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Orgınal Article

Investigation of Complementary and Alternative Medicine Use in Turkish Patients with Epilepsy

Epilepsili Türk Hastalarda Tamamlayici ve Alternatif Tip Kullaniminin Araştirilmasi

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Abstract

Background: New generation antiepileptic drugs, adopted in treating epilepsy in recent years, yield better results. Yet, patients may perceive themselves as helpless due to the burden of epilepsy and, thus, seek any treatment approach to relieve their problems. Complementary/alternative medicine (CAM) has recently become preferred among patients worldwide. In this study, we attempted to investigate CAM use among Turkish patients with epilepsy and their knowledge, attitude, and behavior profiles regarding CAM. **Materials and Methods:** We carried out this prospective cross-sectional study with epileptic patients aged 18 years and older. After noting down their demographic and clinical characteristics, we inquired the patients about CAM methods. In addition, we collected the data using the Perception of Health Scale (PHS), the Dispositional Hope Scale (DHS), and the Problem-Solving Inventory (PSI).**Results:** There were 135 patients with epilepsy, 45.92% males and 54.1% females, with a median age of 29 years (IQR=22-42). While 81.5% of the patients had focal-onset, 18.5% had generalized-onset seizures. The mean disease duration was 9 years (IQR=4-19). About one-third (29%) used at least one CAM method. The most common CAM methods reported by the patients were massage therapy (30.2%), herbal therapy (25.2%), and hijamat-cupping (18.6%). In addition, 78.95% stated the CAM method they used was helpful. Finally, we found disease duration to be significantly higher among CAM users (p=0.02). **Conclusion:** CAM use was prevalent among patients with epilepsy, and those with prolonged disease duration used CAM more; therefore, patients should be inquired about CAM use. Further research may consider scientifically evaluating all aspects of CAM use and methods. **Keywords:** Complementary and alternative medicine; CAM; Traditional medicine; Epilepsy; Turkish patients; Perception of health scale; Dispositional hope scale; Problem-solving inventory

ÖZ **Amaç:**Son yıllarda epilepsi tedavisinde kullanılmaya başlanan yeni kuşak antiepileptik ilaçlar, epilepsi tedavisinde hem yan etki profili hemde etkililik açısından daha iyi sonuçlar vermektedir. Ancak epilepsinin kendi hastalık yükü, gerekse de ilaçların yan etkileri nedeniyle hastalar hem fiziksel hem de psikososyal olarak kendilerini çaresiz görmekte, çözüm olabilecek her türlü tedavi yaklaşımını araştırma yoluna gitmektedirler. Tamamlayıcı/Alternatif Tıp (TAT) da ülkemizde ve dünyada hastaların tercih ettikleri modern tıp dışı yöntemlerden biridir. Bu çalışmada TAT yöntemlerinin kullanım sıklığını ve bu yöntemler konusundaki bilgi, tutum ve davranış profilini araştırmayı amaçladık.**Materyal ve Metod:** Bu prospektif tanımlayıcı kesitsel çalışmaya nöroloji polikliniğinde takipli 18 ve üstü, gönüllü hastalar dahil edildi. Hastaların demografik ve klinik bilgileri kaydedildi. Hastalara TAT yöntemlerini kullanım durumları, bilgi düzeyleri ve TAT yöntemleri konusundaki düşüncelerinin sorgulandığı sorular soruldu. Ayrıca Sağlık Algısı Ölçeği (SAÖ), Sürekli Umut Ölçeği (SUÖ), Problem Çözme Envanteri (PÇE) hastalara anket yöntemi ile uygulandı.

Bulgular: Çalışmaya dahil edilen 135 epilepsi hastasının % 45,92'si (n=62) erkek, %54,1'i (n=73) kadın cinsiyete sahipti. Yaş ortalamaları 29 (IQR, 22-42) idi. Hastaların %81.5'i (n=110) fokal başlangıçlı, %18.5'i (n=25) jeneralize başlangıçlı nöbet tipine sahipti ve hastalık süresi ortalama 9 (IQR, 4-19) yıl idi. Hastaların %29'u (n=38) en az bir TAT yöntemini kullanmıştı. Hastaların en sık kullandıkları TAT yöntemleri masaj uygulaması (%30,2 (n=13)), bitkisel tedavi (%25.2 (n=11)) ve kupa- hacamat (%18.6 (n=8)) dı. Kullanan hastaların %78,95'i (n=30) TAT yönteminin faydalı olduğunu ifade etti. Hastalık süresi TAT kullananlarda anlamlı olarak yüksek saptandı (p=0.02).**Sonuç:** Epilepsi hastalarında TAT kullanımı yaygındır ve hastalık süresi uzun olan hastalar daha fazla TAT kullanmaktadır. Hastalar mutlaka TAT kullanımı açısından sorgulanmalıdır. Gelecekteki çalışmalar TAT kullanımının ve yöntemlerinin tüm yönleri ile bilimsel açıdan değerlendirilmesi yönünde olmalıdır.

Anahtar Kelimeler: Tamamlayıcı ve alternatif tıp; TAT; Geleneksel tıp; Epilepsi; Türk hastalar; Sağlık algısı ölçeği; Sürekli umut ölçeği; Problem çözme envanteri.

Highlights

- We reported that 29% of the patients used at least one CAM method.
- The most commonly used CAM methods were massage and herbal treatments.
- 79% of CAM users stated that they found CAM methods useful.
- As the duration of the disease increased, the use of CAM increased.

INTRODUCTION

Epilepsy is a chronic, non-communicable brain disease that is likely to affect people of all ages. It is considered among the most prevalent neurological disorders, affecting about 50 million people worldwide. Although a significant part of the seizures in people with epilepsy can now be controlled thanks to antiseizure drugs, patients still experience many psychosocial problems due to the disease burden and drug side effects (1,2). The declined academic and professional performance, decreased familial and environmental support, disease burden, seizure/fear of seizure, social stigma, and undesirable attitudes toward epilepsy patients lead to psychosocial issues in patients, making them isolated from society (3). Thus, epilepsy patients perceive themselves as helpless and seek every possible treatment approach to relieve their problems. Complementary/alternative medicine (CAM) has recently become preferred among patients worldwide (4,5,6).

According to the World Health Organization (WHO), traditional medicine refers to "the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, used in the maintenance of health and in the prevention, diagnosis, improvement or treatment of physical and mental illness." The terms "complementary medicine" or "alternative medicine" refer to a broad set of healthcare practices that are not part of a country's own tradition or traditional medicine and are not fully integrated into the prevailing health system in that country (7). According to the National Center for Complementary and Alternative Medicine (NCCAM), while the use of CAM practices with conventional medicine refers to complementary medicine, its use rather than conventional medicine practices is called alternative medicine (8). As a result of the recent discussions in Turkey based on the definition of WHO, it was decided that there is no alternative to medicine, but only an alternative to treatment, highlighting the definition of 'traditional and complementary medicine' (9).

The methods accepted in the Turkish traditional and complementary medicine (TCM) regulation are phytotherapy (herbal treatment), larva (Maggot) therapy, prolotherapy, music therapy, osteopathy, mesotherapy, chiropractic, homeopathy, reflexology, cupping, leech therapy, apitherapy, hypnotherapy, and acupuncture (10). For these practices, many universities and state hospitals have established TCM centers.

The literature hosts a paucity of research investigating CAM use and the factors affecting its use among Turkish epilepsy patients. Besides, to the best of our knowledge, research interest seems to have missed the use of CAM by analyzing the psychosocial states of individuals with epilepsy.Thus, the present study investigated the frequency of and factors affecting CAM use in epilepsy patients and their knowledge, attitude, and behavior profile regarding these methods.

Materials and Methods:

Study popilations

The sample of this descriptive cross-sectional study consisted of epilepsy patients aged 18 years and older having good cognitive functions and followed up in the neurology outpatient clinic of a tertiary healthcare center.

Data collection

We collected the demographic (age, sex, educational attainment, marital status, place of residence, family structure, income status, smoking-alcohol use) and clinical characteristics (disease duration, seizure type, frequency, and time, and antiseizure drug use), CAM use, and knowledge and opinions on CAM methods) of patients with epilepsy through face-to-face interviews. Then, the patients were administered the Perception of Health Scale (PHS), the Dispositional Hope Scale (DHS), and the Problem-Solving Inventory (PSI) to analyze psychosocial factors that might affect their CAM use. Besides, we used the 2017 International League Against Epilepsy (ILAE) classification to classify epileptic seizures (11).

Perception of Health Scale

Developed by Diamond et al., the PHS is a relatively novel instrument (12). Kadıoğlu and Yıldız (2012) adapted the PHS into the Turkish context (13). Fifteen items on the scale are covered by four subscales: center of control, self-awareness, certainty, and importance of health. The responses are scored on a five-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree), and items with negative statements are reverse-coded. One may obtain a score ranging between 15 (min) and 75 (max).

Dispositional Hope Scale

The 12-item DHS was designed by Snyder et al. (14) and adapted into Turkish by Tarhan and Bacanlı (15). The pathways and agentic thinking subscales host four items each, and the other four consist of filler statements irrelevant to hope. Responses are scored on an eight-point Likert-type scale, and only the scores on the pathways (items 1, 4, 6, and 8) and agentic thinking (items 2, 9, 10, and 12) subscales are considered to calculate a total dispositional hope score. One may obtain a score ranging between 8 (min) and 64 (max).

Problem-Solving Inventory

Heppner and Peterson developed the PSI (16), and Şahin et al. carried out the validity and reliability study of its Turkish version (17). The 6-point Likert-type inventory consists of 35 items. While determining the total score, items 9, 22, and 29 are excluded from the calculation, and items 1, 2, 3, 4, 11, 13, 14, 15, 17, 21, 25, 26, 30, 32, and 34 are reversely scored. Therefore, one may obtain a score ranging between 32 (min) and 192 (max).

Ethical considerationsThe Ethics Committee of Gulhane Medical Faculty, Health Sciences University granted ethical approval to our study (No: 2019-115 dated 03.23.2019). In this study, we strictly followed the principles of the revised Declaration of Helsinki and obtained written informed consent from the patients.

Statistical analysis

While categorical variables are presented as percentages and numbers, continuous variables are shown as means ± standard deviations or medians (interquartile range). We used the Kolmogorov-Smirnov test to check the normality of the data distribution. Accordingly, we compared normally distributed data using an independent samples *t*-test and non-normally distributed data using a Mann-Whitney U test. In addition, categorical variables were compared with a chi-square test. We performed all statistical analyses on SPSS 22.0 and accepted a *p*-value < 0.05 as statistically significant.

RESULTS

Participants' demographic characteristics

We carried out this study with 135 patients with epilepsy, 45.92% (n=62) males and 54.1% (n=73) females, with a median age of 29 years (IQR = 22-42). Five (3.7%) patients were illiterate, 21.5% (n=29) were primary school graduates, 49.6% (n=67) held a high school diploma, and 25.2% (n=34) held a higher education degree. While 13.3% (n=18) lived in a rural area, 86.7% (n=117) were urban dwellers. Finally, 26.7% (n=36) of the patients had a smoking habit, and 9.6% (n=13) had alcohol consumption (Table 1).

Participants' clinical characteristics

The median disease duration among the participants was 9 years (IQR=4-19). Most of the patients (81.5%; n=110) had focal-onset seizures, while 18.5% (n=25) had generalized-onset seizures. Given the use of antiseizure drugs, 68.1% (n=92) were receiving monotherapy, and 31.8% (n=43) were receiving polytherapy. About 44.4% (n=60) had one year ≤ seizure-free, but 37.8% (n=51) had seizures less than once a month, and 17.8% (n=24) had more than one seizure per month (Table 1).

Participants' CAM use

We found that 29% (n=38) of the patients used at least one CAM method. The majority (78.95%; n=30) stated that the CAM method was helpful, but 21.05% (n=8) did not find it useful. When asking all patients, 'Do you think CAM use is helpful?', 47.7% (n=62) among the respondents (n=130) thought that CAM use was helpful, 28.5% (n=37) thought that the CAM methods were not helpful, and 23.8% (n=31) had no idea about CAM use. The most common sources of learning about CAM were physician advice (36.5%; n=72) and the internet (33.5%; n=66). Moreover, the participants thought CAM methods to be used for every disease/to prevent aging (22.8%; n=75) and for chronic conditions (19.5%; n=66). We also discovered that the patients preferred the following CAM methods the most: massage therapy (30.2%; n=13), herbal treatment (25.2%; n=11), and hijamat-cupping (18.6%; n=8) (Table 2).

The patients' PHS, DHS, and PSI scores

The participants' median PHS score was found to be 47 (IQR=44-52), which may correspond to a moderate perception of health. Moreover, they got a median score of 52 (IQR=46-56) on the DHS; therefore, we can assert that the participants had high dispositional hope. Finally, the median PSI score of the participants was found to be 97 (IQR=86-107), implying moderate problem-solving ability.

Comparison of the research variables by CAM use

Our findings revealed no significant difference between the patients' demographic characteristics (age, sex, educational attainment, place of residence, perceived income status) by CAM use (p=0.92, 0.46, 0.68, 0.23, and 0.36, respectively; Table 3). While we found that disease duration was significantly higher among the CAM users (p=0.02), the patients' other clinical characteristics (antiseizure drugs (monotherapy-polytherapy), seizure type, and frequency of seizures) did not significantly differ by CAM use (p=0.08, 0.06, and 0.15, respectively; Table 4). Finally, we discovered the patients' PHS, DHS, and PSI scores did not significantly differ by CAM use (p=0.79, 0.95, and 0.54, respectively; Table 5).

Table 1. Patients' demographic and clinical characteristics

Age, median (IQR)	29 (22-42)	
Sex (n=135)	n	%
Male	62	45.9
Female	73	54.1
Educational attainment (n=135)		
Illiterate	5	3.7
Primary school	29	21.5
High school	67	49.6
Higher education	34	25.2
Marital status (n=135)		
Married	60	44.4
Single	75	55.6
Place of residence (n=135)		
Rural area	18	13.3
Urban area	117	86.7
Family structure (n=135)		
Nuclear	115	85.2
Extended	20	14.8
Perceived income status (n=135)		
Very good	21	15.6
Good	76	56.3
Moderate	26	19.3
Poor	12	8.9
Smoking (n=135)		
Yes	36	26.7
No	83	61.5
Ceased	16	11.9
Alcohol consumption (n=135)		
Yes	13	9.6
No	122	90.4
Disease duration, median (IQR)	9 (4-19)	
Antiseizure drug (n=135)	n	%
Monotherapy	92	68.1
Polytherapy	43	31.8
Seizure frequency (n=135)		
One year ≤ seizure-free	60	44.4
Less than one per month	51	37.8
More than per month	24	17.8
Seizure type (n=135)		
Focal-onset	110	81.5
Generalized-onset	25	18.5
Seizure time (n=135)		
Daytime	45	33.3

Night	33	24.4
Daytime-night	57	42.2

IQR: Interquartile range.

Table 2. Patients' CAM use and views on CAM methods

		n	%
Have you used any or more of the CAM methods? (n=131)	Yes	38	29.0
	No	93	71.0
Have you found the CAM methods you use helpful? (n=389	Yes	30	78.95
	No	8	21.05
Do you think CAM use is helpful in general? (n=130)	Yes	62	47.7
	No	37	28.5
	No idea	31	23.8
Where have you learned about CAM methods? (n=199*)	Friends, family members, neighbors	34	17.3
	Internet	66	33.5
	TV, radio	18	9.1
	Physician advice	72	36.5
	Newspaper, magazine	7	3.6
In which conditions do you think CAM can be used? (n=329*)	For every disease	75	22.8
	In the case of no benefit from medical treatment	3	0.9
	In chronic conditions	64	19.5
	In malignancies	10	3.0
	In obesity	48	14.6
	For aesthetic purposes	54	16.4
	For preventing aging	75	22.8
What do you think are the purposes of CAM use? (n=170*)	I have heard the success of these methods	67	39.4
	My medical treatment has failed	15	8.8
	Due to concerns about the side effects of medical treatments	17	10.0
	Alternative treatment methods are safer	30	17.6
	Physician advice	41	24.1
Which CAM methods have you heard/do you know?* (n=150*)	Massage therapy	37	24.7
	Herbal treatment	35	23.3
	Hijamat	29	19.3
	Acupuncture	25	16.7
	Ozone therapy	10	6.7
	Energy healing	4	2.7
	Homeopathy	3	2.0
	Other	7	4.7
Please specify CAM methods you use.* (n=43)	Massage therapy	13	30.2
	Herbal treatment	11	25.6
	Hijamat	8	18.6
	Acupuncture	5	11.6
	Ozone therapy	3	7.0
	Homeopathy	2	4.7
	Meditation	1	2.3

Table 3. Comparison of the patients' demographic characteristics by CAM use

		CAM Use		*p**
		YES (n=38)	NO (n=93)	
Age, years	Median (IQR)	28.50 (24-42.5)	30 (22-42.5)	0.92
Sex	Male	19 (14.5%)	40 (30.5%)	0.46

	Female	19 (14.5%)	53 (40.5%)	
Educational attainment	Illiterate	2 (1.5%)	3 (2.3%)	0.68
	Primary school	6 (4.6%)	23 (17.6%)	
	High school	19 (14.5%)	44 (33.6%)	
	Higher education	11 (8.4%)	23 (17.6%)	
Place of residence	Rural area	7 (5.3%)	10 (7.6%)	0.23
	Urban area	31 (23.7%)	83 (63.4%)	
Perceived income status	Very good	4 (3.1%)	16 (12.2%)	0.36
	Good	26 (19.8%)	48 (36.6%)	
	Moderate	5 (3.8%)	20 (15.3%)	
	Poor	3 (2.3%)	9 (6.9%)	

Table 4. Comparison of the patients' clinical characteristics by CAM use

		CAM Use		*p**
		YES (n=38)	NO (n=93)	
Disease duration, years	Median (IQR)	13.50 (5-22.5)	8 (4-17)	0.02
Antiseizure drug	Monotherapy	22 (16.8%)	68 (51.9%)	0.08
	Polytherapy	16 (12.2%)	25 (19.1%)	
Seizure type	Focal-onset	27 (20.6%)	79 (60.3%)	0.06
	Generalized-onset	11 (8.4%)	14 (10.7%)	
Seizure frequency	One year ≤ seizure-free	12 (9.2%)	45 (34.4%)	0.15
	Less than one per month	19 (14.5%)	31 (23.7%)	
	More than one per month	7 (5.3%)	17 (13.0%)	

* $p < 0.05$; IQR: Interquartile range.

Table 5. Patients' PHS, DHS, and PSI scores by CAM use

	CAM Use	Median (IQR)	*p*
PHS (n=126)	Yes (n=37)	47.00 (44-52)	0.79
	No (n=87)	47.00 (44-52)	
DHS (n=122)	Yes (n=37)	100.00 (88.75-104.25)	0.54
	No (n=87)	96.00 (85-108)	
PSI (n=124)	Yes (n=37)	52.50(43.50-55.75)	0.95
	No (n=87)	51.00 (46.00-56.00)	

DHS: Dispositional Hope Scale; PHS: Perception of Health Scale; PSI: Problem-Solving Inventory. IQR: Interquartile range.

Discussion

Our findings uncovered that about one-third of the patients with epilepsy used at least one CAM method. The most preferred CAM methods were determined to be massage therapy, herbal treatment, and hijamat-cupping. Moreover, 78.95% of CAM users stated that the CAM method they used was helpful. Yet, we could not establish a significant relationship between CAM use and the patients' demographic and clinical (except for disease duration) characteristics. Similarly, we could not detect a significant relationship between the patients' scores on the PHS, DHS, and PSI, which were administered to assess their psychosocial status.

The literature documented varying frequencies of CAM use among patients with epilepsy. A review study including 30 studies reported the percentage of CAM use ranging between 7.5%-73.3% (4). In India, Tandon et al. and Bhalerao et al. reported it to be 32% and 7.7%, respectively (18-19). The frequency of CAM use was found to be 76% by Tan et al. among patients living Erzurum and 22.6% by Goker et al. in a Turkish pediatric sample (6,20). It was also reported as 56.6% in a Nigerian pediatric sample and 27.5% among pediatric patients in a multi-ethnic population (21-22). Hartmann et al. pronounced CAM use as 13% in pediatric patients in a university hospital, while Girgis et al. reported it to be 7.9% (23-24). It was uttered to be 26.8% in a university hospital in Poland and 58% by Farrukh et al. (25-26). The inconsistencies in the prevalence of CAM use in the

literature may be attributed to population- or culture-specific differences, different applications in healthcare systems, or the reluctance of patients to explain it.

The type of CAM used may also differ due to differences in cultural norms and healthcare environments. Ayurveda (18), herbal preparations, herbs, multivitamins, dietary regime, ginseng, antioxidants (6,22,25,26,27), prayer, spirituality (20-21,27), energy healing, cannabis (25), homeopathy, osteopathy (18,23), acupuncture, and chiropractic (22,26) are frequently adopted CAM methods by patients with epilepsy in previous studies. In an analysis of 16 studies, Farrukh et al. reported the most common types of CAM to be herbal practices, prayer/ spirituality, and yoga/exercise (4). Besides, hijamat-cupping is a type of CAM mostly adopted in Muslim communities and was reported among epilepsy patients in Oman being with the least frequency (29). The high frequency of this method in our study may be because it is already widely adopted in Turkey and performed by experienced physicians with the permission of the Ministry of Health (30).

Massage therapy, which was found to be preferred the most frequently in this study, may be helpful in terms of providing relaxation to patients with epilepsy, who are often under intense psychosocial stress, besides their medical treatment. Moreover, the unconscious and inappropriate use of herbal treatment, another mostly preferred method, may interact with antiseizure drugs and cause changes in their effects and increase the risk of seizures by showing a proconvulsant effect. It can also cause life-threatening organ dysfunction (26,31,32). Neurologists should be aware of this issue, and patients should be inquired about the CAM methods they use.

We also explored the factors affecting CAM use and discovered a relationship between disease duration and CAM use. Accordingly, the patients with prolonged disease duration tended to use CAM methods more. Similarly, Bosak et al. examined patients with epilepsy in a university hospital in Poland and determined disease duration to be an independent predictor of CAM use (25). Contrary to what we expected, there were no significant relationships between CAM use and other variables such as seizure frequency, which indicates disease severity, and polypharmacy. Moreover, we evaluated the patients' perception of health, dispositional hope, and problem-solving skills to explore their psychosocial status but could not show their effects on CAM use. Our findings uncovered that about one-third of the patients with epilepsy used at least one CAM method. The most preferred CAM methods were determined to be massage therapy, herbal treatment, and hijamat-cupping. We showed that those with prolonged disease duration had significantly more CAM use. To the best of our knowledge, this is a pioneering study to explore CAM use among epilepsy patients with their psychosocial status.

Limitations

Despite uncovering significant findings, our study is not free of a few limitations. First, a few patients were reluctant to respond to some questions on the scales, further limiting the data for the relatively small number of patients. Secondly, the sample included only adult patients followed in our neurology clinic and, therefore, may not be representative of the general population.

Conclusion

CAM use was prevalent among our patients with epilepsy, and those with prolonged disease duration used CAM more. In this sense, healthcare professionals should be aware of CAM use, and patients should be inquired about the CAM methods they use. Future studies should be in the direction of scientific evaluation of all aspects of CAM use and methods among patients with epilepsy.

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