher prevalence of CAM usage may be due to the multi-racial culture in Malaysia where the people have various treatment choices ranging from culturally specific traditional medicines to modern CAM.

The most popular CAM reported in this study were vitamins and minerals, ginseng, antioxidants, and acupuncture. The type of CAM usage varied between different age-groups. Acupuncture, traditional Chinese and Malay medicines were mostly used by elderly patients while the younger population was seen to be widely using vitamins and supplements due to marketing and promotional strategies used by the companies to attract younger patients. The higher use of CAM in the elderly can be justified by the increased number of chronic diseases, most of which can only be controlled and not cured in the current therapeutic scenario.<sup>[15,16]</sup> The types of CAM used in this study were comparable to previous studies, other than some variation that was caused by differences in cultural and traditional norms.<sup>[17,18]</sup> For example, in Western countries, the use of vitamins, herbs, and yoga was more prevalent.<sup>[19-21]</sup> Prayer for health and amulets was common in Middle-eastern countries.<sup>[22]</sup> In India, Ayurveda was more frequently practiced.<sup>[23,24]</sup> Whereas, in Taiwan, traditional Chinese medicines were seen to be used more frequently.<sup>[25]</sup>

There was a significant association between CAM usage and patient self-perceived cognitive impairment, patients with higher self-perceived cognitive impairment were more likely to rely on CAM as compared to patients with low selfperceived cognitive impairment. This highlights the need for further examination of such patients. Community pharmacists and doctors should educate the patients on the safety of AEDs and expected side effects and also encourage them to report healthcare professionals upon appearing any unwanted side effects. Moreover, appropriately counsel the patient on CAM use and misuse, and possible interactions with AEDs. This may indirectly optimize the therapeutic outcome and minimize interactions with AED, hence improving a patient's quality of life.

#### Limitations

Although the current study has highlighted a significant association between self-reported cognitive symptoms and CAM usage, this finding should be utilized in caution due to several possible limitations. A substantial number of patients refused to take part in this survey, the study cohort may not fully represent the whole epilepsy population. As we have described earlier, cultural components may also influence the practice of CAM, thus different geographical regions may have different findings. Additionally, an intensive investigation into the effects of CAM's use on epilepsy control would provide insight into the potential benefit and harm of CAM.

# CONCLUSION

A high prevalence of CAM usage among epilepsy patients was identified. There was a significant association between CAM usage and subjective cognitive impairment. The use of CAM and its types should be explored with patients before clinical decisions are made to achieve the best treatment outcomes from AED therapy. There is a need for patient education related to CAM use and AED therapy.

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Item	self-perceived cognitive impairment		p-value	CAM Usage		p-value
	Yes	No		Yes	No	-
Age in years, mean (SD)	49.00 (16.43)	44.71 (16.88)	0.239 <sup>a</sup>	47.67(17.27)	43.79 (15.09)	0.255ª
Gender, n (%)						
Male	17 (32.1)	36 (67.9)	o oosh	32 (60.4)	21 (39.6)	0.609 <sup>b</sup>
Female	14 (29.8)	33 (70.2)	0.805 <sup>b</sup>	26 (55.3)	21 (44.7)	
Race, n (%)						
Malay	13 (25.5)	38 (74.5)		26 (51)	25 (49)	0.214 <sup>b</sup>
Chinese	9 (25.0)	27 (75.0)	0.006 <sup>b</sup>	22 (61.1)	14 (38.9)	
Indian	9 (69.2)	4 (30.8)		10 (76.9)	3 (23.1)	
Education Level, n (%)						
No formal education	0 (0)	2 (100.0)		0 (0)	2 (100)	
Primary school	8 (44.4)	10 (55.6)		12 (66.7)	6 (33.3)	0.080 <sup>b</sup>
Secondary school	16 (33.3)	32 (66.7)		30 (62.5)	18 (37.5)	
Diploma	3 (50.0)	3 (50.0)	0.174 <sup>b</sup>	4 (66.7)	2 (33.3)	
Degree	2 (10.0)	18 (90.0)		7 (35)	13 (65)	
Post-graduate degree	2 (33.3)	4 (66.7)		5 (83.3)	1 (16.7)	
Marital Status, n (%)						
Single	15 (28.8)	37 (71.2)		32 (61.5)	20 (38.5)	0.751 <sup>b</sup>
Married	15 (32.6)	31 (67.4)	0.776 <sup>b</sup>	25 (54.3)	21 (45.7)	
Divorced	1 (50.0)	1 (50.0)		1 (50)	1 (50)	
Religion n (%)						
Muslim	13 (24.5)	40 (75.5)		20 (37.7)	33 (62.3)	
Hindu	9 (75.0)	3 (25.0)	0.002 <sup>b</sup>	2 (16.7)	10 (83.3)	0.375 <sup>b</sup>
Christian	0 (0)	7 (100.0)		3 (42.9)	4 (57.1)	
Buddhist	9 (32.1)	19 (67.9)		7 (25.0)	21 (75.0)	
umber of co-morbidities, mean (SD)	1.94 (0.99)	1.84 (1.02)	0.667 <sup>a</sup>	2.0 (1.0)	1.69 (0.9)	0.132ª

Table 1. Socio-demographic characteristics, patient self-perceived cognitive impairm	ent, and CAM usage
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<sup>a</sup> = Independent t-test, <sup>b</sup>= Chi-square test

Table 2. Number of patients with moderate/serious symptoms in each of the ABNAS domains			
ABNAS Domain	Patients, n (%)		
Fatigue	51 (51)		
Slowing	60 (60)		
Memory	54 (54)		
Concentration	34 (34)		
Motor coordination	23 (23)		
Language	31 (31)		

Table 3. Type and distribution of CAM usage			
Types of CAM used	% of user n (%)		
Mind and Body practice (n=41)			
Acupuncture	10 (17.2)		
Aromatherapy	5 (8.6)		
Cupping	5 (8.6)		

11 (18.9)	
5 (8.6)	
5 (8.6)	
15 (25.8)	
1 (1.7)	
16 (27.5)	
4 (6.8)	
6 (10.3)	
36 (62)	
3 (5.17)	
8 (13.7)	
4 (6.89)	
7 (12)	
	5 (8.6) $5 (8.6)$ $15 (25.8)$ $1 (1.7)$ $16 (27.5)$ $4 (6.8)$ $6 (10.3)$ $36 (62)$ $3 (5.17)$ $8 (13.7)$ $4 (6.89)$

Table 4. Relationship of	CAM usage and self-perce	vived cognitive impairment	
ABNAS	CAM	<i>p</i> -value	
-	Yes	No	-
	n (%)	n (%)	
Impaired	25 (80.6%)	6 (19.4%)	<0.01 <sup>a</sup>
Normal	33 (47.8%)	36 (52.2%)	

a= Chi-square test.