



## Assessment of knowledge, attitude and practice (KAP) of parents/ caregivers towards epilepsy in children – A cross-sectional observational study

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### ABSTRACT

**Objectives:** The study aimed to assess the knowledge, attitude, and practice (KAP) of parents/ caregivers toward epilepsy in paediatric patients at a tertiary care centre of North India.

**Methods:** A cross sectional study was carried out among 418 parents or caregivers using convenience sampling technique with 16-item questionnaire in English language and also translated to local language that is Hindi. Children with epilepsy who visited the paediatric outpatient department within a year were included in the study (January 2021–22). A total of 450 children visited the clinic, 32 of whom were excluded for various reasons, and the final analysis was conducted among the 418 parents or caregivers who completed the questionnaire.

**Results:** The male and female patients were 56.7% (n = 237) and 43.3% (n = 181) respectively. The age distribution of patients with less than 5 years, 6–10 years and more than 10 years were 35.6% (n = 149), 54.5% (n = 228), 9.8% (n = 41) respectively. Only one third of parents and caregivers did not consider epilepsy as psychiatric illness. Most of the parents and caregivers think that epilepsy affects school performance (77.2%) and hinders family life (71.0%). More than half of the parents or caregivers believes that the society discriminates against person with epilepsy and around 46.6% consider that alternative medicine can cure epilepsy. The parents or caregivers felt financial burden due to epilepsy was in 72.5% and approximately 78.5% perceived that their work is affected because of their child's epilepsy. Perception of epilepsy as a psychiatric illness was found to be significantly higher in parents with primary and secondary level education, when compared to parents who were graduates. The practice of the parents or caregivers towards administration of drugs to their child was good, however around 36.6% (n = 153) missed the dose of anti-seizure medications.

**Conclusion:** The study highlights the substantial knowledge, attitude and practice gap amongst parents and caregivers for children with epilepsy which indirectly has huge impact on the

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management of epilepsy. Thus it becomes utmost important to educate the family as well as the community regarding epilepsy which will help in improving the therapeutic outcomes, overall quality of life and interpersonal and social relationships of these children.

## 1. Introduction

Epilepsy is a chronic neurological condition which is responsible for more than 0.5% of the global burden of disease. Around 7.6 per 1000 persons have epilepsy during their lifetime [1]. Prevalence is higher in children up to 1 in 150 [2]. Persons with epilepsy have high rates of co-morbid psychiatric illnesses, including depression and anxiety, and psychosis. Around 70% of the epilepsy is treatable with cost-effective anti-seizure medications. A large proportion of this population does not receive the treatment. In India, this treatment gap varies between 22% in urban area to up to 90% in rural areas [3]. In comparison to general population, people with epilepsy have a significantly increased risk of premature mortality. This risk is higher in low to middle income countries when compared to high income countries [3].

Despite increasing awareness in the medical field regarding pediatric epilepsy and better accessibility to health care facilities, parental knowledge, attitude and practice towards epilepsy remains a major determining factor in management of children with epilepsy. There is great hindrance for managing epilepsy in India due to negative sociocultural attitudes. This chronic condition seems to be engulfed in superstition, discrimination, and social stigma. Religious and socio-cultural beliefs influence the practice of people in seeking and compliance with the medical care for their children. The false belief regarding epilepsy due to evil spirits also lead to major roadblock in the successful management. The parents and care givers of children with epilepsy are discriminated socially in India as epilepsy is considered highly contagious and shameful disease in the eyes of the public which leads to treatment gap [3]. Also, there is paucity of literature regarding the knowledge, attitude and practices of parents/caregivers regarding pediatric epilepsy especially in developing countries like India and there was need to study these factors which will have huge impact on the management and compliance for the treatment of epilepsy in children.

The main aim of the study was to improve the utilization of primary care services for epilepsy treatment by bridging the treatment gap between the communities and health facilities by assessing the knowledge, attitude and practice (KAP) of parents/caregivers towards epilepsy in pediatric patients in northern India.

## 2. Materials and methods

### 2.1. Study design and the sample

A cross-sectional study was conducted at the tertiary care centre in North India. The study included children below the age of 18 years who had epilepsy (at least two unprovoked (or reflex) seizures occurring >24h apart; one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; diagnosis of epilepsy syndrome) and were accompanied by parents or caregivers to the paediatric outpatient department between January 2021 and January 2022. Parents or caregivers who could speak and read English or local Hindi language were included whereas those who were unwilling to participate or not able to read and write or not ready to give informed consent were excluded. The study was approved by the institute ethical committee (09/01/CHWC/2021) and informed consent from parents or caregivers were obtained for inclusion in the study. A sample size of 418 was calculated considering the knowledge regarding epilepsy among parents or caregivers to be 50% with 95% confidence interval and 5% absolute precision and 10% of non-response rate using the following formula  $n = z^2 p (1-p)/d^2$  where  $n$  = sample size  $z$  = the normal standard deviate ( $z = 1.96$ )  $p$  = the frequency of occurrence of an event,  $1-p$  = (the frequency on non-occurrence of an event),  $d$  = degree of precision (0.05%).

A 16-item closed questionnaire was developed after reviewing the search engines like science direct, Scopus, Pubmed. The questionnaire was validated by Institute ethical committee members and 3 experts from Pediatric Neurology. The questionnaire used for this cross-sectional study included questions related to knowledge, attitude and practice of parents and care givers towards epilepsy in children.

The data was collected using the same questionnaire, prepared in English, and translated in local Hindi language to assess the knowledge, attitude and practice of parents or caregivers towards children with epilepsy. The parents and caregivers were given questionnaire sheet and were asked to mark their response as yes or no or don't know. (Supplementary file 1,2).

The number of respondents to the English and Hindi questionnaire were 286 and 132 respectively. The questionnaire focused on the parents or caregiver's beliefs and misconceptions about the disease, issues related to personal, familial, and financial condition, attitude of the treating physician and practice of drug administration of the parents or caregivers. The demographic profile of the children (i.e., age and sex) and the educational qualification of the parents was also recorded.

### 2.2. Statistical analyses

The collected data were recorded in a Microsoft Excel spreadsheet. Statistical analysis was performed by using Statistical Package for the social sciences (SPSS Version 20). Descriptive and analytical statistics including Chi Square test was used wherever applicable. A probability of  $<0.05$  was considered as significant.

### 3. Results

During the study period, a total of 450 children with epilepsy accompanied with parents or caregivers attended the paediatric outpatient department, of which 32 were excluded due to various reasons and final analysis included 418 parents or caregivers who responded to the questionnaire (Fig. 1).

Of the included children, 237 (56.7%) were boys and 181 (43.3%) were girls. The age distribution of patients is mentioned in Table-1. Most of the parents or caregiver has completed their secondary level of education (313, 74.8%) and only 9.5% (n = 40) of parents of the patients were graduates.

Responses to questions about epilepsy are summarized in Table-2. Only a third of parents or caregivers did not consider epilepsy as psychiatric illness. Most of the parents and caregivers thought that epilepsy affects school performance (323, 77.2%) and hinders family life (297, 71.0%).

The association between knowledge of parents or caregivers and level of education is in Table 3. A significant association was observed with education level and the perception of “epilepsy as psychiatric illness”. Parents who were graduate believed that epilepsy is less likely to be a psychiatric illness compared to parents who had primary or secondary education.

More than half of the parents or caregivers believed that the society discriminates against person with epilepsy and 46.6% (n = 195) considered that alternative medicine can cure epilepsy. The parents/caregivers incurred financial burden due to epilepsy (303, 72.5%) and nearly 78.5% (n = 328) perceived that their work gets affected as a result of their child’s epilepsy. The practice of the parents or caregivers towards administration of drugs to their child was good, however around 36.6% (n = 153) missed the dose of anti-seizure medications. Around 42.3% parents or caregivers bought wrong medicine for epilepsy. Most of the caregivers followed the doctor’s instruction. Nine out of ten parents or caregivers think that timely administration of drugs can cure epilepsy and more than 80% said that they received information about epilepsy from the doctor every time and also followed doctors’ instruction.

### 4. Discussion

Pediatric epilepsy is a common neurological disorder seen by practicing pediatricians and pediatric neurologists. Children living with epilepsy are at an increased risk of learning impairment, behavioral issues like inattention, hyperactivity and psychiatric disorders like anxiety, depression and psychosis [4]. Thus, epilepsy has a significant impact not only on the children, but also their caregivers and parents. Most caregivers are not aware of the actual risks associated with epilepsy. Despite having adequate knowledge, attitude, and practice regarding epilepsy in children, many of these caregivers do not take appropriate curative and preventive measures owing to various reasons. Hence, parental awareness about care of such children greatly influences the well-being of the child by decreasing the morbidity and mortality [5].

This study assessed the knowledge, attitude, and practice (KAP) of 418 parents or caregivers of children with epilepsy and found many knowledge gaps among the caregivers regarding epilepsy as the disease. The male to female ratio in our study was 1.31, which is comparable to other similar studies in India and abroad [6]. Among the respondents, around three-fourths of them had an educational status beyond secondary level, while only less than one-tenth were graduates. According to the already available literature, awareness about epilepsy is generally poor, especially with regard to etiology of epilepsy and its effect on quality of life [7–9].

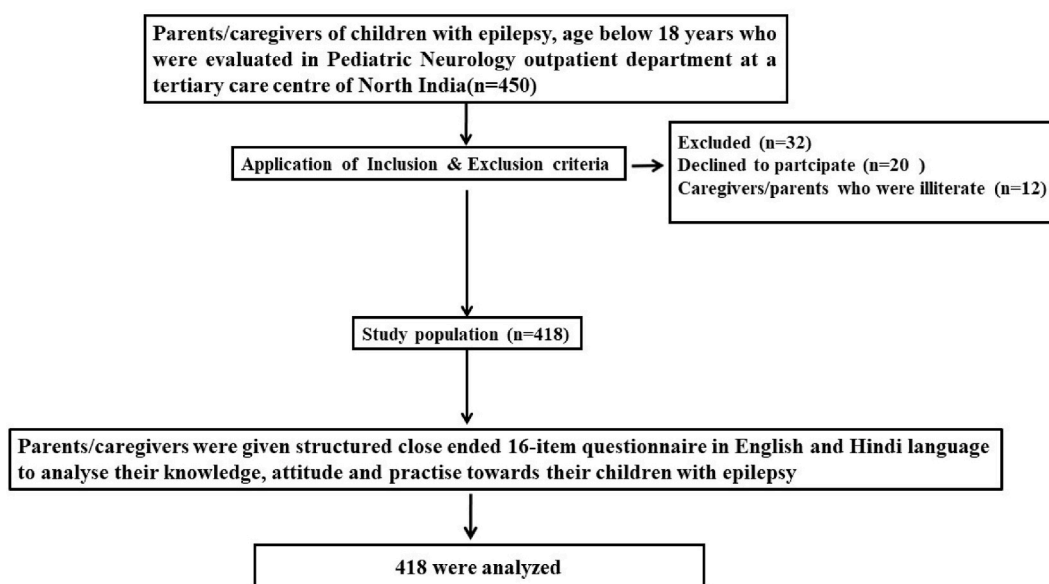


Fig. 1. Patient consort flow.

**Table 1**  
Demographic Characteristics of the parents/caregivers and their children.

Characteristics	Frequency (%) n-418
Gender	
Boys	237 (56.7%)
Girls	181 (43.3%)
<b>Age of Patients</b>	
Less than 5 years	149 (35.6)
6 years-10years	228 (54.5)
More than 10 years	41 (9.8)
Level of Education	
Primary	65 (15.5)
Secondary	313 (74.8)
Graduate	40 (9.5)

**Table-2**  
Response of Parents/Caregivers to questions towards epilepsy.

S.No.	Knowledge Questions	Response	Frequency	Percent
1	Is epilepsy a mental illness?	Yes	290	69.4
		No	128	30.6
2	Is epilepsy a hereditary disease?	Yes	154	36.8
		No	264	63.2
3	Is epilepsy contagious?	Yes	147	35.2
		No	271	64.8
4	Do you think epilepsy is caused by supernatural power?	Yes	86	20.5
		No	332	79.4
5	Do you think epilepsy hinders family life?	Yes	297	71.0
		No	121	28.9
6	Do you think epilepsy affects school performance?	Yes	323	77.2
		No	67	16.0
		Don't Know	28	6.7
7	Do you think timely administration of medicines can cure epilepsy?	Yes	386	92
		No	32	7.6
8	Does society discriminate against person with epilepsy?	Yes	220	52.6
		No	198	47.3
9	Do you think alternate medicine can cure epilepsy?	Yes	195	46.6
		No	223	53.3
10	Do you feel financial burden of epilepsy?	Yes	303	72.5
		No	115	27.5
11	Will you allow your child to play with an epileptic child?	Yes	268	64.1
		No	150	35.8
12	Does your work get affected because you have a child with epilepsy?	Yes	328	78.5
		No	90	21.5
13	Have you ever tried to miss the dose of anti-epileptic drugs?	Yes	153	36.6
		No	265	63.4
14	Did you ever purchase wrong medicine for epilepsy?	Yes	177	42.3
		No	241	57.6
15	Do you follow doctor's instructions?	Yes	358	85.6
		No	60	14.3
16	Does your doctor explain about epilepsy every time?	Yes	351	83.9
		No	67	16.0

More than two-thirds of the caregivers considered epilepsy to be a psychiatric illness in this study, which is slightly higher than previous studies Reddy et al. and Zaini et al. conducted few years back [10]. However, in similar studies, less than 5% of the individuals considered epilepsy to be contagious disease, compared to almost one-third of the caregivers in the present study, and less than 10% considered epilepsy to be hereditary in origin, compared to 37% reported in the current study [11]. An earlier population-based study from Kerala, had suggested that around 27% of caregivers considered epilepsy to be a supernatural phenomenon, compared to 21% in our study [12]. A majority of them considered that epilepsy in childhood affects school performance as well as hampers family life, which is in consonance with the previous studies [13]. The association between the level of education of caregivers with knowledge about epilepsy and its management is significant. Most of the caregivers with a lower level of educational status considered epilepsy to be a psychiatric illness. This indicates that the educational status of the parents/caregivers had a significant impact on their general understanding of the disease as well as the care they provide to their children. Hence, it was also observed that this affected the appropriate administration of anti-seizure medications. All the three groups of parents with different levels of educational status were equally unaware about the various etiological perspectives of epilepsy. This slight discordance in the results of the present study and previously done studies from India and abroad could be attributed to the different study setting as well as the difference in the status of

**Table 3**  
Association between knowledge of parents/caregiver with level of education.

Knowledge Questions	Response	Primary (n, %)	Secondary (n, %)	Graduate (n, %)	P value*
Is epilepsy a mental illness?	Yes	47 (72.3)	227 (72.5)	16 (40)	<0.001
	No	18 (27.7)	86 (27.5)	24 (60)	
Is epilepsy a hereditary disease?	Yes	23 (35.4)	119 (38.0)	12 (30)	0.59
	No	42 (64.6)	194 (61.9)	28 (70)	
Is epilepsy contagious?	Yes	26 (40)	114 (36.4)	7 (17.5)	0.04
	No	39 (60)	199 (63.5)	33 (82.5)	
Do you think epilepsy is caused by supernatural power?	Yes	19 (29.2)	62 (19.8)	5 (12.5)	0.09
	No	46 (70.7)	251 (80.2)	35 (87.5)	
Do you think epilepsy hinders family life?	Yes	46 (70.7)	223 (71.2)	28 (70)	0.98
	No	19 (29.2)	90 (28.7)	12 (30)	
Do you think epilepsy affects school performance?	Yes	51 (78.5)	243 (77.6)	29 (72.5)	0.98
	No	10 (15.3)	49 (15.6)	8 (20)	
	Don't Know	4 (6.1)	21 (6.7)	3 (7.5)	
Do you think timely administration of medicines can cure epilepsy	Yes	49 (75.3)	305 (97.4)	32 (80)	0.65
	No	8 (12.3)	15 (4.7)	10 (25)	

\*Chi Square test statistic p value.

education level of the caregivers [14–16]. Children suffering from epilepsy have long been subject to stigmatization, which has manifold effects leading to social isolation, low self-esteem, reduced quality of life and worsening of seizures [17,18].

Appropriate medication adherence is related to the knowledge regarding the importance of regular drug intake. A KAP study from the rural parts of Western India showed the lack of awareness about the proper usage of medications, which was similar to our study, where almost one-third caregivers missed the dose of medications and nearly 40% had purchased wrong medications [19]. This low level of knowledge was consistent with findings of many other studies [6,12,14,20].

This study reiterates the fact that a significant proportion of parents of children with epilepsy are unaware of the implications of antiseizure medications of their children. As most parents and caregivers of children with epilepsy have numerous beliefs, bad attitudes, and poor parenting practices, the level of knowledge and understanding among them needs to be improved. In order to reduce myths and fear about epilepsy, epilepsy awareness (through mass media, social media, lectures etc) and education of parents by the physician, particularly by the pediatrician will be helpful. This is likely to improve knowledge of the disease which will further aid in the development of more positive attitudes and practices towards epilepsy.

The larger sample size of the study is its main advantage. Even with a larger sample size, the study findings can only be generalized to one part of India, namely North India, due to the country's diverse cultural and social norms. The 16-item questionnaire does not cover the entire complexity of the issue and has limitations. Hence, a thorough and in-depth assessment of parents' or caregivers' knowledge, attitude, and practice should be conducted in order to obtain more precise findings that can aid in the development of more effective health promotion and awareness programs. However, some of limitations of the study include heterogeneity of the study population in terms of diverse geographic location from where they come from, their native language and educational background. These factors in turn might influence the caregiver's interpretation of the questionnaire and their response. A tendency to withhold information in view of perceived social stigma also could confound the precision of the study findings. A larger multicentric study covering different strata of population will further add meaningful data.

## 5. Conclusion

The study highlights the substantial knowledge, attitude and practice gap amongst parents and caregivers of children with epilepsy which indirectly has huge impact on the management of epilepsy. Thus, it becomes utmost important to educate the family as well as the community regarding epilepsy which will help in improving the therapeutic outcomes, overall quality of life and interpersonal and social relationships of these children.

## Ethical considerations

The study was approved by the institute ethical committee (09/01/CHWC/2021) and informed consent from parents or caregivers were obtained for inclusion in the study. All procedures performed in this study were in accordance with the 1964 Declaration of Helsinki and its later amendments, and followed national and international ethical standards.

## Author contribution statement

Rahul Sinha: Conceived and designed the experiments; Contributed reagents, materials, analysis tools or data; Wrote the paper.  
 Dharmesh Soneji: Performed the experiments; Contributed reagents, materials, analysis tools or data.  
 Vishal Vishnu Tewari, Abhilash Patra: Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data.  
 Sonali Singh: Contributed reagents, materials, analysis tools or data; Wrote the paper.  
 Priyabrata Kalikinkar Ojha, Vandana Bansal, Pavithra V: Contributed reagents, materials, analysis tools or data.

Gautam Kamila: Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.  
Sandeep Dhingra, Gurpreet Dhillon: Conceived and designed the experiments.

### Data availability statement

Data will be made available on request.

### Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.heliyon.2023.e19849>.

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