

Original Article

ASSESSMENT OF KNOWLEDGE OF EPILEPSY IN EPILEPTIC PATIENTS ATTENDING A  
TERTIARY CARE CENTRE IN KERALA, INDIA

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ABSTRACT

**Objective:** Patient's knowledge of his/her disease plays a vital role in epilepsy care. Studies assessing epileptic patient's knowledge of epilepsy have not been done in the state of Kerala, South India, which is distinguished from the rest of India by the high level of literacy and health awareness. The study results can lead to suggestions for appropriate intervention strategies for epileptic patients.

**Methods:** A prospective, observational study was carried out in the department of neurology at Amrita Institute of Medical Sciences and Research Centre, Kochi, Kerala, India. Newly referred patients fulfilling the inclusion and exclusion criteria were enrolled in the study. A 15-item validated questionnaire was used to assess patient's awareness of epilepsy, safety aspects, social issues and treatment.

**Results:** 105 epileptic patients with a mean age of 34.4±14.66 years were enrolled in the study. A high percentage of correct responses were observed in relation to epilepsy as not a mental (74.4%), hereditary (74.3%) or contagious disease (95.2%). Encouraging responses were also obtained regarding confidence in leading a married life (77.1%), overall capability of epileptic patients compared to others (77.1%) and the possibility of epilepsy being controlled with treatment (83.8%). Correct responses on safety issues (40.9%), first aid measures (12.3%), driving (31.4%) and swimming (29.5%) were poor. 47.6% of patients feared from the side effects of anti-epileptic drug treatment and only 3.8% were knowledgeable about epilepsy treatment options other than that with medications.

**Conclusion:** The patients in our study had a basic understanding of epilepsy, but knowledge in terms of safety measures, social issues and treatment options were poor. Educational interventions by health care professionals should focus on these facets of epilepsy apart from the general aspects.

**Keywords:** Assessment, Knowledge of epilepsy, Questionnaire method.

INTRODUCTION

Epilepsy is one of the world's most prevalent non-communicable diseases [1] affecting approximately 25 million people in the world [2]. The prevalence rate of epilepsy in the developing world is reported to be 2 to 25 times higher when compared to the average prevalence rate of 5 to 6 per 1,000 in developed countries [3,4]. With such a high prevalence of epilepsy together with the misconceptions associated with the disease, there is a necessity for improvement in the care of epileptic patients. The right treatment combined with patient education should be the focus in epilepsy treatment. A clear understanding of one's disease is directly related to their proper coping mechanisms [5]. It is also known that improvement in patient's knowledge may improve symptom control [6]. Studies assessing knowledge of epilepsy in patients with epilepsy (PWE) in India have been conducted only in the northern parts of the country [7,8,9,10,11,12]. A study reported from Kerala assessed the knowledge, attitude and practice (KAP) on epilepsy in only the general public [13]. Studies on epileptic patients have not yet been done in the state of Kerala which is distinguished from the rest of India by a high level of literacy and health awareness [14]. Hence it is worthwhile to assess the knowledge of PWE in Kerala. The present study was undertaken to measure the baseline knowledge of the epileptic patients in Kerala, regarding their disease with a view to make appropriate interventions in the future, if required.

MATERIALS AND METHOD

The study was carried out in the outpatient department of neurology at Amrita Institute of Medical Sciences and Research Centre, Kochi, a 1250 bedded, tertiary care referral hospital in Kerala, India. The hospital has an established epilepsy clinic providing services to referred patients from various parts of Kerala, a state in the south-western India with a population of 33.39 million. Ethical clearance for the study was obtained from the hospital ethics committee. All the newly referred epileptic patients attending the clinic from 1<sup>st</sup>

October 2011 to 31<sup>st</sup> December 2011 and satisfying the inclusion and exclusion criteria were enrolled in the study. Inclusion criteria included a diagnosis of epilepsy, male or female patients of age ≥18 years, those willing to participate in the study and provide written informed consent, ability to read English or the vernacular language, Malayalam. Patients with known sensory or cognitive impairment were excluded.

A 15- item self-developed, validated questionnaire was used to assess the patient's awareness of epilepsy, safety aspects, social issues and treatment. The questionnaire was translated into Malayalam and accuracy was ascertained by back translation. The responses were recorded as 'yes', 'no' or 'don't know'. A score of one was given for the right answer, a score of minus one for the wrong answer and a score of zero for answers marked 'don't know'. Patients answering all the questions correctly, can get a maximum score of fifteen. Data on patient demographics and level of education were collected using a predesigned data collection form.

RESULTS

A total of 105 patients was included in the study of which 64.76% were males and the male to female ratio was 1:8. Figure 1 shows the gender distribution of the patients.

The mean age of the patients was 34.4±14.66 years and the median age 30 (range 18 to 66 years) with 61.9% of patients in the younger age group of 18 to 35 years. Details of patient characteristics are given in Table 1. The epilepsy knowledge questionnaire and the percentage of patients given correct responses are given in Table 2.

Positive attitude was shown regarding epilepsy as not a mental disease (74.4%), not a hereditary disorder (74.3%) and not a contagious disease (95.2%). Encouraging responses were also obtained regarding confidence in leading a married life (77.1%), epileptic patients as capable as other people (77.1%) and the

possibility of epilepsy controlled with treatment (83.8%). Correct responses related to safety, first aid measures, driving and swimming were reported only by 40.9%, 12.3%, 31.4%, and 29.5% of the patients respectively. 47.6% of the patients feared from the side-effects of anti-epileptic drug treatment and only 3.8% were knowledgeable about epilepsy treatment options other than that with medications. It is clear from the responses of the patients that they had a general understanding of epilepsy but lacked knowledge in terms of safety, social issues and treatment of epilepsy. Figure 2 represents the awareness of the patients regarding first aid measures to be taken during an epileptic attack. 65.7% of the patients were not aware of the first aid measures while 21.9% of the patients gave erroneous responses. Various sources of epilepsy related information of the patients are shown in Figure 3.

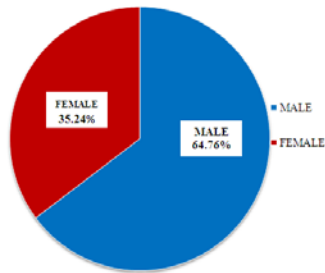


Fig. 1: It shows gender distribution of patients in the study sample (n=105)

Table 1: It shows the characteristics of patients in the study (n=105)

S. No.	Characteristics	No. (%) of patients
1	<b>Age Groups</b>	
	18-35	65 (61.9)
	36-45	17 (16.2)
	46-55	9 (8.6)
	56-65	10 (9.5)
≥ 66	4 (3.8)	
2	<b>Marital Status</b>	
	Single	51 (48.6)
	Married	54 (51.4)
3	<b>Education</b>	
	Middle School	15 (14.3)
	High School	40 (37.1)
	Higher Secondary	13 (12.4)
	Graduate	32 (30.5)
Post Graduate	5 (4.8)	
4	<b>Occupation</b>	
	Employed	57 (54.3)
	Unemployed	26 (24.8)
	Students	22 (22.9)

**DISCUSSION**

In the present study, basic knowledge of epileptic patients referred to a tertiary care center was found to be on the higher side and this finding was similar to another study from India [8]. But knowledge in terms of safety measures, social issues and treatment of epilepsy was found to be poor when compared with other studies [8,15]. Patients in our study displayed an obvious lack of knowledge related to safety issues during seizures. Only 40.9% of our patients knew that it was inappropriate to place an object in the patient's mouth during a seizure. A study in Seoul, Korea documented similar findings [16]. But studies from USA [15] and Oman [17] showed a greater proportion by 59.4% and 50% respectively of the patients reporting the practice to be inappropriate. Placing an object in the patient's mouth can lead to tooth breakage or injure the hand of the rescuer. Similarly, correct responses (12.4%) in terms of first aid measures were found to be poor. This aspect is of much concern in a country like India, as various age-old measures such as placing keys in the

hands of the patient, making the patient smell a shoe are in practice to terminate an epileptic attack.

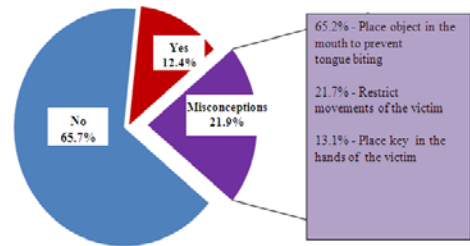


Fig. 2: It shows the patient awareness on first aid measures to be taken during an epileptic attack (n=105). (The inset shows the various misconceptions among the patients and their respective percentages.)

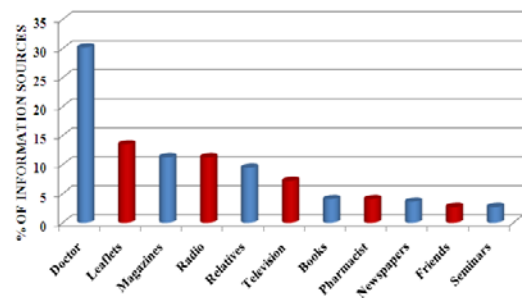


Fig. 3: Sources of epilepsy information (n=105)

The patient and care-giver must be clearly informed of the 'do's and 'don'ts' during and after a seizure so that the patient is not harmed in the process of helping. The current first aid rules for a tonic-clonic seizure include removing all sharp objects from the vicinity of patient and protecting the head from injury. Place the patient in recovery position once the seizure stops. In case of frothing, tilt the head to one side so that the froth comes out of the mouth and prevents choking. Allow the patient to rest and do not feed the patient till consciousness is regained [18].

Laws regarding driving in PWE vary from country to country. In general, only people whose seizures are under control should be licensed to drive. In India, anyone who has had a recent attack of any form of seizure should get clearance from the doctor for driving [19]. In spite of strict rules, most epileptic patients continue to drive, causing risk to themselves as well as to other commuters. The present study revealed that 52.4% of the patients believed that it was safe to drive even when seizures were not under control. A study in US reported that 25% of epileptic patients felt that it was appropriate to drive if they double the dose of the medication, are not driving alone or is able to stop driving at the onset of a seizure [15]. Though these aspects were not investigated in our study, in general, PWE did not refrain from driving. This could be because the ability to drive is essential in the present day society to meet various personal and social needs. This emphasizes the need for educating the patient on the risks associated with driving.

Swimming can lead to life-threatening conditions when seizure occurs in water. Studies report that epileptic patients are 19 times more likely to get drowned than those in the general population [20]. Patients are best told to avoid swimming and if at all they go for swimming, only in the presence of a lifeguard or friend who is aware of the patient's condition and familiar with the safety measures to be taken. In the present study, 48.6% of patients held the belief that PWE could swim without an accompanying person.

Long term use of anti-epileptic drugs (AEDs) may increase the chance of side-effects. Starting medications at low doses and

increasing it slowly can lower the probability of developing side-effects. Also keeping the drug therapy as simple as possible lowers the risk of side-effects. A significant observation of our study was that 47.6% of the patients feared from the side effects of long term anti-epileptic drug treatment. This fear could lead to sub-optimal compliance, discontinuing drug therapy thereby causing seizure relapse and poor treatment outcomes.

Patients must be counseled on the importance of drug therapy and explained how the benefits of the treatment out-weigh the risks. Promoting long term medicine intake is a complex task and should involve both educational and behavioral interventions. Behavioral interventions such as the use of reminders and linking medication intake with daily activities have shown more positive results [21].

**Table 2: It shows the epilepsy knowledge questionnaire and the percentage correct responses of PWE (n=105)**

S. No.	Questions	Correct Answer	% of patients with correct responses
1	Do you think epilepsy is a mental disease?	No	74.4
2	Do you think epilepsy is a hereditary disorder?	No	74.3
3	Do you think epilepsy is a contagious disease?	No	95.2
4	Do you think that a person with epilepsy can marry?	Yes	77.1
5	Do you believe that people with epilepsy are as capable as others?	Yes	77.1
6	Do you think people with seizures should not swim without an accompanying person?	Yes	29.5
7	Do you think it is safe to drive when your seizures are not under control?	No	31.4
8	Do you think people with epilepsy can take an active part in sports?	Yes	66.7
9	Do you think that epileptic seizures always result in loss of consciousness?	No	56.2
10	Do you believe that all people with epilepsy have similar symptoms?	No	61.9
11	Do you think that epilepsy can be controlled with treatment?	Yes	83.8
12	Do you fear from the side-effects of long term anti-epileptic drug treatment?	No	40.9
13	Can you mention any epilepsy treatment options other than with drugs?	Yes	3.80
14	Do you think, during a seizure attack, it is right to place an object in the patient's mouth to prevent tongue biting?	No	40.9
15	Do you know the first aid measures to be taken during a seizure attack? (If yes mention).	Yes	12.3

Studies have revealed that PWE appears to know little about their disease condition compared to those without the disease [22]. A pertinent question is whether this could be due to lack of education? In the present study, educational status of 85.7% of the patients were high school and above, with none being illiterate. All patients could read and write Malayalam or English. This clearly indicates that epilepsy is no longer a hindrance to acquire education and similar results were reported in other studies [15,17]. Though our patients had a basic understanding of epilepsy, knowledge on important aspects on safety measures, social issues and treatment were neglected. Information available in the media (T.V, Radio, Magazines, etc.) presents a general overview regarding the disease but not in-depth or patient specific details. This lacuna in knowledge can be addressed by health care professionals alone. Physicians, clinical pharmacists and other health care professionals must work jointly to promote patient education.

Patient and caregiver education should focus on general aspects of the disease as well as first aid measures during an epileptic attack, driving and swimming restrictions and treatment of epilepsy – pharmacological and non-pharmacological. Educational interventions given verbally should be supplemented with patient information leaflets and videos on first aid measures to enhance the understanding of the patient and caregiver. Also patient's understanding should be ascertained and apprehensions allayed. Future studies should focus on improvement of knowledge through educational interventions, correlating knowledge scores with medication adherence, quality of life, seizure frequency and seizure severity. Enabling each patient to take the right decision regarding his/her disease ensures quality care and optimal outcome of patient treatment.

#### CONCLUSION

The patients in our study had a basic understanding of epilepsy, but knowledge in terms of safety measures, social issues and treatment options were poor. Health care professionals like physicians and clinical pharmacists can play an important role in identifying these lacunas in knowledge among the patient and caregiver. Educational interventions should focus on general aspects of the disease as well as first aid measures during an epileptic attack, driving and swimming restrictions and treatment of epilepsy –pharmacological and non-pharmacological.

#### DISCLOSURE

None of the authors has any conflict of interest to disclose.

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