

ORIGINAL ARTICLE

Complementary and alternative medicine as preferable management of epilepsy among the population of Makkah City: a cross-sectional study

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ABSTRACT

Background: Complementary and alternative medicine (CAM) usage is widespread. Epilepsy patients may believe in administering CAM as a therapy. However, evidence-based data about frequency, types, and drivers for CAM use are scarce. This study aimed at evaluating CAM as preferable management of epilepsy among the population of Makkah City.

Methods: A cross-sectional observational study conducted in Makkah, involving adult patients aged ≥ 18 years diagnosed with epilepsy using a survey questionnaire for 10 months in 2021.

Results: Out of the screened patients, a total of 131 patients fulfilled inclusion criteria, (100%) agreed to participate in the study with a mean age (\pm SD) of 31.4 ± 12.3 years, and 76 (58%) patients were males. About 56.5% of the patients tried using any type of CAM. The most commonly used CAM types were religious healers (78.4%), followed by herbal (56.8%), cupping (33.8%), and acupuncture (33.8%). 52.7% reported that they had no benefit. In comparison, 28.4% reported feeling better and more relaxed, 17.6% experienced staying positive, 12.2% of patients had reduced symptoms or side effects, and 9.5% had more feeling of being in control. Most patients (86.5%) had no complications from CAM. No significant predictive factors were detected for the use of CAM as regards age, gender, education, employment, seizure frequency, and duration, in addition to a family history of epilepsy or usage or compliance to antiepileptic drugs.

Conclusion: Almost half of the people with epilepsy used CAM, mainly through religious healers or herbal medicine. Half of them reported no benefit from CAM usage. Most of them had no complications.

Keywords: Complementary and alternative medicine (CAM), adults, epilepsy, religious healers, herbal medicine, cupping, acupuncture.

Introduction

Epilepsy is a common chronic non-communicable neurological disease. Epilepsy is primarily characterized by unprovoked and recurrent seizures [1]. The clinical diagnosis of epilepsy has been divided into three levels, starting with seizure type described by the revised 2017 International League Against Epilepsy (ILAE) Seizure Classification. Following the seizure type diagnosis, the epilepsy type is determined, which includes focal epilepsy, generalized epilepsy, combined generalized and focal epilepsy, and an unknown epilepsy group. Epilepsy syndrome is the third stage, where a particular syndromic diagnosis can be made [2,3]. According to the World

Health Organization, approximately 50 million people worldwide have been diagnosed with epilepsy [1]. While

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in Saudi Arabia, the prevalence of epilepsy has reached nearly 6.54 per 1,000 [4]. The incidence of seizures is estimated to be 5 to 8 new cases per 1,000 populations by 11, with nearly 50% of all epilepsy beginning under the age of 16 years [5]. When assessing an adolescent or adult with epileptic symptoms, an accurate diagnosis is critical as life-changing consequences, including cognitive impairment, declined neurologic functionality, neurotoxic adverse effects, and increased behavioral side effects may result from an erroneous diagnosis [6,7]. Epilepsy stigma in Saudi Arabia, as in any other Islamic country, is due to religious, cultural, and several conflicting beliefs about the etiology and treatment of epilepsy. Holding religious beliefs, practicing religious rituals, and having family support were vital in dealing with epilepsy, and their contribution needs to be considered in medical management. The vast majority of Muslim people believe that they are totally under God's will and control. People with epilepsy hold this view simultaneously and hold other beliefs and explanations of the causes of their illness, which may include medical, cultural, and psychosocial causes. So that people with epilepsy generally and sincerely believe that God's will determines whether or not a person will be cured or whether treatment (including medical treatment) will be effective [8-10].

Patients diagnosed with epilepsy have multiple treatment options, including antiepileptic drugs (AEDs), surgery, and others [9]. Otherwise, a person with epilepsy (PWE) has a risk of depression, anxiety, physical and mental impairment, and family relationship disturbances [11]. Complementary and alternative medicine (CAMs) include natural products such as herbs, vitamins, dietary supplements, antioxidants, minerals, acupuncture, and massage. Notably, the common practice in Saudi Arabia includes the recitation of the Holy Quran (in Arabic, Roqia), religious prayers, the use of honeybee products and black seeds (*Nigella sativa*), Hijamah (cupping), and fasting [12,10]. Although the recent improvement in epilepsy management in Saudi Arabia through an increase in specialized centers, well-trained medical staff, and yearly public awareness of the purple day still, the use of CAM is genuine due to experiencing adverse effects from AEDs, poor seizure control, limited contact time with physicians and the patient's belief that epilepsy is a psychological and spiritual effect, rather than a neurological disease [4,13]. This study aims to estimate the prevalence of using CAM in terms of epilepsy management among the population of Makkah.

Subjects and Methods

A cross-sectional observational study was conducted in the Makkah region where male or female patients older than 18 years old and diagnosed with epilepsy were recruited via their treating neurologist. Patients with provoked seizures and psychological non-epileptic seizures were excluded. The study's objectives were explained to the involved patients, and informed consent was obtained. The whole patients included in our

sampling were assured of confidentiality, with their names remaining anonymous. The primary objective of this study is to measure the prevalence of using CAM to treat epilepsy. The secondary objectives were to identify types of CAM commonly used, to explore the factors that lead to prefer alternative medicine, to investigate the specific age group of adults that use CAM more, and to study the complications related to using CAM. After obtaining the approval of the local Ethics Committee, this cross-sectional observational study was performed in Makkah city in the eastern part of Saudi Arabia for 10 months in 2021 (from March to December 2021). We consecutively included all patients older than 18 with the diagnosis of "epilepsy." Informed consent was gained from all participating patients. An electronic survey questionnaire was distributed. The investigators developed the questionnaire and tested it on 10 epilepsy patients in a pilot phase for validation. Those patients were included in the analysis of the results. The questionnaire included three sections: section 1 was about demographic data, section 2 asked about the patient's disease for inclusion and exclusion criteria, and finally, section 3 had further questions about using CAM, types, frequency, benefits, complications, and its predictive factors; the participant could choose more than one answer in this section.

After data were extracted, it was revised, coded, and fed to the statistical software Statistical Package for the Social Sciences version 22 (Inc. Chicago, IL). All statistical analysis was done using two-tailed tests. A *p*-value less than 0.05 was statistically significant. Descriptive analysis based on the frequency and percent distribution was done for all variables, including PWE's demographic data, clinical and medical history, family history of epilepsy, epileptic seizures clinical data, antiepileptic medications, and CAM utilization and effect besides the cause of not trying CAM among non-users. Cross-tabulation was used to show the distribution of patients' use of CAM by their bio-demographic data. The significance of the relation was assessed using the Pearson chi-square test, mean, standard deviation, and exact probability test for small frequency distributions.

Results

A total of 131 patients with epilepsy who fulfilled the inclusion criteria completed the study questionnaire. Patients' ages ranged from 18 to 72 years, with a mean age of 31.4 ± 12.3 . 76 (58%) patients were males, and 55 (42%) were females. As for educational level, 36 (27.5%) held below the secondary level of education, 54 (41.2%) had a secondary level of education, and 41 (31.3%) had a university level of education. Considering employed, 43 (32.8%) were not employed, 43 (32.8) were students while 32 (24.4) were employed, and 13 (9.9%) were retired. Only 12 patients (9.2%) had a history of head surgical operations (not related to epilepsy). About 32 (24.4%) patients receive medications for other diseases. A family history of epilepsy was reported among 33 (25.2%) patients (Table 1).

Table 1. Bio-demographic data of patients with epilepsy in Makkah, Saudi Arabia.

Personal data	No.	%
Age in years		
<30	71	54.2
30-39	28	21.4
40+	32	24.4
Gender		
Male	76	58.0
Female	55	42.0
Educational level		
Below secondary	36	27.5
Secondary	54	41.2
University/above	41	31.3
Employment		
Not employed	43	32.8
Student	43	32.8
Employed	32	24.4
Retired	13	9.9
Previous head operations (surgeries not related to epilepsy)?		
Yes	12	9.2
No	119	90.8
If yes, followed by complications?		
Yes	3	25.0
No	9	75.0
On medications for other diseases?		
Yes	32	24.4
No	99	75.6
Family history of epilepsy?		
Yes	33	25.2
No	98	74.8

Regarding the clinical data of epileptic seizures among study patients in Makkah, Saudi Arabia, the frequency of the seizures was reported as 53 (40.5%) patients had the seizures 2-3 times per month. In comparison, 36 (27.5%) had less than 2 times per month, 18 (13.7%) had seizures once per 6 months, and 24 (18.3%) had seizures once per year. Considering the duration of seizures, 50 (38.2%) had the seizure for 1 minute, 39 (29.8%) had the seizure for 2-3 minutes, 21 (16%) had the seizure for more than 5 minutes while 21 (16%) had the seizure for more than 10 minutes. Most of the patients (84%; 110) reported that they experienced a loss of consciousness during the seizure. As for the type of seizure, it was generalized tonic-clonic among 51 (38.9%), while 24 (18.3%) had focal seizures and 42 (32.1%) did not know about the type of seizures while 14 (10.7%) reported absence seizures according to physician diagnosis. Regarding seizure, provoking factors, sleep disturbance was the most reported (51.9%), followed by emotional stress (48.9%), missing meals (14.5%), infections (13.7%), medications

(13.7%), chronic diseases (11.5%), and use an electronic device for a long time (9.2%). The last reported factors were systemic diseases and electrolyte imbalance (1.5% for each) (Table 2).

Epilepsy medications among study patients in Makkah, Saudi Arabia, revealed that the vast majority (70.2%; 92) of the study patients went to the ER after the first seizure while 37 (28.2%) went to the neurologist. Almost all study patients (93.9%; 123) are now on antiepileptic medication. A total of 46 (37.4%) use one type of antiepileptic medication, 44 (35.8%) use two types, and 28 (22.8%) use three types. As for antiepileptic medications side effects, fatigue was the most reported (29.2%), followed by poor concentration (26.1%), weight changes (19.2%), dizziness (13.8%), nausea (12.3%), speech problems (10%), depression (9.2%), visual problems (6.2%), hyperactivity (5.4%) and vomiting (0.8%). About 109 (83.2%) patients were compliant with antiepileptic medications (Table 3).

Table 2. Clinical data for epileptic seizures among study patients in Makkah, Saudi Arabia.

Epileptic seizures clinical data	No.	%
Frequency of seizures		
2-3 times/month	53	40.5
<2 times/month	36	27.5
1 time/6 months	18	13.7
1 time/year	24	18.3
Do you experience loss of consciousness during a seizure?		
Yes	110	84.0
No	11	8.4
I don't know	10	7.6
Type of seizure?		
Generalized tonic-clonic	51	38.9
Focal seizure	24	18.3
Absence seizure	14	10.7
I don't know	42	32.1
Provoking factors of seizures		
Sleep disturbance	68	51.9
Emotional stress	64	48.9
Previous head injuries	21	16.0
Missing meal	19	14.5
Infections	18	13.7
Medications	18	13.7
Chronic diseases	15	11.5
Use an electronic device for a long time	12	9.2
Smoking	11	8.4
Brain lesions	9	6.9
Systemic diseases	2	1.5
Electrolyte's imbalance	2	1.5
How many seizures have you had in the last 12 months		
None	36	27.5
1-2 times	45	34.4
3-4 times	16	12.2
5-6 times	5	3.8
>6 times	29	22.1

As for the prevalence and used types of CAM among patients with epilepsy in Makkah, Saudi Arabia, 74 (56.5%) patients tried using any type of CAM with their medication, the most used types were religious healers (78.4%), followed by herbal (56.8%), cupping (33.8%), acupuncture (33.8%), vitamins (17.6%), burning (13.5%), and relaxation and meditation (6.8%). While a total of 18 (24.3%) patients never used CAM during the last month, 34 patients (45.9%) used these medications once during this month, 9 patients (12.2%) used CAM 2 times, while 11 (14.9%) used for more than 3 times. As for the effect of CAM, 39 (52.7%) reported that they had no benefit, while 21 (28.4%) reported feeling

better and more relaxed. Also, 13 patients (17.6%) experienced staying positive, 9 (12.2%) patients had reduced symptoms or side effects, and 7 (9.5%) had more feeling of being in control. A total of 64 (86.5%) of the patients had no complications from using CAM, but 4 (5.4%) patients experienced a bad psychological impact, 4 (5.4%) had infectious, and 2 (2.7%) experienced more frequent seizures. The most reported reasons for having complications were a poor standard of care (33.3%), followed by incorrect use (22.2%), non-adherence to CAM (22.2%), interaction with certain medication (11.1%), and the need for lifestyle changes (11.1%) (Table 4).

Table 3. Epilepsy medications among study patients in Makkah, Saudi Arabia.

Epilepsy medications	No.	%
In the first seizure, what was your action?		
Went to ER	92	70.2
Went to neurologist	37	28.2
CAMs	13	9.9
Nothing	17	13.0
Now, are you on AEDs?		
Yes	123	93.9
No	8	6.1
If yes, how many drugs are you using?		
One	46	37.4
Two	44	35.8
Three	28	22.8
More than three	5	4.1
Did you note any side effects from the medication?		
None	65	50.0
Fatigue	38	29.2
Poor concentration	33	26.1
Weight loss or gain	25	19.2
Dizziness	18	13.8
Nausea	16	12.3
Speech problems	13	10.0
Depression	12	9.2
Visual problems	8	6.2
Hyperactivity	7	5.4
Vomiting	1	0.8
Are you compliant with medication?		
Yes	109	83.2
No	22	16.8

The most reported reasons for not using CAM among PWE in Makkah, Saudi Arabia, among non-users were that they don't feel comfortable with medications (42.6%). Followed by a lack of belief in CAM (38.9%), thinking it is unuseful (22.2%), having mild symptoms (13%), thinking it is harmful (9.3%), fear of interaction with other medications (7.4%), and 5.6% reported for other reasons (Figure 1).

Their bio-demographic data distribution of CMA uses among PWE in Makkah revealed that 54.9% of patients aged less than 30 years used CAM compared to 53.1% of others aged 40 years or more with no statistical significance ($p = 0.634$). Also, CAM was used by 60% of female patients versus 53.9% of males ($p = 0.490$). About 60.6% of patients who did not have any other medications had CMA compared to 43.8% of those who used medications for other diseases with recorded statistical significance ($p = 0.048$) (Table 5).

Discussion

The use of CAM is popular among the population of the study; CAM therapies are defined by both the National Center for Complementary and Alternative Medicine of the (NIH) National Institutes of Health and the (NCCIH) National Center for Complementary and Integrative Health of NIH as "a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine" [14]. NCCIH differentiated between the terms "alternative" and "complementary" as: "If a non-mainstream practice is used together with conventional medicine, it's considered "complementary. If a non-mainstream practice is used in place of conventional medicine, it's considered an "alternative" [15]. In the (MENA) the Middle East and North Africa region, CAM evolved from cultural and religious faiths in a population characterized by religiosity and spirituality to

Table 4. Prevalence and used types of CAMs among patients with epilepsy in Makkah, Saudi Arabia.

CAMs data	No.	%
After you were diagnosed with epilepsy, have you tried using any type of CAMs with your medication?		
Yes	74	56.5
No	57	43.5
What type of CAMs do you use? (n = 74)		
Religious healers	58	78.4
Herbal	42	56.8
Falk medicine (Cupping)	25	33.8
Acupuncture	25	33.8
Vitamins	13	17.6
Burning	10	13.5
Relaxation and meditation	5	6.8
How many times have you used CAMs in the last month?		
None	18	24.3
1 time	34	45.9
2 times	9	12.2
3 times	2	2.7
>3 times	11	14.9
What effect of CAMs have you had?		
No benefit at all	39	52.7
Feel better and more relaxed	21	28.4
Staying positive	13	17.6
Reducing symptoms or side effects	9	12.2
Feeling more in control	7	9.5
Boosting your immune system	6	8.1
Comfort from touch, talk and walk	5	6.8
Looking for a cure	2	2.7
Do you have any complications from using CAMs?		
None	64	86.5
Bad psychological effect	4	5.4
More frequent seizures	2	2.7
Infections	4	5.4
If yes, what do you think are the reasons for complications?		
Poor standard of care	3	33.3
Incorrect using	2	22.2
Irregular intake	2	22.2
Interact with certain medication	1	11.1
Require lifestyle changes	1	11.1
Has the use of complementary medicine affected antiepileptic use?		
Yes	25	33.8
No	49	66.2

widely become low-cost therapy, compared to the high cost of modern epilepsy treatment in the western world. Although many CAM therapeutic applications go back centuries, even earlier, patients continue to adopt these practices and remedies, which are still an essential part of the therapeutic armamentarium not only in the MENA

but also in many regions of the world [16]. According to a cross-sectional survey that included 2,946 individuals from the 13 administrative armamentaria regions of Saudi Arabia, the overall prevalence of CAM use was 62.5% [17]. CAM use was 7.5% in some studies and 73.3% in others [9,13].

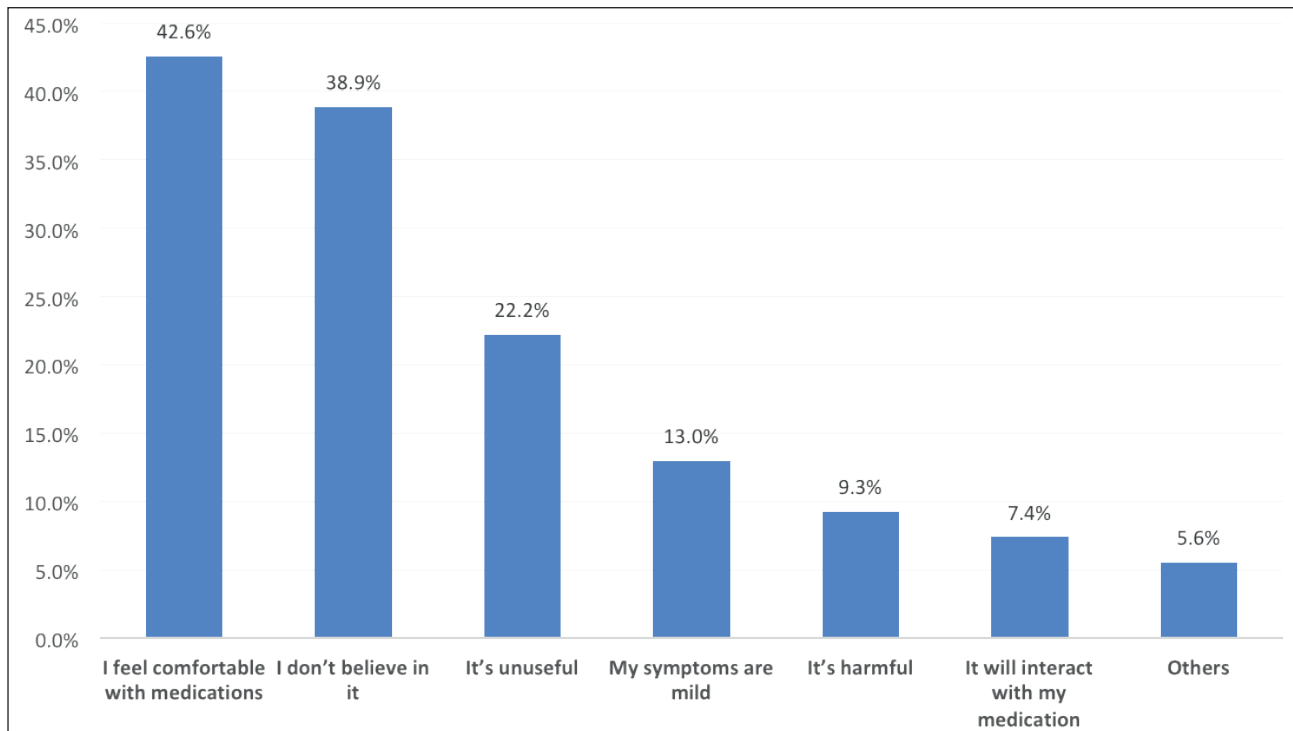


Figure 1. Reasons for not using CAMs among PWE in Makkah, Saudi Arabia.

In this study, we performed a cross-sectional study on CAM use in the routine care of adults with epilepsy by performing an electronic survey questionnaire with patients. Approximately 56.5% of all recruited patients used at least one of the CAM therapies for epilepsy treatment in conjunction with their medications. About half of them reported positive effects of CAM either by feeling better and more relaxed, staying positive, reducing symptoms or side effects, feeling more in control, boosting the immune system, comfort of touch, talking and walking, or looking for a cure. At the same time, most of them reported no complications from CAM. The most frequently used CAM therapies reported in the MENA region are incantations, fumigations, herbal concoctions, prayer, religious healers, and olive oil massage [13]. The CAM methods most frequently used in our study have been religious healers (78.4%), followed by herbal (56.8%), cupping (33.8%), acupuncture (33.8%), vitamins (17.6%), burning (13.5%), and relaxation and meditation (6.8%).

According to previous studies, the most significant driver ($p = 0.004$) for CAM use in the MENA region was the belief that the cause of epilepsy is non-biomedical factors. Moreover, religious and cultural beliefs and the high cost or unavailability of anti-seizure medications (ASMs) are being reported as motives for CAM use [13]. In this study, precisely 109 (83.2%) of the patients were compliant with antiepileptic medications, although around half of the patients reported that they had benefited from CAM use; mostly 28.4% reported feeling better and more relaxed, 17.6% experienced staying positive, 12.2% patients had

reduced symptoms or side effects, and 9.5% have more feeling of being in control. These reported benefits seem to be attributed to the psychological factor.

None of the tested independent variables to predict CAM use was detected as significant predictive factors for the use of CAM as regards age, gender, education, employment, seizure frequency, and duration, in addition to family history of epilepsy or usage or compliance with ASM. On the other hand, the reasons for not using CAM among PWE reported by non-users were that they don't feel comfortable with medications (42.6%). Followed by a lack of belief in CAM (38.9%), thinking it is unuseful (22.2%), having mild symptoms (13%), thinking it is harmful (9.3%), fear of interaction with other medications (7.4%), and 5.6% reported for other reasons. Conventional epilepsy treatment relies on typical pharmacological interventions besides epilepsy-related surgery, such as temporal lobotomy. Despite the presence of more than 30 ASM licensed and approved by the Food and Drug Administration (FDA) for long-term treatment of epilepsy, nearly 40% of patients never achieve seizure freedom [18].

PWE managed with ASMs may have a risk of depression, anxiety, and physical and mental impairment in addition to disturbances in family relationships [8]. A systematic review of 30 studies reported that the ASM non-adherence rate was between 25% and 66% [9,13]. In the MENA region, CAM use is most frequent in patients aged >30 years [13]. In this study, no significant impact of age was detected as a predictive factor in the use of CAM. In our

Table 5. Distribution of CMA use among PWE in Makkah by their bio-demographic data.

Factors		Using any type of CAMs with your medication				p-value
		Yes		No		
		No	%	No	%	
Age in years	<30	39	54.9	32	45.1	0.634
	30-39	18	64.3	10	35.7	
	40+	17	53.1	15	46.9	
Gender	Male	41	53.9	35	46.1	0.490
	Female	33	60.0	22	40.0	
Education	Below secondary	20	55.6	16	44.4	0.950
	Secondary	30	55.6	24	44.4	
	University/above	24	58.5	17	41.5	
Employment	Not employed	26	60.5	17	39.5	0.453
	Student	20	46.5	23	53.5	
	employed	20	62.5	12	37.5	
	Retired	8	61.5	5	38.5	
Number of seizures experienced before	2-3 times/month	34	64.2	19	35.8	0.222
	<2 times/month	17	47.2	19	52.8	
	1 time/6 months	12	66.7	6	33.3	
	One time/year	11	45.8	13	54.2	
On medications for other diseases?	Yes	14	43.8	18	56.3	0.048*
	No	60	60.6	39	39.4	
Family history of epilepsy?	Yes	18	54.5	15	45.5	0.795
	No	56	57.1	42	42.9	
Now, are you on AEDs?	Yes	70	56.9	53	43.1	0.702 [§]
	No	4	50.0	4	50.0	
If yes, how many drugs are you using?	One	22	47.8	24	52.2	0.134 [§]
	Two	26	59.1	18	40.9	
	Three	17	60.7	11	39.3	
	> three	5	100.0	0	0.0	
Are you compliant with medication?	Yes	59	54.1	50	45.9	0.225
	No	15	68.2	7	31.8	

p: Pearson X² test

§: Exact probability test.

*p < 0.05 (significant).

study, the majority of patients (86.5%) had no complications from using CAM, but 4 (5.4%) patients experienced a bad psychological impact, 4 (5.4%) had infectious diseases, and 2 (2.7%) experienced more frequent seizures. The most reported reasons for complications are a poor standard of care, incorrect use, non-adherence to CAM, interaction with certain medications, and the need for lifestyle changes (11.1%). Our study was performed in Makkah city in Eastern Saudi Arabia. CAM user rates can differ in other parts of Saudi Arabia, other institutions, and for chronic diseases other than epilepsy.

Conclusion

Almost half of the PWE in Saudi Arabia used CAM, primarily through religious healers or herbal medicine.

Half of them reported no benefit from CAM usage. Most of them had no complications. Further studies are needed to explore the main drivers and predictors for CAM usage and to investigate its interactions.

List of Abbreviations

AED	Antiepileptic drugs
CAM	Complementary and alternative medicine
PWE	Person with epilepsy

Conflict of interest

The authors declare that there is no conflict of interest regarding the publication of this article.

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None.

Consent to participate

Written informed consent was obtained from all the participants.

Ethical approval

Ethical approval for the current study was obtained from Umm AlQura University (Ethical Approval Code HAPO -02-K-012-2021-02-559), Date of approval 14-02-2021.

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