Original Article

Perception and Use of Alternative Treatments among Patients with Epilepsy

Sunee Lertsinudom BSc, BCP[1,4], Somsak Tiamkao MD[2,4],
Sineenard Pranboon MSN[3,4], Supinya Tuntapakul BPharm, BCP[1,4]

[1] Department of Clinical Pharmacy, Faculty of Pharmaceutical Sciences, Khon Kaen University, Thailand
[2] Department of Medicine, Faculty of Medicine, Khon Kaen University, Thailand
[3] Nursing Division, Srinagarind Hospital, Faculty of Medicine, Khon Kaen University, Thailand
[4] Integrated Epilepsy Research Group, Khon Kaen University, Thailand

Objective: Epilepsy is a common neurological disease which affects the quality of life of patients physically, mentally, and socially, and an increase in use of alternative treatments has been found in epileptic patients. The purpose of this study was to investigate alternative treatments used by epileptic patients and to determine the perceptions of epileptic patients toward alternative treatments.

Materials and Methods: A qualitative descriptive study was conducted using in-depth interviews with patients with epilepsy at an epilepsy clinic at a university hospital in Thailand between January and March 2015 by 3 interviewers who were standardized training of semi structure interview questionnaire. The end of interview was until saturation.

Results: Interviewees included 30 patients averaging 46.9±17.1 years of age, 60 % of whom were female. The most frequent type of seizure patients had experienced was generalized tonic-clonic seizures (had occurred in 50% of patients), and the average frequency of seizures was 1.71 times/month. We found that 56.7% of patients had used more than 1 type of alternative treatment and 33.3% of patients were still using alternative treatments at the time of the interview. Alternative treatments which patients used the most were dietary supplements (20 persons, 36.4%), followed by herbs or herbal products (17 persons, 30.9%) and superstition (16 persons, 29.1%). Most reasons patients gave for their use of alternative treatments were psychological, physical, or belief-based in nature. On average, patients spent 38±9 USD per person per month for alternative treatments. Perceptions of epileptic patients toward dietary supplements, herbs or herbal products, and superstitious methods were unsatisfied (40%, 41.2%, and 18.8% of patients, respectively), satisfied (30%, 35.3%, and 50% of patients, respectively), and indifferent (20%, 5.9%, and 31.3% of patients, respectively).

Conclusion: Most of the patients used more than 1 type of alternative treatment. Common reasons provided for using an alternative treatment were psychological, physical, or belief-based in nature. Beliefs seemed to play an important role in one's faith in an alternative treatment to treat seizures. When a healthcare team recognizes the perceptions of their patients, they can more effectively counsel patients to prevent antiepileptic drug-herb or antiepileptic drug-food supplement interaction and educate patients about the importance of anti-epilepsy drug use.

Keywords: Alternative treatment, Epilepsy, Perceptions

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Epilepsy is one of the most common neurological diseases and affects people both psychosocially and in terms of lifestyle. There are an estimated 50 million people with epilepsy [PWE] in the world, of which more than 80 percent are in developing countries[1]. An incidence of 7.2 per 1,000 population, or 468,000 patients with epilepsy per 65 million people, has been estimated[2]. Epilepsy is a major public health problem in Thailand, as well.

PWE who had undergone treatment at the Epilepsy Clinic of Srinagarind Hospital were interviewed about their medical histories, which showed that the number of patients at Srinagarind Hospital undergoing alternative treatments had increased. Not only have alternative treatments that have been studied and approved increased, but also treatments that have not been approved in terms of effectiveness and safety.

Correspondence to:
Tiamkao S. Department of Medicine, Faculty of Medicine, Khon Kaen University, Khon Kaen 40002, Thailand.
Phone: +66-43-348399, **Fax:** +66-43-347542
E-mail: somtia@kku.ac.th

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For example, use of herbs and supplements has increased steadily. Some products may stimulate more seizures or cause adverse reactions or side effects, as well as potentially lead to interactions with antiepileptic drugs received by patients. Certain alternative medicines may be toxic or cause seizures to occur.

Therefore, the present research investigated alternative treatments used by epilepsy patients who had undergone treatment at Srinagarind Hospital. This article will present information about alternative treatments, the reasons that patients choose alternative treatments, and patients' perceptions toward alternative treatments. It is anticipated that the information collected will be beneficial for the provision of pharmaceutical care to PWE in the future.

Objective

The present study aimed to identify alternative treatments used by epilepsy patients at the Epilepsy Clinic of Srinagarind Hospital and to consider patients' reasons for choosing alternative treatments, as well their perspectives toward such treatments.

Expected outcomes/benefits of the project

1) An improvement in pharmaceutical care guidelines for epileptic patients.

2) A better understanding of patients' reasons for choosing alternative treatments and their perspectives toward such treatments.

Study design

A qualitative descriptive study was conducted using in-depth interviews with patients with epilepsy by 3 interviewers who were standardized training of semi structure interview questionnaire. The end of interview was until saturation.

Study scope

This project studied PWE who had undergone epilepsy treatment at the Epilepsy Clinic between January and March 2015 (3 months).

Place of study

Epilepsy Clinic at Srinagarind Hospital, Thailand.

Definitions

1) "Alternative treatments" refers to care options apart from modern medicine and surgery that are currently the main forms of treatment for epilepsy. Alternative treatments can be used in conjunction with these traditional methods or in place of them altogether.

2) "Epilepsy patients" refers to patients who have been diagnosed with epilepsy and admitted to the Epilepsy Clinic of Srinagarind Hospital.

3) "Herbs" means plants, animals, and micro-organisms. "Elements" refers to traditional plant extracts or animals used for the treatment or prevention of disease or for maintaining the health of the human body.

4) "Herbal products" refers to products derived from herbs or herbal ingredients that are intended to treat or prevent disease or maintain the health of the human body.

5) "Dietary supplements" refers to products consumed in addition to a usual diet. These products are made up of nutrients or other substances and come in the form of tablets, capsules, powders, pellets, liquids, etc. They are not conventional foods; however, consumers expect them to have health benefits.

Population

Epilepsy patients who have undergone treatment at the Epilepsy Clinic of Srinagarind Hospital.

Sampling

Epilepsy patients who had undergone treatment at the Epilepsy Clinic of Srinagarind Hospital and who had used alternative treatments between January and March 2015 (a 3-month period). Data collection continued until data saturation was reached.

Inclusion criteria

1) Epileptic patients or relatives of patients who had provided direct patient care and were 18 years of age or older.

2) Patients with epilepsy who had undergone treatment at the Epilepsy Clinic of Srinagarind Hospital and who had used alternative treatments between January and March 2015.

Exclusion criteria

1) Epilepsy patients who were unable to participate in an interview.

2) Epilepsy patients who did not consent to an interview.

Instruments

1) A program documenting pharmaceutical care for patients and managed by the routine pharmacist at the Epilepsy Clinic.

2) Patient information form

3) In-depth interview questions
4) Voice recorder

Statistical analysis

Microsoft Excel 2007 was used for record-keeping, and information and analysis have been presented in the forms of quantitative and qualitative data, with the former presented as percentages and the latter as content analysis.

Results

General information

The in-depth interviews with 30 PWE who had received services at the Epilepsy Clinic and pharmaceutical care from a pharmacist showed that all interview respondents had used alternative treatments. The mean age of respondents was 46.92±17.07 years and most respondents were female. The frequency of seizures averaged 1.71 times per month. The percentage of patients who had used more than one form of alternative treatment was 56.70, and the percentage of patients who had continued their use of alternative treatments until the time of the interview was 33.3. The category of alternative therapy that patients used the most was dietary supplements (20 cases, 36.36 percent), followed by herbs and herbal products (17 patients, 30.91 percent) and rituals and magic or superstition (16 cases, 29.09 percent).

Alternative treatment options for epilepsy patients

Type classification of alternative treatments showed that the treatment of choice for most patients was food supplements (20 cases, 36.36 percent), followed by herbs or herbal products (17 patients, 30.91 percent), superstition (16 cases, 29.09 percent), and other treatment options (2 patients, 3.64 percent).

Reasons for using alternative treatments

PWE expressed several reasons for using alternative treatments, of which the main reasons can be divided into 3 classes: physical, mental, and belief-based. Some PWE gave more than one reason. The most common reasons were related to mental factors (19 cases, 54.29 percent of the total reasons), followed by physical factors (10 cases, 28.57 percent of the total reasons) and finally, reasons pertaining to beliefs (6 patients, 17.14 percent of the total reasons). The specific reasons PWE expressed for using alternative treatments are presented in Table 1.

PWE who had used herbs or herbal products had undergone a range of alternative treatment time periods, from 1 month to 10 years. On average, the period for treatment had been 17.00±45.68 months. For those who had taken dietary supplements, time periods ranged from 1 day to 3 years, with an average of 8.00±26.00 months. For those who had used superstition, time periods ranged from 1 day to 20 days, with an average of 2.25±9.16 days, and for those patients using other alternative therapies, time periods ranged from 1 month to 1 year, with an average of 6.5±7.78 months.

Perceptions of patients toward alternative treatments:

The perceptions of PWE toward the different alternative treatment options were divided into 4 main responses: satisfied, no difference, dissatisfied, and other opinion. For the 17 patients who used herbs or herbal products, most were dissatisfied (7 cases, 41.18 percent), 6 patients were satisfied with the treatment (35.29 percent), in 3 cases patients responded “other

Table 1. Reasons for using alternative treatments

Reason for choosing treatment	Number (cases)	Percentage of thetotal reasons
1) Physical	10	28.57
1.1) To care for the blood supply	3	8.57
1.2) To care for the brain and nervous system	4	11.43
1.3) For skincare	1	2.86
1.4) To help with bowel movements	1	2.86
1.5) To gain weight	1	2.86
2) Mental	19	54.29
2.1) To try it because others had used and recommended it	11	31.43
2.2) For peace of mind of the patient or their family	8	22.86
3) Belief-based	6	17.14
3.1) Due to a sacred belief/superstition	5	14.29
3.2) Due to a belief in the body’s need for food	1	2.86

opinion" (17.65 percent), and in just 1 case a patient felt no difference (5.88 percent). There were 20 patients who took dietary supplements. Most of them were dissatisfied with the alternative treatment (8 cases, 40 percent), 6 patients were satisfied with treatment (30 percent), in 4 cases patients experienced no difference (20 percent), and in 2 cases they responded "other opinion" (10.0 percent). There were 16 patients who used superstition. Most felt satisfied with this type of alternative treatment (8 cases, 50.0 percent), in 5 cases patients experienced no difference (31.25 percent), and in 3 cases patients were dissatisfied (18.75 percent). For the 2 patients who used other types of alternative treatment, 1 was satisfied (50 percent) and the other experienced no difference (50 percent). The results are summarized in Table 2.

Discussion

According to the interviews with 30 PWE, 36.36 percent of interviewees chose dietary supplements as alternative treatment, 30.91 percent chose herbs or herbal products, 29.09 percent chose superstition, and 3.64 percent chose other options. This is consistent with work by Kaiboriboon et al[3] which reported on the incidence of dietary supplement and herb use by 56 PWE in the United States.

No herbs, herbal products, or superstitious methods chosen by the patients in this study have been shown to yield any treatment effectiveness for epilepsy, nor have they been shown to be safe for PWE. However, a systematic review conducted by Lee et al[4] revealed that certain dietary supplements consumed by patients, such as Vitamin B6 and Magnesium, have yielded treatment effectiveness for epilepsy.

Table 2. Perceptions of PWE toward alternative treatments

Type of alternative treatment	Number	Percentage
Herbs or herbal supplements	17	100.00
Satisfied	6	35.29
No difference	1	5.88
Dissatisfied	7	41.18
Other opinion	3	17.65
Dietary supplements	20	100.00
Satisfied	6	30.00
No difference	4	20.00
Dissatisfied	8	40.00
Other opinion	2	10.00
Superstition	16	100.00
Satisfied	8	50.00
No difference	5	31.25
Dissatisfied	3	18.75
Other opinion	0	0.00
Other treatment type	2	100.00
Satisfied	1	50.00
No difference	1	50.00
Dissatisfied	0	0.00
Other opinion	0	0.00

Reasons why PWE in the present study chose to undergo alternative treatments can be described as follows: 54.29% of respondents chose alternative treatments for psychological reasons, 28.57% chose for physical reasons, and 17.14% chose for belief-based reasons. These responses correspond to a study by Khemka et al[5] that explored knowledge of epilepsy among 500 people in Khon Kaen and showed that most people lacked knowledge of epilepsy. According to the study, 12 people (2.4%) thought that epilepsy was caused by superstitious rites and 8 people (1.6%) thought that epilepsy was a punishment inflicted by a holy body. These findings are consistent with findings from the present study, where 5 patients chose an alternative treatment because they believed in a holy being or a superstition (being possessed by a spirit or the existence of superstitious rites). The study by Khemka et al[5] also explored the aspect of people making suggestions to their relatives or friends with epilepsy and found that 56 people (11.2%) had suggested traditional medicine or herbal treatment, 37 people (7.4%) had suggested acupuncture, 31 people (6.2 %) had suggested spirulina as a dietary supplement, and 12 people (2.4%) had suggested superstitious methods of treatment. These findings are also consistent with the present study, which indicates that most patients interviewed had received suggestions for alternative treatments from other people, with 24 PWE (54.54%) having received suggestions from neighbors and friends and 17 PWE (38.64%) from their family members. Only 3 patients (6.82%) had explored treatment by themselves. The results of this study show that 1 patient used spirulina, 1 patient used acupuncture, and 16 PWE used superstitious methods. Additionally, 8 PWE (22.86%) chose an alternative treatment due to factors relating to their own and their family's comfort. This may indicate that their family members recommended they choose an alternative treatment, so they felt obligated to do so.

PWE's attitude toward alternative treatments by alternative treatment type can be described as follows: 7 PWE out of 17 using herbs or herbal products (41.18%) were dissatisfied with their alternative treatment; 8 PWE out of 20 using dietary supplements

(40.00%) were dissatisfied with their alternative treatment; 8 PWE out of 16 using superstitious methods (50.00%) were dissatisfied with their alternative treatment; of the 2 PWE using other types of alternative treatment, 1 felt satisfied and 1 (50.00%) felt indifferent. Most PWE using herbs or herbal products or using dietary supplements were dissatisfied with their alternative treatment due to the fact that they still had epilepsy or became even worse and had experienced side effects. The PWE using superstition had the highest rate of satisfaction (50.00%) due to psychological reasons. For instance, the treatment made them feel comfortable or gave them some mental reassurance. Most PWE did not use superstition continuously, but rather used it intermittently. As a result, superstitious methods had a psychological effect.

The results from the present study can lead to guidelines for pharmaceutical care for epilepsy patients who choose to use alternative treatments, as these findings reveal the true reasons for the patients' choices. Such guidelines can prevent or solve problems that may occur with individual patients so that they will get maximum benefit from their treatment.

Based on the present study, guidelines for pharmaceutical care for PWE are effective for when PWE prefer using alternative treatments, which may lead to the patient neglecting to take anticonvulsant. Pharmacists should point out the importance of taking anticonvulsant and the negative effects of dietary supplements and herbs, as well as the negative effects experienced among PWE when undergoing treatment from unreliable sources.

Conclusion

The results of the present study show that epilepsy patients choose several treatment methods based on psychological factors and do not know whether the treatment they have chosen is effective or safe. Medical personnel can seek to prevent and solve this issue by attempting to understand the individual patient, searching for the real reasons or causes for why a patient is choosing to use an alternative treatment, and providing advice and proper knowledge to the individual patient. This will lead to more effective treatment of epilepsy in the future.

Limitations

The present study is a qualitative descriptive study that uses in-depth interviewing of patients with epilepsy at an epilepsy clinic at a university hospital. Patients' perceptions may differ in other areas of Thailand because of cultural differences.

What is already known on this topic?

Prior to the present study, we knew that reasons for using alternative treatments involved psychological, physical, and belief-based factors and that these factors probably played an important role in a person's ability to have faith in an alternative treatment to treat their seizures.

What this study adds?

The researcher anticipates that the information collected for this study will be beneficial to the provision of pharmaceutical care to patients with epilepsy in the future. When a healthcare team recognizes patients' perceptions, they can more effectively counsel patients in order to prevent antiepileptic drug-herb or antiepileptic drug-food supplement interaction and can educate patients about the importance of anti-epilepsy drug use.

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Potential conflicts of interest

The authors declare no conflict of interest.

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