

Patient's Practice of Complementary and Alternative Medicine (CAM) for the Management of Epilepsy

Boon-Tiang Lau¹, Mohd Makmor-Bakry², Hui Jan Tan³, Siew-Yen Ng⁴, Adyani Md Redzuan^{5*}

¹ Department of Pharmacy, Hospital Port Dickson, Malaysia. ² Faculty of Pharmacy, Universiti Kebangsaan Malaysia, Kuala Lumpur, Malaysia. ³ Division of Neurology, Department of Medicine, Faculty of Medicine, Universiti Kebangsaan Malaysia, Kuala Lumpur, Malaysia. ⁴ Ampangan Health Clinic, Malaysia. ⁵ Faculty of Pharmacy, Universiti Kebangsaan Malaysia, Kuala Lumpur, Malaysia.

Correspondence: Adyani Md Redzuan, Faculty of Pharmacy, Universiti Kebangsaan Malaysia, Jalan Raja Muda Abdul Aziz, 50300 Kuala Lumpur, Malaysia.
E-mail: adyani @ ukm.edu.my

ABSTRACT

Background: In Malaysia, the prevalence of complementary and alternative medicine (CAM) usage among patients with epilepsy was unknown. We aimed to assess epilepsy patient's practice of complementary and alternative medicine, as well as their beliefs about medicines for the management of epilepsy. **Method:** A cross-sectional study was conducted in a Neurology Clinic in a tertiary teaching hospital in Malaysia. A convenience sampling method was used to recruit epilepsy patients in the study. The main outcome measures were the types of CAM being used and beliefs about medicines questionnaire-epilepsy specific (necessity-concerns differential score). **Results:** A total of 61 patients completed the questionnaire distributed to them, yielding an 89.7% response rate. The majority of the respondents were ≤ 30 years old, Malay, single, employed, had lower monthly income, and on monotherapy of anti-epileptic drugs. There was 42.6% of total respondents used complementary and alternative medicine. The mean Necessity-Concerns Differential score was 0.37(SD \pm 0.768). The bivariable analysis showed employment status was significantly associated with the use of complementary and alternative medicine ($\chi^2 = 8.548$, $p=0.003$). There was also a significant association between education levels and the Necessity-Concerns Differential score [$t(59) = 2.425$, $p=0.018$]. The results from multiple logistic regression suggested that respondents' employment status significantly influenced the use of CAM. Those who were employed/self-employed had an increased odds of 3 times (AOR=3.375, 95% CI 1.154:9.867) in using the therapy compared with those who were not employed. **Conclusion:** The majority of the epilepsy patients were non-user of the therapy, and convinced of the necessity of anti-epileptic drugs.

Keywords: Complementary and alternative medicine; traditional medicine; epilepsy; beliefs about medicines; beliefs about anti-epileptic drugs

Introduction

Epilepsy, one of the most common neurological disorders, ranks fifth for its impact on the disability and premature mortality

among mental health, neurological, and substance use disorders in low- and middle-income countries [1]. Statistics from the World Health Organization (WHO) show that approximately 50 million people suffer from epilepsy [2], and it has accounted for 9.9% of disability-adjusted life years of neurologic disorders and cerebrovascular disease combined burden [3]. The incidence of epilepsy has been reported to be 40-70/100,000 persons/year in developed countries, and above 120/100,000 persons/year in resource-poor countries [4]. In Asia, the prevalence of epilepsy ranges between 1.5 and 14 per 1000 people [5], while Malaysia has approximately 1% of its population diagnosed with epilepsy [6].

It is estimated that 4-10 per 1000 people in a general population require or need to continue treatment for epilepsy [2]. Although

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antiepileptic drugs (AEDs) remain as the mainstay for epilepsy treatment, some patients prefer to use complementary and alternative medicine (CAM) for their epilepsy management. Various CAM have been practiced among people of different ethnic, regional, and religious backgrounds globally. National Centre for Complementary and Integrative Health (NCCIH) defined CAM as a group of healthcare approaches that is not part of Western, or conventional medicine [7]. The term "complementary" is used when a non-mainstream practice is used together with conventional medicine [7]. On the other hand, the term "alternative" is used when a non-mainstream practice is used in place of conventional medicine [7].

It is estimated that more than 40% of the population in Western countries and greater than 80% of the population in developing countries use CAM for various health conditions [8,9]. In Malaysia, the prevalence of ever-used traditional and complementary medicine in the lifetime of non-institutional living quarters residents is 69.4% [10], indicating that the CAM utilization rate is high among Malaysian. Importantly, patients may not reveal the use of CAM to doctors or allied healthcare professionals, including those patients with epilepsy [11-13]. There are studies reporting patients with epilepsy (PWE) expressed their personal need for AEDs but worried about the adverse effects of AEDs at the same time [14, 15]. This eventually affected their adherence to AEDs [15].

Given the limited information regarding CAM usage and beliefs about AEDs among PWE in Malaysia, it was the objective of this study to assess factors affecting patients' beliefs about AEDs, also, to explore their practice of CAM for the management of epilepsy at a tertiary teaching hospital in Malaysia.

Methods

Study Design

This was a cross-sectional study conducted among PWE who attended the Neurology Clinic in a tertiary teaching hospital in an urban area of Malaysia. Data collection was conducted over six months.

Study Subjects

Patients with documented epilepsy, 18 years old and above, prescribed with AEDs prior to the study, and able to read and understand English or Malay language met the inclusion criteria. Patients were excluded if they could not and/or unwilling to conduct the research questionnaire, with concomitant psychosis and schizophrenia, or diagnosed with mental retardation. Written informed consent was obtained from all participants before their inclusion in the study.

The targeted sample size for this study was 48, with an alpha of 0.05, a power of 0.80, an odds ratio of 2.11 [16], nine predictors and a two-tailed test [17, 18]. The number was then escalated to account for a 20% non-response rate. Based on the aforementioned assumptions, the desired sample size was 58.

Potential study subjects were identified on every Neurology Clinic day (Tuesday, 8 am to 1 pm) throughout the study period

excluding public holidays. On the appointment dates, the researcher screened through patients' hardcopy medical records to identify patients that fulfilled the inclusion criteria. Subsequently, patients who attended the clinic were approached by the researcher and were asked if they would agree to take part in the study. The study questionnaires were then distributed to those participating subjects and they would be assisted by the researcher upon request. Nonetheless, data of patients would not be recorded if they missed the appointment or presented other than the scheduled date.

Data Collection

A set of questionnaires consisting of three sections was used. Section A was about the socio-demographic values of respondents, section B was about the practice of CAM [10-13], and section C was about beliefs about medicines questionnaire (BMQ).

In section C, BMQ-Epilepsy Specific was adopted [15]. The tool has 2 scales, namely AED-Necessity and AED-Concerns. It had 6 statements in the AED-Necessity scale, and 10 statements in the AED-Concerns scale. Each statement in the BMQ-Specific was scored on a 5-point Likert-scale. The AED-Necessity scale had a score between 6 and 30, and the AED-Concerns scale scored between 10 and 50. The scores summed for AED-Necessity and AED-Concerns were divided according to the number of items in the scales respectively, to obtain the mean item score, i.e. ranged between 1 and 5. The necessity-concerns differential was computed to estimate a rough risk-benefit analysis from a patient's perspective, i.e. the need for taking AEDs (necessity) against the possible negative effects from taking AEDs (concerns). This was done by subtracting the mean AED-Concerns score from the mean AED-Necessity score. Therefore, the score would range between -4 and +4. Positive necessity-concerns differential scores indicated higher ratings of AED-Necessity compared to AED-Concerns.

Validation of Study Instrument

All statements in the questionnaire were developed in both Malay and English languages. The content was then reviewed by 10 pharmacists with at least 5 years of working experience and was not involved in this study. Subsequently, amendments were made accordingly. Further validation of the questionnaire was done among 30 PWE attended Neurology Clinic in UKMMC. The composite Cronbach's alpha coefficient for AED-Necessity and AED-Concerns scales was 0.764, while the individual Cronbach's alpha coefficient for these 2 scales was 0.772 and 0.761 respectively, indicating acceptable internal consistencies [19].

Statistical Analysis

IBM SPSS Statistics version 22.0 was used for data analysis. The Pearson Chi-square analysis was used to compare the use of CAM and socio-demographic data. Conversely, independent t-test or Student's t-test was used to compare necessity-concerns differential with socio-demographic data, and use of CAM.

Subsequently, all variables were included in the multiple logistic regression analysis regardless of the significant level of an individual variable in the bivariable analysis. The adjusted odds ratio, 95% confidence interval, and p-value were computed accordingly. A confidence interval of 95% was utilized and a p-value of less than 0.05 was determined as statistically significant.

Results

Socio-Demographics of Respondents

68 epilepsy patients met the inclusion criteria. However, 7 patients were unwilling to be interviewed. Thus, this yielded an 89.7% response rate at the end of the study period. There was similar distribution in gender and age of the respondents but most of them were Malay, single, employed, had lower monthly income, and prescribed with monotherapy of AEDs. The socio-demographic values of respondents were presented in Table 1.

The Practice of Complementary and Alternative Medicine

Less than half of the respondents (42.6%) used CAM in the past year or by the time of the study. The massage was reported to be the most common CAM practiced in the previous year, while respondents mainly practiced prayer currently. Vitamin and supplement were the main ingestible CAM taken by the respondents currently. Many respondents used CAM specifically for epilepsy (23.1%) or for both epilepsy and general health (23.1%). CAM users were generally satisfied with the CAM they practiced (92.3%). The majority of the respondents revealed that they would rather discuss the use of CAM with CAM practitioners than with the prescriber. The sources of CAM reported in this study were mainly family members and friends. Details on the practice of CAM among the respondents were summarized in Table 2 and Table 3.

Beliefs about Medicine Questionnaire-Epilepsy Specific

73.8% of respondents expressed their necessity for AEDs (scored 19 and above in the AED-necessity scale) and over half of them (54.1%) showed their concerns about the potential negative effects of taking AEDs (scored 31 and above in AED-Concerns scale). The mean necessity-concerns differential score computed was 0.37 (SD=0.77), indicating that respondents perceived they had a higher need for AEDs in comparison to their worry about negative consequences of AEDs.

Association between Socio-Demographics, Use of Complementary and Alternative Medicine, and Beliefs about Medicine Questionnaire -Epilepsy Specific

Those who were employed/self-employed were more likely to use CAM compared with those who were unemployed, students, retirees, and housewives ($p=0.024$). In the context of beliefs about AEDs, those who received low-middle education had significantly higher necessity-concerns differential scores (0.56

+/- SD=0.642) compared to those who received tertiary education (0.10 +/- SD=0.860), $p=0.018$. There was no significant association between the use of CAM and BMQ-Epilepsy Specific.

Predictors for the Usage of Complementary and Alternative Medicine

Multiple logistic regression was conducted to predict the use of CAM from socio-demographic values and necessity-concerns differential. Both forward and backward likelihood ratio were used and the model fulfilled statistical assumptions. There was no interaction and collinearity found in the model. The results showed that employment status was the only statistically significant variable. Respondents who were employed/self-employed had an increased odd of 3 times (AOR=3.4, 95% CI 1.2-9.9) in using CAM compared with those who were not employed.

Discussion

This study was conducted to explore the usage of CAM and beliefs about AEDs among epilepsy patients from a tertiary hospital. The CAM utilization rate among PWE in the current study was found to be similar to other countries e.g. 31.3% in Seoul, South Korea [20], 32% in North India [21], 34.6% in United Kingdom [22], 39% in the Midwestern United States [11], and 49.1% in Taiwan [16]. It was contrary to the claim that approximately greater than 80% of the population in developing countries dependent on CAM [9], indicating that local PWE preferred conventional medicines rather than seeking CAM for their diseases. Apart from that, lack of understanding about or confidence in the quality, safety, and efficacy of CAM might be accounted for the lower usage of CAM than as expected. Most importantly, there was a potential underreporting of CAM utilization among PWE, because patients who were not interviewed and those who did not take part in this study might use CAM but relevant data was not captured.

Overall, studies reported PWE used CAM for a general health condition and specifically for seizures or epilepsy [11, 13, 20, 22]. This reflected that most of the CAM users considered CAM was useful for general health and believed epilepsy as part of the health issues they would like to tackle along with other co-morbidities. On the other hand, adverse effects were estimated to occur among 2.6% - 43% of CAM users [11, 13, 16, 20]. In this study, there were 2 (7.7%) study subjects that reported the occurrence of adverse effects from the CAM they practiced. Some studies reported that CAM increased patients' seizure frequency and/or severity [11, 13, 16, 20]. The exact figures would be higher because adverse effects were not commonly described in many studies. Although most of the CAM users were satisfied with their practices, not many intended to stop AEDs in favor of CAM. This might be due to satisfactory epilepsy control with AEDs, and patients perceived CAM as part of the treatment that would control epilepsy effectively with AEDs. This was in-line with a national survey

conducted by Eisenberg *et al.* which reported 79% of respondents in the United States agreed that using both conventional and alternative therapies was better than using either one for their problems^[23].

It was not surprising that the majority of PWE used prayer, as well as vitamin and supplement as their main CAM. Prayer^[11, 13] and recitation of the Holy Qur'an^[24] have been reported as the main CAM practiced by PWE in certain parts of the world. Among industrialized nations, the United States has the highest rate of regular church attendance, thus prayers have become the main CAM for them^[22]. Healing of illness such as epilepsy based on spirituality/religion and biologically based practices had been documented too^[24]. Cohen explained PWE who lived in cultures that value spirituality usually turned to this form of CAM because of the hypothesized connection between epileptic seizures and mystical states^[25]. These explained the high usage of the aforementioned modalities among a population with more religious influence or background, and this trend could be observed in the current study.

Studies had shown that PWE preferred not to disclose their CAM utilization due to variable reasons^[11-13]. One of the most common reasons was that doctors did not enquire about it. Prescribers should actively investigate patients' intentions or actual use of CAM because patients would not always voluntarily reveal this information to them. Prescribers should also equip themselves with the knowledge about CAM to enable them to educate patients on the safe use of CAM. Given this, CAM practice and education should be incorporated into the medical and health sciences curriculum in the future^[26]. Additionally, since patients were keen to discuss CAM with a practitioner, healthcare professional and CAM practitioners such as pharmacists should be well-prepared and ready to give appropriate information to patients to improve their understanding of CAM and AEDs.

Most PWE were convinced of the necessity of the AEDs prescribed and concerned about the potential adverse consequences of the drugs^[15]. Necessity-concerns differential scores in this study were lower than previous studies conducted among PWE^[19, 20] and in other chronic illnesses^[27-29]. Chapman *et al.* showed that 84.9% of the respondents expressed their necessity for the AEDs, while 36.4% of them concerned about the potential negative effect of taking AEDs (scores >midpoint on respective scales)^[15]. Specifically, the majority (55.5%) doubted that they would be very ill without AEDs, and almost half (48.7%) concerned about the long-term effects of AEDs^[15]. On the other hand, almost all (95.1%) respondents in the current study doubted that AEDs protected them from becoming worse, and more than half (67.2%) concerned about AEDs would disrupt their life. The dissimilarities observed could be due to a population of different cultural and religious background or beliefs have varied perception towards epilepsy and their prescribed medicines. Besides, the authors suggested that patients' experience with newer AEDs would affect their beliefs towards medicines. In Malaysia, not all the latest AEDs in the market were available in the government-subsidized hospitals and/or primary health clinics. Thus, local patients might have limited access to and/or experience with newer AEDs with

better efficacy and lesser adverse effects. This could, in turn, affect patients' beliefs towards AEDs prescribed for them.

The findings in this study did not support any significant association between the use of CAM and socio-demographic values except for employment status. Although there was no significant association between household income and use of CAM, the authors believed that PWE who were employed/self-employed were more likely to use CAM due to their more secure financial status. Patients with chronic illnesses usually had negative beliefs about medicines and results in poor adherence^[28]. Since patients who are not adherent to medications may look for other options for their illnesses, CAM seems to be an attractive substitute for drug therapy. Therefore, it seems to be a logical indirect relationship between the use of CAM and beliefs about medicines. A lower necessity-concerns differential in this study implied that patient worries about negative consequences of medicines, and subsequently affect their medication-taking behavior. Nonetheless, one must aware that behavior change is a dynamic process and it can be subjected to various influences. At a point in time, people may think about changing when they aware that a problem exists, yet, they have not committed themselves to a plan of action^[30]. A national survey reported use of CAM was significantly correlated with age, education, income, presence of chronic disease, and unmet health need after adjustment for other variables using multivariate logistic regression^[31]. Another study done specifically among PWE in the United States revealed that gender, economic status, and a belief in the safety of CAM were independently related to CAM use in the past^[20]. In Taiwan, a preliminary study reported CAM use was associated with gender, frequency of seizures, educational level of parents, and religious beliefs^[16]. The results aforementioned were not similar to the current one due to differences in the socio-demographic/religious background of the study subjects examined, in addition to different variables being investigated.

Limitations

Despite several important findings highlighted, the results must be interpreted with caution. Due to the nature of the study design, acquiescence biases could occur because study questionnaires were administered by respondents in the presence of the researcher. Besides, the convenience sampling method was used to select eligible patients for the research. A longitudinal study or randomized controlled trial is necessary to reduce possible biases and to answer the causal relationship between the variables. The results obtained currently might not be generalized because it was restricted to PWE in a tertiary teaching hospital in an urban area. Also, limited clinical information and variables were being investigated in this study. More variables can be included for further evaluation in the future.

Conclusions

There were approximately half of the respondents in this study were CAM users. Most of them believed in the necessity of AEDs rather than worried about the potential adverse effects associated with AEDs. The employment status of the respondents was found to be associated with the utilization of CAM. Due to the high usage of CAM among PWE, the doctor should always take initiative to identify which patients are potential CAM users and provide timely education to prevent adverse effects or drug interactions arise from CAM. In the future, studies can involve more participants and investigate the influence of other variables such as adherence, culture, religious background, etc. to CAM utilization patterns among PWE.

Ethics Approval and Consent to Participate

This study was performed after obtaining the approval of the Research Ethics Committee of Universiti Kebangsaan Malaysia, with reference number UKM 1.5.3.5/244/NF-051-14. Informed consent to participate in this study was obtained from each participant at the time of enrollment.

Consent for Publication

All authors provided consent for the publication.

Availability of Data and Materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing Interests

The authors declared that they have no competing interests.

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Table 1: Socio-Demographic Values of Respondents

Characteristics (N = 61)	n	%
Age		
<30 years old	31	50.8
≥30 years old	30	49.2
Gender		
Male	32	52.5
Female	29	47.5
Race		
Malay	33	54.1
Chinese	20	32.8
Indian	8	13.1
Marital status		
Single	37	60.7
Married	24	39.3
Widower/Widow	0	0
Highest educational level		
Primary or lower	7	11.5
Secondary	29	47.5
Tertiary education	25	41.0
Employment status		
Student	6	9.8
Housewife	2	3.3
Unemployed	20	32.8
Employed	24	39.3
Self-employed	8	13.1
Retiree	1	1.7
Household income		
Less than RM 1,000 monthly	12	19.7
RM 1,000 – RM 1,999 monthly	13	21.3
RM 2,000 – RM 2,999 monthly	14	23.0
RM 3,000 – RM 3,999 monthly	8	13.1
RM 4,000 – RM 4,999 monthly	5	8.2
RM 5,000 monthly and above	9	14.8
Number of medicines		
Monotherapy	30	49.2
Polytherapy	31	50.8

Table 2: Respondents' practice of complementary and alternative medicine

Response to Statement	n (%)
Overall Respondents (n=61)	
Use of CAM	Yes = 26 (42.6) No = 35 (57.4)
Among CAM user (n = 26)	
Purpose of using CAM ^a	
For general health	17 (65.4)
For epilepsy	18 (69.2)
For other health problems	8 (30.8)
Assumed efficacy of CAM	18 (69.2)
Satisfaction with CAM	24 (92.3)

Side effects experienced with CAM	2 (7.7)
Discussions with doctor	Yes = 6 (23.1) No = 20 (76.9)
Reason for not discussing CAM with doctor ^b	
Doctor never asked about CAM	11 (55)
No need to discuss with doctor	3 (15)
Doctor might disapprove the use of CAM	0 (0)
Doctor would not be interested about CAM	0 (0)
Never thought about it	10 (50)
Others	1 (5)
Discussion with CAM provider	15 (57.7)
Intention to stop prescribed medication	3 (11.5)
Source of CAM information	
Family	14 (53.8)
Friends	9 (34.6)
Doctors	2 (7.7)
Newspaper/magazine	3 (11.5)
Brochure	1 (3.8)
Others ^c	6 (23.1)

^aSome respondents used CAM for more than one reason^bSome respondents answered more than one reason^cOthers included Pharmacist (n=1), self-volition (n=4), and television (n=1)

CAM = complementary and alternative medicine

Table 3: Types of complementary and alternative medicine used by respondents (n=26)

Types of CAM	Previous ^a	Current ^a
	n of use (%)	n of use (%)
Natural Products ^b		
Herbs	0 (0)	3 (11.5)
Vitamin and supplement	2 (7.7)	6 (23.1)
Mind and Body Practices ^b		
Acupuncture	2 (7.7)	1 (3.8)
Aromatherapy	1 (3.8)	0 (0)
Cupping	0 (0)	1 (3.8)
Massage	4 (15.4)	2 (7.7)
Prayer	3 (11.5)	7 (26.9)
Reflexology	2 (7.7)	1 (3.8)
Tai chi	1 (3.8)	0 (0)
Others ^b		
"Enchanted drinks"	3 (11.5)	2 (7.7)
Traditional Chinese medicine	1 (3.8)	0 (0)

^a Each subject might use more than one CAM previously and/or currently^b CAM was categorized according to NCCAM classification

CAM = complementary and alternative medicine