



Original Article

Perception of the General Population on Epilepsy and Antiepileptic Drugs: A Questionnaire-based Study

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ABSTRACT

The impact of epilepsy is multidimensional, ranging from socioeconomic to medical to psychological problems. The additional burden on quality of life is not only due to disease but also to the antiepileptic medication-related adverse effects. Though the majority of epileptics dwell in developing countries, studies have found a lack of knowledge, attitude, and practice towards epilepsy and its management, leading to a large treatment gap. This study aimed to assess the knowledge, attitude, and practice of epilepsy and antiepileptic medication among the general population, including epileptics or caregivers. A 6 month (August 2022 to February 2023) prospective, cross-sectional online questionnaire-based study utilizing Google Forms as a data collection tool was conducted among the general population at a tertiary care hospital in Coimbatore, employing convenient sampling. Descriptive and inferential statistics (paired t-test, chi-square test) were used. The results were presented as numbers and percentages. The data obtained was analyzed using Statistical Package for the Social Sciences, version 27. We received 123 responses. 87.8% and 85.4% linked epilepsy to insanity and spiritual possession/trance, respectively. More than 90% opined that epilepsy was contagious, due to patient or ancestral sins, and treatable by faith healers. The mean knowledge, attitude, and practice scores (%) were found to be 78.04 ± 1.32 , 71.23 ± 1.23 , and 53.15 ± 1.38 , respectively. Even though the urban population had satisfactory knowledge, the same was not translated into attitude and practice. There was a wide gap between knowledge, attitude, and practice. Considering the significant disparities in awareness, attitude, and practice even after decades in urban regions, policymakers and public health professionals must incorporate health education programs and healthcare services for the masses to bring about changes in a country like India.

Keywords: Knowledge; Attitude; Practice; Stigma; Quality of life; People living with epilepsy

INTRODUCTION

Epilepsy is a chronic disorder of brain function characterized by the recurrent and unpredictable occurrence of seizures¹. Around 1% of the world's population has epilepsy, which is the fourth most common neurologic disorder after migraine, stroke, and Alzheimer's disease¹. The annual incidence of epilepsy in India is approximately 40 to 50 per 100,000 per year, and the disease burden is higher (80%) in developing countries². Epilepsy significantly impacts the medical, psychological, economic, and social aspects of

the affected individuals, their families, and the community^{3,4}. Studies have shown that, despite advancements in educational and social parameters, including technology and communication, there has been no significant change in the deep-rooted stigmas, perceptions, and discrimination of epilepsy throughout India and other developing countries compared to the developed countries⁴⁻⁶. There is also a noteworthy treatment gap among epilepsy patients due to this lack of cognizance^{2,7,8}. Improving disease awareness and comprehension can aid in epilepsy prevention and

treatment². Hence, understanding the public's perception, attitudes, and practices regarding epilepsy and antiepileptic drugs (AEDs) is critical, as misconceptions about the disease have a negative impact on sufferers' quality of life (QOL)⁹. Though there are some original research articles on this topic from different states of India, because of the differences in the population investigated as well as the questionnaires and procedures utilized, the results are not strictly comparable^{2,5,6,8,10-19}. Except for a few Knowledge, Attitude, and Practice (KAP) studies in rural northeastern Tamil Nadu (TN), explorations targeting the non-epileptic general population of TN are very limited; hence, this research may help to assess the extent of the problem and provide additional insight into public KAP^{5,10}. It will also help in the planning of future studies in the region and, hopefully, will motivate interested officials and organizations to initiate interventions that include not only the extension of services but also staff training and education for the general public and the people living with epilepsy (PLE). Therefore, the present study aims to assess the KAP of epilepsy and its treatment among non-epileptic and epileptic patients or caregivers (EP/CG).

MATERIALS AND METHODS

After approval from the KMCH Institute of Health Sciences and Research (KMCHHSR), Institutional Human Ethics Committee (Approval No. 13/IHEC/2022), a prospective online cross-sectional survey using convenient sampling was carried out at KMCHHSR, Coimbatore, for a duration of 6 months (Aug 2022 to Feb 2023) among the general population without epilepsy and EP/CG. We received 123 responses, which may be justified based on the completed responses received from the willing participants during the destined period.

- **Inclusion criteria:** All participants aged 18 years and older, with or without epilepsy, of either gender, should be able to understand, read, speak, or write in English or Tamil.
- **Exclusion criteria:** Participants who were unwilling to participate, incomplete responses, participants belonging to the medical background, and epileptic patients or caregivers who were mentally or critically ill.

Study Procedure

The prevalidated online questionnaire, (derived from a 2016 KAP study in a South Indian village and a 2020 study by Sethi *et al.* in North India) was designed in both English and Tamil using Google Forms as a data collection tool and it was shared via WhatsApp with non-medical friends, family members, relatives, and their mutual contacts^{2,5}. A description of the nature of the study and willingness to participate was incorporated at the beginning of the Google Form. The first part of the form was open to both the

general population and EP/CG and it had questions under the following sections:

Section A: Demographic Data: Age, Gender, Occupation, Education, and Living Status.

Sections B and C had 13 questions each on knowledge (cause, manifestation, and treatment options for epilepsy) and attitude (perspectives of epilepsy in the workplace, school, and marriage), respectively.

Section D had eight questions on the practices related to first aid, treatment, and local beliefs towards epilepsy.

The second part of the form was designed to be filled out only by EP/CG, and it had 7 questions on knowledge, 3 questions on attitude, and 4 questions on practice. Questions were formatted in a descriptive, binary, and multiple-choice fashion. Options were provided to add other events or descriptions. The performance was assessed by scores (0 = Incorrect responses and 1 = Correct responses) and the mean scores were calculated.

Statistical analysis

Categorical data was expressed using frequency and percentage. The association between variables was assessed with the chi-square test. Quantitative data was represented as the mean and standard deviation. Intergroup comparisons were done using paired t-tests; for more than two groups, an ANOVA was used. A P value < 0.05 was considered statistically significant. Anonymized data obtained via Google Forms was entered and analyzed using Statistical Package for the Social Sciences (SPSS) version 27.

RESULTS

Demographic data

Out of the 123 responses received, 12 were filled by EP/CG. The majority of participants (46.3%) were aged 18 to 25, with the maximum and minimum age being 65 and 18, respectively. Most (55.3%) were female respondents, and the majority (77.9%) were unemployed, of which 44.1% were students and 33.8% were housewives. 61.0% possessed an undergraduate literacy level. Participants hailed from urban regions (78%) compared to rural areas (Table 1). Two-thirds of EP/CG belong to the 30-year-old age group and possess a higher secondary level of education. 75% of them were urban females. 58.33% were employed. Concerning KAP, no significant association was found between age, socioeconomic status, and education. Students had better knowledge than the unemployed ($P < 0.05$), but no significant association was observed between attitude and practice.

Knowledge

89.4% of participants had heard about epilepsy. Half of them were aware of PLE and AEDs. The majority of respondents (68.3%) correctly identified epilepsy as a brain

Table 2: Knowledge of the respondents(N=123) ^{2,5}

Questions	Answers n (%)	
	Yes	No
Have you heard about the disease called “epilepsy” or convulsive seizures?	110(89.4)	13(10.6)
Do you know anyone who has epilepsy?	62 (50.4)	61 (49.6)
Is epilepsy a brain disorder?	84 (68.3)	39(31.7)
Is epilepsy a mental disease?	108 (87.8)	15(12.2)
Is epilepsy a hereditary disorder?	87(70.7)	36(29.3)
Is epilepsy due to supernatural powers?	119(96.7)	4(3.3)
Is it due to the sins of the patient/ ancestors?	120(97.6)	3(2.4)
Is epilepsy contagious?	118(95.9)	5(4.1)
Epilepsy manifests as convulsion/Loss of consciousness/behaviour change/ Periods of amnesia	87 (70.7)	36(29.3)
Is epilepsy treatable with Allopathy medicine?	75(61.0)	48(39.0)
Is epilepsy treatable with Ayurvedic medicine?	103(83.7)	20(16.3)
Can faith healers treat epilepsy?	113(91.91)	10(8.1)
Are you aware of Antiepileptic Drugs (AEDs)?	62(50.4)	61 (49.6)

Table 1: Demographic Profile of the Study Participants (N=123)

Variables	Categories	N (%)
Age	18-25	57(46.3)
	26-35	11(8.9)
	36-45	26(21.1)
	46-55	18(14.6)
	56-65	6(4.9)
	>65	5(4.1)
Gender	Male	55(44.7)
	Female	68(55.3)
Epileptic patient	Yes	12(9.75)
	No	111(90.24)
Education	Middle school	2(1.6)
	Higher Secondary	12(9.8)
	Undergraduate	75(61.0)
	Postgraduate	34(27.6)
Occupation	Student	52(42.3)
	Employed	43 (34.9)
	Unemployed	28(22.8)
Socioeconomic status	Rural	27(22.0)
	Urban	96(78.0)

disease, with 61% believing it can be treated with allopathic medicine and 70.7% correctly identifying symptoms. Most of them (97.6%, 87.8%, and 70.7%) incorrectly presumed that epilepsy was caused by patient or ancestor sin, a mental and hereditary disease. Participants misunderstood epilepsy as supernaturally caused (96.7%), contagious (95.9%), treatable by faith healers (91.91%), and ayurvedic medicine (83.7%) (Table 2).

Attitude

Participants’ attitude toward PLE was positive for various medical and psychosocial issues like treatment options,

QOL, marriage, procreation, scholastic performance, and job. The majority (67.5%) of the respondents felt that AEDs were safe, and part (55.3%) of them thought that it would not affect the epileptic patient’s activity. Half (52.8%) believed that epilepsy could be cured. The larger part of the participants rationalized the link between spiritual possession or trance (Godly frenzy) and epilepsy (Table 3).

Practice

Our research revealed that 55.3% of participants know first aid for epileptic fits, with 29.3% learning from doctors and 17.1% from the internet. 53.7% objected to handing over keys, and 91.9% and 85.4% would seek medical help. The majority of respondents (86.2%) and 75.6% favored the incorrect practice of contacting the patient and providing water during an epileptic attack, respectively (Table 3).

KAP of Epileptic Patients or Caregivers

For the first part of the questionnaire, 83.3% of respondents provided accurate answers. 66.7% of EP/CG know the names of the drugs taken for epilepsy. The most common drugs included levetiracetam (33.3%), followed by phenytoin (25%). Sodium valproate (16.6%) and carbamazepine (8.3%) were less commonly used. The majority had a positive awareness and perspective towards taking the right dose (phenytoin -25 mg/100 mg, levetiracetam -500mg, valproate -1000mg) and the right frequency (once daily). A larger number of people (91.6%) correctly revealed the time to withdraw the therapy if seizure-free (3 to 7 years after the last seizure) and consumed missed doses within 6 hours. Part of them were cognizant, and 83.3% of participants rightly thought that therapeutic drug monitoring (TDM), a test that measures the levels of certain medicines in the



Table 3: Attitudes and practices of the respondents (N=123)^{2,5}

Attitude based questions	Answers n (%)	
	Yes	No
Do you think an epilepsy patient can lead a normal life?	95 (77.2)	28(22.8)
Do you think epileptic drugs affect a patient's activity?	55 (44.7)	68 (55.3)
Do you think there is surgical treatment for epilepsy?	99(80.5)	24(19.5)
Can epilepsy be cured?	65 (52.8)	58(47.2)
Do you think antiepileptic drugs are safe?	83(67.5)	40(32.5)
Do you think an epileptic child needs to be treated differently/specially?	65 (52.8)	58(47.2)
Do you think an epileptic child has the capability for school achievement?	104 (84.6)	19(15.4)
Do you think an epileptic child can participate in any type of sport?	52(42.3)	71(57.7)
Can a person with epilepsy take up a job?	106(86.2)	17(13.8)
Can a person with epilepsy marry?	108 (87.8)	15(12.2)
Can a person with epilepsy have children?	99 (80.5)	24 (19.5)
Do you think there is a relationship between 'Saami aaduthal' (intense wild disorderly compulsive agitated activity in the name of God) and epilepsy?	105(85.4)	18(14.6)
Will you reveal the status of epilepsy of your child before marriage?	103(83.7)	20(16.3)
Practice-based questions		
Do you know how to do first aid during an epileptic attack?	68(55.3)	55(44.7)
During an epileptic attack will you put keys in the hands of patients?	57(46.3)	66(53.7)
During an epileptic attack will you give the patient water?	93(75.6)	30(24.4)
During an epileptic attack will you make the patient smell a shoe?	10(8.1)	113(91.9)
During an epileptic attack will you avoid contact with the patient?	17(13.8)	106(86.2)
During an epileptic attack will you take the patient to hospital?	105(85.4)	18(14.6)
Will you treat epilepsy by consulting a medical doctor?	113(91.9)	10(8.13)
Will you allow your child to play with an epileptic child?	115 (93.5)	8(6.5)

Table 4: Knowledge, attitude, and practice of epileptic patients/caregivers (N=12)

Questions	Answers n (%)	
	Correct responses	Incorrect responses
Knowledge		
Do you know the names of the drugs taken for epilepsy?	8(66.7)	4(33.3)
What are the drugs you have taken for epilepsy?	10 (83.3)	2(16.7)
What is the dose of the drug you can take for epilepsy?	8(66.7)	4(33.3)
How often should you take antiepileptic drugs?	8(66.7)	4(33.3)
When is treatment for epilepsy stopped, if the patient is seizure-free?	11(91.6)	1(8.34)
Is discontinuing Antiepileptic drugs life-threatening to the patient?	8(66.7)	4(33.3)
If yes, how will the antiepileptic drug be stopped?	10(83.3)	2(16.7)
Are you aware of Therapeutic Drug Monitoring (TDM), a test measuring the level of certain medicines in your blood?	6 (50)	6(50)
Attitude		
Do you think Antiepileptic drugs need Therapeutic Drug Monitoring (TDM)?	10(83.3)	2((16.7)
Do you think it's okay to take a higher or lower dose of medicine than prescribed?	12(100)	0(0.00)
Do you feel antiepileptic drugs can be safely taken during pregnancy?	6(50)	6(50)
Practice		
Will you change the brand of the antiepileptic drug during treatment?	10(83.3)	2(16.7)
Do you maintain a Seizure diary?	8(66.7)	4(33.3)
Has your doctor educated you about the strategies to minimize missing doses?	8(66.7)	4(33.3)
What will you do if you miss a dose?	11(91.6)	1(8.34)

blood, was required. Similarly, they denied changing the drug brand. Two-thirds of respondents correctly agreed that discontinuing AEDs was life-threatening to the patient and should be stopped slowly and gradually. They also kept a seizure record after learning ways to reduce missing doses. 50% believed AEDs were safe during pregnancy when taken correctly and according to a doctor's advice, and the rest felt they were harmful to the fetus. Overall, KAP was good among EP/CG (Table 4).

KAP Scores

The participant's overall mean knowledge (78.04 ± 1.32) score was more than attitude and practice. The mean comparison between the three shows that knowledge was not completely converted to attitude and the attitude in turn to practice. There was a wide gap between KAP. A p-value of <0.001 was considered significant (Table 5).

DISCUSSION

This questionnaire-based study assessed the KAP towards epilepsy and its treatment among the 123 general public including 12 EP/CG. We found that participants' knowledge was not completely converted into attitude, and the attitude in turn to practice, and there was a wide gap between KAP. Nevertheless, the EP/CG had a satisfactory KAP.

Out of the 123 responses received, most were females (55.3%); this may be owing to their engaging and willing attitude to participate in surveys and also due to the rising stigma that affects the female gender^{5,8,10}. Most of our respondents were students (42.3%), and they had better knowledge than the unemployed, similar to studies done in Delhi and Bangalore^{11,12}.

The majority of our participants were aware of epilepsy, its symptoms, and its relation to brain disorders, similar to other studies^{8,13,14}. But most of our subjects muddled epilepsy with insanity and overstated the role of hereditary factors in epilepsy, in line with several other works^{2,8,12,15,16,20}. Contrarily, developed countries had a greater understanding of the lack of connection between epilepsy and insanity or hereditary²¹. In comparison to earlier Indian studies, a considerably higher number of individuals in our study believed epilepsy was contagious, caused by supernatural powers, and the sins of ancestors or patients^{2,5,8,12,14,16}. An Ethiopian and Jordanian study also misrepresented the contagious nature of the disease and its occurrence due to God's curse, respectively^{22,23}. However, studies done in Saudi Arabia and Brazil showed that most students had a good understanding of the non-contagious nature and the non-relationship to supernatural powers^{20,24}. These disparities might be because of the differences in the population studied and the methods used. Bateman proposed rapid, repetitive, and effective education to combat stigmas and enhance the therapeutic outcome²⁵. So, it's

evident that India's population still grapples with social stigmas and outdated beliefs, necessitating the provision of epilepsy education to all sectors.

In our current study also, a maximum number of participants had a positive attitude towards QOL, employment, marriage, giving birth, and revealing the epileptic history before marriage, congruent with other papers^{2,10,20,21}. Unlike our analysis, most others discovered widespread negative attitudes about the aforementioned characteristics^{5,8,10,14-16,22,26-28}. The dissimilarity shown by our answerers could be attributed to younger participants from urban and diverse locations, gradual public attitude change due to improved awareness, and sociocultural diversity. Our article suggests a potential link between agitated dancing to God and epilepsy. An American study found a connection between religious activity and neuropsychological processes within the human brain²⁹. Although Indian research on this aspect is limited.

The majority of our survey takers acknowledged that epileptic children can achieve in school, though they can't participate in all kinds of sports, and they need to be treated differently, identical to a Bangalore study¹². But in the same study only 33% and 34% felt that epileptic kids have an appropriate level of intelligence and the need to be sent to special schools respectively¹². Our study's maximum number of respondents had no objection to playing with epileptic children, corresponding to other works^{2,8,10,11,16}. But, Chaitra, Kankane (15-20%) and a rural Ethiopian study (39%) found a negative attitude towards playing with epileptic children^{14,15,22}. Our respondent's positive attitude toward epileptic children may be linked to their urban background and higher literacy status.

Only a few of our participants were aware of the AEDs, but in other groundworks, many of them were aware^{2,27}. Two-thirds of our population felt AEDs were safe, but as per other articles, 60-80% feared the side effects^{12,16,17}. Our subjects opined that epilepsy can be cured, which was identical to other explorations^{7,8,16,26,30}. A higher percentage (83.7%) of our individuals preferred Ayurvedic medicine, compared to other studies in TN (42.3%) and Kerala (64.1%)^{8,10,13}. This shows the inclination of the south Indian population towards Ayurveda. More than 90% of our respondents favored treatment by faith healers as opposed to other fact-findings (19-34%)^{2,10,11,14,16}. According to Sharma *et al.*, integrating spiritual healing traditions and medical practitioners at the local level may aid in early referral and the beginning of appropriate therapy³¹. Most of our surveyees believed in surgical treatment for epilepsy, similar to a work by Santhosh NS⁷. Nonetheless, in other investigations, the majority were unaware of the same^{13,18,27,30}.

Bringing the patient to the hospital and getting professional medical attention was one of our other promising results; this was also supported by other

Table 5: Comparison of Mean Knowledge, Attitude, and Practice scores

Comparison	Parameters	Knowledge Percentage		t value	P Value
		Mean	Standard Deviation		
Knowledge vs Attitude	Knowledge	78.04	1.32	4.661	0.00002*
	Attitude	71.23	1.23		
Knowledge vs Practice	Knowledge	78.04	1.32	28.651	0.00001*
	Practice	53.15	1.38		
Attitude vs Practice	Attitude	71.23	1.23	21.53	0.00004*
	Practice	53.15	1.38		

(*P< 0.001- significant)

data^{2,8,10,14,21}. However, the ratio of people who do these practices was comparatively lower in other studies done in TN (25.8%) and Uttarakhand (49.8%)^{5,16}. Compared to our project (46.3%), a larger fraction of people in TN (69.9%), Kerala (54.7%), in contrast to the north and central India (1-27%), had an incorrect practice of holding a bunch of keys during an attack^{2,5,8,14,16}. The practice of providing iron rods to the patient was observed in a Villupuram-based study¹⁰. The majority (75-86%) of our poll-takers wrongly opined that they would provide water and contact the patient during an attack, akin to a study by Dhikale¹⁰. Nevertheless, only a lesser proportion of people in rural TN (5.3%) and Bangalore (13.5%) adopted such methods^{5,15}. The practice of smelling the shoe during an epileptic attack was infrequent in the current study, compared to studies done in Central and North India and some other developing countries^{2,14,16,27,32}. A study done among EP/CG found that educational interventions improve first-aid practices³³. All these variations clearly state the cultural and geographic differences among people and their practices and the need to educate and counsel them.

Our patients commonly used levetiracetam, followed by phenytoin, valproate, and carbamazepine, identical to a study done in Trivandrum³³. As per Joshi *et al.*, valproate and levetiracetam were the most commonly prescribed older and newer AEDs, respectively³⁴. Investigations proved carbamazepine, levetiracetam, and clonazepam to be safe in females^{34,35}. More preference towards levetiracetam was observed in our study since the majority of our epileptic population were females and valproate has a teratogenic potential. Seizure type, patient age, and tolerability could be additional variables. Lekshmi *et al.* discovered that a twice-daily dose was more typically administered, although, a once-daily regimen as prescribed in our study was found to be more compliant³³.

Our EP/CG had good KAP related to the right dose, brand, and withdrawal of the therapy and its consequences, akin to a study by Shaju *et al.*^{17,26}. Analogous to our finding, 58.7% of science graduates in Karnataka agreed on the life-threatening aspects of discontinuing AEDs, but contrary to our study, 59.3% believed AED discontinuation was impos-

sible even after a three-year seizure-free interval¹². This lack of cognizance could be attributed to non-epileptic population involved in that study. Similar to previous explorations, our subjects also maintained a seizure diary and adhered to the doctor’s advice (reminders) to avoid missing doses^{18,19}. Our study identified positive awareness and attitudes towards TDM, but in a Kochi-based survey, most individuals were ignorant¹⁷. Half of the answerers felt AEDs were safe during pregnancy, similar to a review that has stated the need for individualizing the therapy based on the risk and benefit³⁶. On the whole, the KAP of EP/CG was better than that of nonepileptic individuals, in line with other studies^{2,19}.

According to published data, urban dwellers have better knowledge and attitudes than rural residents^{37,38}. Due to our study duration, geographical constraints, and sampling technique, most of our survey participants belong to urban regions, which might contribute to sample bias and increased levels of KAP. Even though the majority of our people were urban educated, there was still a large gap between KAP, consistent with few works^{8,12,38}.

This analysis confirms the existence of a wide gap in KAP regarding epilepsy and the AEDs that still prevail in the Indian public even after decades, despite advancements in technology, educational campaigns, and improving literacy. It’s noteworthy to mention that the findings of our study add value to the existing literature due to the relatively limited research conducted among the urban population in TN and reinstate the emergent need to incorporate adequate awareness programs and interventions that may guide lay public healthcare providers, policymakers, executors, and authorities to eliminate the stigmas, improve the therapeutic outcome, and improve the QOL of PLE.

Limitations

This study was observational, with a limited sample, and reports were based purely on the recipient’s online response and were highly subjective. The sample was not representative of the general public and was limited to people who had a strong liking for the Internet. As a result, it is difficult for our findings to reflect the entire state of South



India throughout this investigation. Furthermore, because of the relatively fewer responses received from EP/CG, generalizations and comparisons of findings could not be made. The study's limitations can be addressed through prospective community-based multicentric, comparative interventional studies with larger sample sizes and a focus on quality of life.

CONCLUSION

Our study discovered that the general population had an acceptable level of knowledge and perspective toward epilepsy and AEDs, but that knowledge was not transferred to attitude, and that attitude was not turned into practice. However, EP/CG had a good KAP. Special educational campaigns and the inclusion of epilepsy education in school and university curricula are crucial to dispel misconceptions and incorrect practices. Government agencies, educators, public health professionals, health sector organizations, mental health professionals, and mass media should work together to erase stigmas, educate, and strengthen public understanding of the disease. These interventions can prevent treatment gaps and improve the health and socio-economic well-being of EP. Future research can look into the impact of social media and educational programs and the role of healthcare professionals in epilepsy education and understanding. Also, one can investigate agitated dancing to God and epilepsy.

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