Assessment of knowledge, awareness and practice of parents/ caregivers towards epilepsy in pediatric patients

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Abstract

Background: *Pediatric seizures are among the most common neurological emergencies in children, associated with misconception and discrimination.*

Objectives: *The major purpose of this study aimed to assess and compare these domains among parents using a structured questionnaire.*

Method: *A descriptive cross-sectional study was conducted among 171 parents using a validated questionnaire containing 17 items: 7 on knowledge, 7 on awareness, and 3 on perception regarding pediatric seizures.*

Results: *Each domain was scored and analysed using descriptive statistics. Paired sample t-tests were performed to assess significant differences between domain scores The mean scores (± SD) were: Knowledge 5.76 ± 1.06, Awareness 5.92 ± 0.94 (out of 7), and Perception 2.57 ± 0.55 (out of 3). While parents demonstrated high knowledge and awareness, perception scores were significantly lower.*

Conclusion: *The Parents knowledge in relation to epilepsy was not adequate as more than half of the parents were having average and below average knowledge. In order to improve the quality of life of the children and their families' proper awareness, guidance and educational programmes are necessary.*

Keywords: *Pediatric seizures , Parental knowledge, Awareness, Perception, Cross- Sectional study, Statistical analysis.*

1. Introduction

Epilepsy is the most common neurological disorder in children, affecting 0.5% to 1% children globally[1]. It is derived from the ancient Greek word epilepsia which means “to seize” is a common neurological condition characterized by recurrent unprovoked seizures. Pediatric epilepsy encompasses a heterogeneous group of syndromes and etiologies, ranging from benign, age-related disorders to severe epileptic encephalopathies associated with developmental delay and significant morbidity.

The incidence of epilepsy is highest in the first year of life and gradually declines with age, reflecting the unique vulnerabilities of the developing brain.According to the World Health Organization(WHO), of the 50 million people with epilepsy worldwide, 80% reside in developing countries. Epilepsy was estimated to account for 0.5% of the global burden of disease in 2005. In India, it is estimated that there are more than 10 million person with epilepsy(PWE). The prevalence is higher in the rural compared to urban population.

Seizures are the most common pediatric neurological disorder. These seizures are transient signs and/or symptoms of abnormal, excessive or synchronous neuronal activity in the brain. Most of seizures in children are provoked by somatic disorders originated outside the brain such as high fever, infection, syncope, head trauma, hypoxia, toxins other causes include genetic syndrome and cerebrovascular diseases[2]. CWE are considered to be at an increased risk of accidental injuries as compared with the general population, and this risk increases with the duration of epilepsy. The overall aim in treating epilepsy should be complete control of seizures without causing any inappropriate reaction due to medication[3].

Understanding pediatric epilepsy requires a multidisciplinary approach that includes insights from neurology, genetics, neuroimaging, and developmental pediatrics. Advances in molecular genetics and neuroimaging have significantly improved our ability to classify and manage epilepsy syndromes in children. Early and accurate diagnosis is essential, as it can influence treatment strategies, prognosis, and long-term neurodevelopmental outcomes. Despite these advances, challenges remain in achieving seizure control, minimizing treatment-related side effects, and optimizing quality of life for both patients and families.

There are several Anti-Epileptic drugs available and are broadly classified as Conventional AEDs and New ADEs[4]. One of the greatest challenges in pediatrics is the age related pk changes in the particular drug and considering the wide variety of adverse events with the AEDs. With all these it becomes very important that there is awareness among parents regarding the disease and its treatment.

In India, lot of myths and misconceptions are associated with the disease. Knowledge about epilepsy is associated with less perceived stigmatization and social isolation, as well as fewer depressive symptoms and misconceptions. Moreover, parents degree of knowledge and misconceptions regarding epilepsy affect the epileptic children. Adequate education is the corner stone in managing the patients and their families. Therefore , to optimally care for epileptic children, all misconceptions and misinformation should be identified and corrected. Considering the issues, we aimed to assess the knowledge, awareness and practice of parents towards children with epilepsy using a questionnaire and to educate the parents the correct practice involved about the disease and its management.

2. Materials and Methods

This study is prospective cross-section observational design. The present study was carried out in public tertiary care teaching Medical College Hospital located in rural part of Tamil Nadu, India. We conducted study on 171 parents who child was having seizures and attended outpatient or inpatient department of pediatrics. The study was conducted from November 2023 to March 2024. Children between 3 months and 12 years of age, with confirmed cases of epilepsy, receiving Anti-Epileptic drugs were enrolled in the study only after obtaining consent from the parents or the legal guardians. Children with Autism and Attention Deficit Hyperactivity Disorder were excluded from the study.

The study protocol was approved by thr Ethics committee of Government Cuddalore Medical College and Hospital. Pre designed proforma was used to extract the information on Age, Gender, Literacy status, present history, Past medical and Medication history, Diagnosis, Clinical features and Medication details. Specially designed questionnaire was used and the questions were asked to the parent of the child with epilepsy. The questionnaire include three parts – knowledge, awareness and practice, among which we had 7 questions for knowledge related and 7 questions for awareness related, and 3 questions are practice related. We are using a 3-point Likert scale. Regarding the total knowledge score, the questionnaire had 7 questions to measure knowledge. Each correct answer scored a 1, which means Agree; and the incorrect answer scored –1 which means Disagree, and those people were very undecided on how to answer (i.e,Neutral) the score is 0. This was noted from each parent to understand the myth and misconceptions associated with disease. All the data was entered and kept confidential. After analyzing data, we counselled about epilepsy disease, signs and symptoms and drugs for treating epilepsy.

SAMPLE SIZE

Based on the assumption of a population of 0.5, and using a 95% confidence level with a margin of error of 7.5%, the required sample size was determined to be approximately 171. This calculation ensured that the resulting confidence interval would likely contain the true population proportion in 95 out of 100 possible samples.

Ethical considerations and statistical analysis:

The current study protocol was approved by the Institutional Human Ethics Committee, for obtaining the data case record or during interview or prescription. The collected data were analyzed using standard statistical tools and the results were tabulated.

3. Results

Table 1: Sociodemographic details of the study participants

Parameters	N (%)	P-Value
Gender		
Male	95 (55.5%)	0.146
Female	76 (44.4%)	
Age		

0 – 1 year	35 (20.5%)	< 0.0001
1 – 6 years	107 (62.6%)	
6 – 12 years	29 (17%)	
Type of comorbidity (n=171)		
Diabetes	2 (1.2%)	< 0.0001
Global developmental delay	11 (6.4%)	
Attention deficit	1 (0.6%)	
Others	9 (5.3%)	
Without comorbidities	148 (86.5%)	

In the present study, males (55.5%) were predominant than females (44.4%), though the gender difference was not statistically significant ($p \approx 0.146$). Age distribution revealed that the majority of patients were between 1–6 years of age (62.6%, n=107), followed by 0–1 year (20.5%, n=35) and 6–12 years (17%, n=29), with a highly significant deviation from uniformity ($p < 0.0001$), indicating that early childhood is the most common age group presenting with the condition under study. Assessment of comorbidities showed that 86.5% (n=148) of patients had no associated medical conditions. Among those with comorbidities (n=23), global developmental delay was the most frequent (6.4%, n=11), followed by other conditions (5.3%, n=9), diabetes (1.2%, n=2), and attention deficit (0.6%, n=1). The distribution of comorbidities was significantly skewed, with a strong predominance of children without any comorbid conditions ($p < 0.0001$). These findings suggest a predominantly healthy pediatric population with a concentration of cases in early childhood, potentially guiding age-specific screening and management strategies.

TABLE 1.2 : FINDINGS BASED ON SEIZURE

PARAMETERS	N(%)	PERCENTAGE(%)
CHIEF COMPLAINTS [Mean : 19.0 ± 29.51]		
Uprolling of eyeballs	22 (12.86%)	< 0.0001
Sudden vacant stare	10 (5.84%)	
Involuntary movements of all 4 limbs	20 (11.69%)	
Frothy from mouth	1 (0.58%)	
Deviation of mouth	5 (2.92%)	
Drooling of saliva	3 (1.75%)	
Clenching of teeth	2 (1.16%)	
Loss of consciousness	8 (4.67%)	
Both uprolling of eyes and involuntary movements off all 4 limbs	100 (58.47%)	
DURATION OF SEIZURE EPISODE [Mean: 1.16 ± 0.44]		
Minutes	150 (87.71%)	< 0.0001
Seconds	17 (9.94%)	
Don’t know	5 (2.92%)	
FAMILY HISTORY OF SEIZURE [Mean: 3.82 ± 0.65]		
Father	6 (3.5%)	

Mother	5 (2.9%)	< 0.0001
Grandparents	3 (1.8%)	
No history of seizure in the family	157 (91.8%)	
PATIENTS RESPONSE AFTER SEIZURE [Mean: 1.05 ± 0.21]		
Consciousness	163 (95.3%)	< 0.0001
Loss of consciousness	8 (4.7%)	

The table 2 depicts that the most common presenting complaint was the combination of uprolling of eyeballs and involuntary movements of all four limbs, observed in 58.47% (n = 100) of cases. Other reported symptoms included uprolling of eyeballs alone in 12.86% (n = 22), involuntary movements of limbs in 11.69% (n = 20), sudden vacant stare in 5.84% (n = 10), loss of consciousness in 4.67% (n = 8), deviation of the mouth in 2.92% (n = 5), drooling of saliva in 1.75% (n = 3), clenching of teeth in 1.16% (n = 2), and frothing from the mouth in 0.58% (n = 1).

The most common presenting complaint was the combination of uprolling of eyeballs and involuntary movements of all four limbs, observed in 58.47% (n = 100) of cases. Other reported symptoms included uprolling of eyeballs alone in 12.86% (n = 22), involuntary movements of limbs in 11.69% (n = 20), sudden vacant stare in 5.84% (n = 10), loss of consciousness in 4.67% (n = 8), deviation of the mouth in 2.92% (n = 5), drooling of saliva in 1.75% (n = 3), clenching of teeth in 1.16% (n = 2), and frothing from the mouth in 0.58% (n = 1).

The vast majority (91.8%, n = 157) reported no family history of seizures, while only a small proportion had a positive history through the father (3.5%, n = 6), mother (2.9%, n = 5), or grandparents (1.8%, n = 3). Among the 171 patients, the vast majority (95.3%, n = 163) regained consciousness following a seizure episode, while only 4.7% (n = 8) experienced a loss of consciousness.

The patients diagnosed with various seizure types, febrile seizures were the most prevalent, accounting for 52% (n=89) of cases, followed by seizure disorder (14.6%, n=25), and unprovoked seizures (14%, n=24). Other seizure types such as status epilepticus (9.3%), breakthrough seizures (4.1%), hypoglycemic seizures (2.3%), and less common types including hypoxic, hypocalcemic, myoclonic, focal, pseudoseizures, and withdrawal seizures comprised the remaining cases. The distribution of seizure types was highly statistically significant ($\chi^2 = 497.31$, df = 11, $p < 0.0001$), indicating a non-random pattern with a marked predominance of febrile seizures in this population. The mean seizure type score, calculated by assigning numerical values to each seizure category, was 2.39 ± 2.00, reflecting the variability in seizure diagnoses, with most patients clustered in the lower categories (febrile and unprovoked seizures). These findings underscore the heterogeneity of seizure presentations and highlight febrile seizures as the most common diagnosis in this study.

Among 171 patients receiving intravenous anti-epileptic drugs, Phenytoin was the most commonly administered (61.98%, n=106), followed by sodium valproate (12.86%, n=22), phenobarbitone (8.77%, n=15), midazolam (8.77%, n=15), and levetiracetam (7.60%, n=13). The distribution was statistically significant ($\chi^2 = 188.96$, df = 4, $p < 0.0001$), indicating that Phenytoin was disproportionately used compared to other agents. When numerically coded, the mean drug use score was 1.91 ± 1.33, reflecting the heavy skew toward first-line treatment with Phenytoin in acute settings.

The majority of patients (94.15%, n=161) showed improvement or relief following therapy, while only 5.84% (n=10) were considered completely cured. This distribution was highly statistically significant ($\chi^2 = 133.34$, df = 1, $p < 0.0001$), indicating that most patients benefited from treatment even if full remission was not achieved. When outcomes were coded numerically (1 = cured, 2 = improved), the mean outcome score was 1.94 ± 0.23, reflecting the skew toward partial therapeutic response rather than full cure.

Apart from these antiepileptic drugs, this study shows that the dosing of anti-epileptic medications for pediatric patients was individualized based on each patient’s body weight. This weight-based dosing approach ensures accurate and safe administration of medications, which is essential in pediatric care due to variations in pharmacokinetics and drug metabolism among children of different ages and sizes. By calculating doses per kilogram of body weight, the study adhered to standard pediatric dosing protocols, minimizing the risk of underdosing or toxicity and optimizing therapeutic efficacy.

Out of 171 pediatric patients, 94.15% (n=161) showed clinical improvement or symptom relief following therapy, while 5.84% (n=10) were fully cured. The distribution of outcomes was statistically significant ($\chi^2 = 133.34$, $p < 0.0001$), indicating that improvement was much more likely than complete resolution. The mean coded outcome score was 1.94 ± 0.23, highlighting a strong skew toward partial recovery rather than full cure.

TABLE-1.3 : VARIOUS OPINIONS AMONG PARENTS OR CAREGIVERS TOWARDS EPILEPSY

KNOWLEDGE QUESTIONNAIRE				
S.NO	**QUESTIONS**	**AGREE N(%)**	**DISAGREE N(%)**	**NEUTRAL N(%)**
1	**Epilepsy is a non communicable disease**	171(100%)	NIL	NIL
2	**Epilepsy affects the brain**	171(100%)	NIL	NIL
3	**Epilepsy can affect people of all ages, including children**	171(100%)	NIL	NIL
4	**Epilepsy is a chronic disorder**	118(69%)	9(5.26%)	44(25.73%)
5	**Epilepsy is a disease**	142(83%)	2(1.16%)	27(15.78%)
6	**Epilepsy can be a hereditary disorder**	169(98.83%)	1(0.58%)	1(0.58%)
7	**Epilepsy has a circardian rhythm**	165(96.49%)	1(0.58%)	5(2.92%)

Table 1.3 depicts that the knowledge assessment of parents regarding pediatric seizures revealed a generally high level of awareness. All participants (100%) correctly identified epilepsy as a non-communicable disease, recognized that it affects the brain, and acknowledged that it can affect individuals of all ages, including children. A majority (69%) also understood that epilepsy is a chronic disorder, although a notable portion (25.73%) remained neutral on this point. Similarly, 83% of parents agreed that epilepsy is a disease, while 15.78% were neutral. A strong understanding of the hereditary aspect of epilepsy was observed, with 98.83% agreeing it can be inherited. Furthermore, 96.49% were aware of epilepsy’s circadian rhythm, indicating a sound grasp of its temporal patterns.

FIGURE 1:DISTRIBUTION OF VARIOUS OPINIONS AMONG PARENTS REGARDING EPILEPSY(KNOWLEDGE)

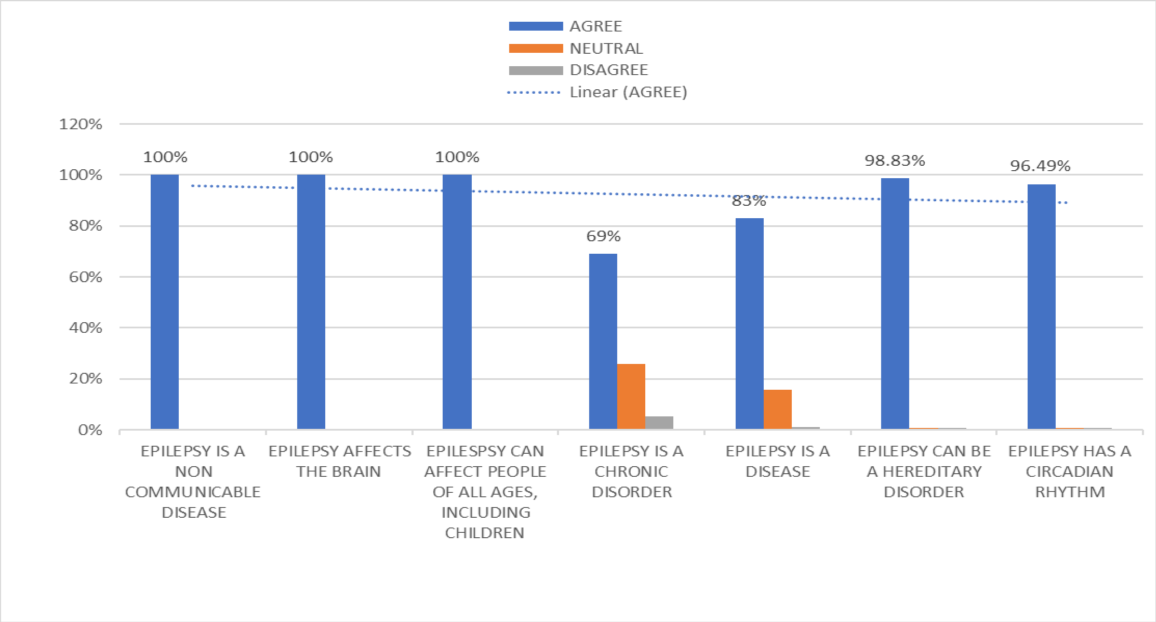


TABLE 1.4 : VARIOUS OPINIONS AMONG PARENTS OR CAREGIVERS TOWARDS EPILEPSY

AWARENESS QUESTIONNAIRE				
S.NO	**QUESTIONS**	**AGREE N(%)**	**DISAGREE N(%)**	**NEUTRAL N(%)**
1	**Epilepsy and seizure are not the same**	96(56.1%)	66(38.5%)	9(5.26%)
2	**Epilepsy does not cause death**	167(97.6%)	3(1.75%)	1(0.58%)
3	**Epilepsy cannot be prevented**	105(61.4%)	40(23.3%)	26(15.2%)
4	**Epilepsy in pregnant women can affect the fetus**	168(98.2%)	2(1.16%)	1(0.58%)
5	**Epilepsy can relapse**	168(98.2%)	2(1.16%)	1(0.58%)
6	**Epilepsy is not curable**	82(47.9%)	50(29.2%)	39(22.8%)
7	**Epilepsy can be treated with allopathic medicine, but can't be cured.**	120(70.2%)	41(23.9%)	10(5.8%)

Table 1.4 depicts that The awareness assessment among parents revealed varying levels of understanding regarding epilepsy. Just over half (56.1%) agreed that epilepsy and seizures are not the same, while a substantial minority (38.5%) disagreed, indicating some confusion between the two terms. Nearly all respondents (97.6%) correctly acknowledged that epilepsy does not inherently cause death, suggesting a strong understanding of its non-fatal nature. Regarding preventability, 61.4% agreed that epilepsy cannot be prevented, though 23.3% disagreed and 15.2% were unsure,

highlighting a need for further education on risk factors and prevention. Awareness was notably high concerning the impact of epilepsy during pregnancy and its potential for relapse, with 98.2% of participants recognizing both these aspects. However, there was a more divided perception on the curability of epilepsy: only 47.9% believed it is not curable, while 29.2% disagreed and 22.8% remained neutral. When asked about treatment, 70.2% agreed that epilepsy can be managed with allopathic medicine even if it cannot be cured, reflecting a generally accurate understanding of treatment options. Overall, while core awareness regarding the risks and management of epilepsy was strong, misconceptions persist about its definition,preventability, and curability, emphasizing the importance of ongoing educational interventions.

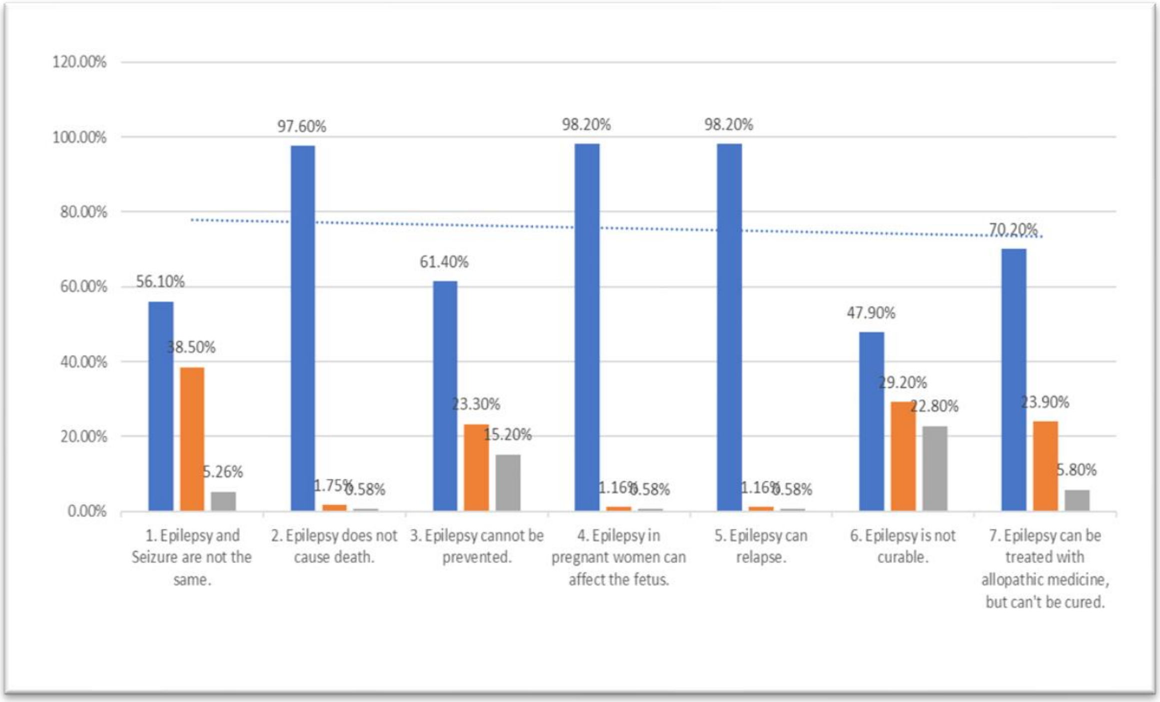


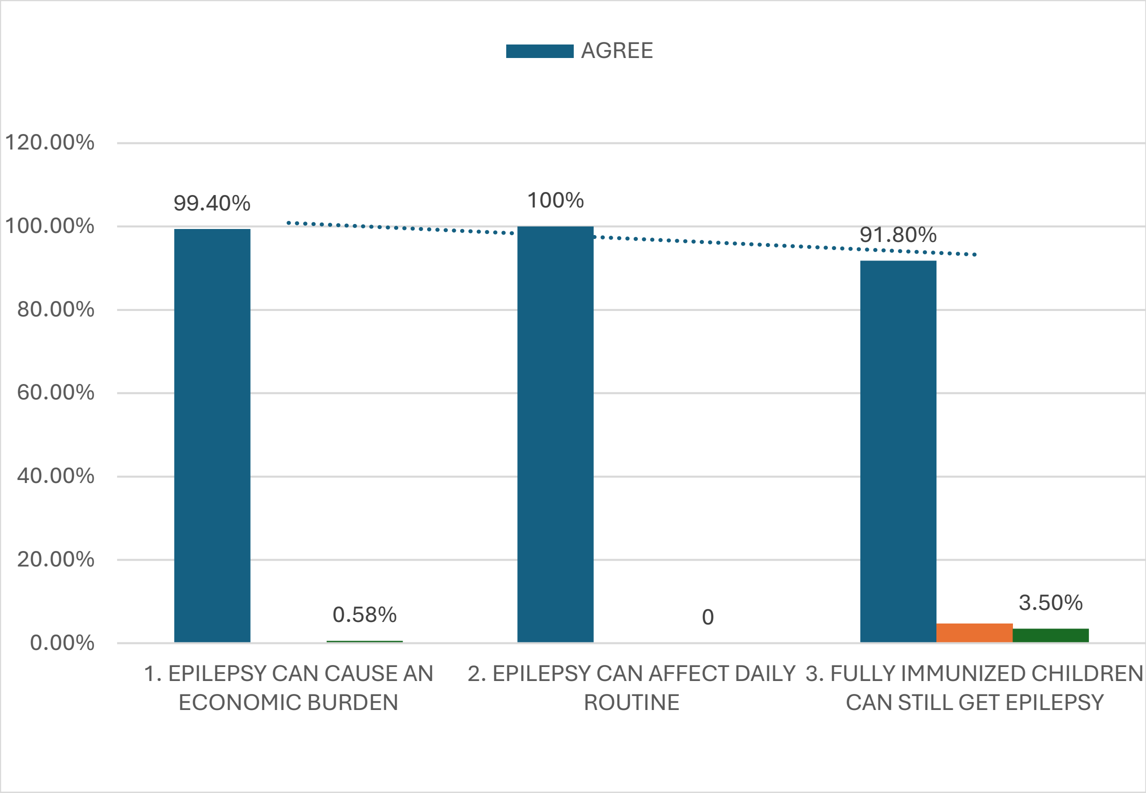
FIGURE 2 ; DISTRIBUTION OF VARIOUS OPINIONS AMONG PARENTS REGARDING EPILEPSY(AWARENESS)

TABLE 1.5: VARIOUS OPINIONS AMONG PARENTS OR CAREGIVERS TOWARDS EPILPSY

PERCEPTION QUESTIONNAIRE				
S.NO	**QUESTIONS**	**AGREE N(%)**	**DISAGREE N(%)**	**NEUTRAL N(%)**
1	**Epilepsy can cause an economic burden**	170(99.4%)	NIL	1(0.58%0
2	**Epilepsy can affect daily routine**	171(100%)	NIL	NIL
3	**Fully immunized children can still get epilepsy**	157(91.8%)	8(4.7%)	6(3.5%)

Table 1.5 depicts that the findings from the perception questionnaire demonstrate a strong consensus among parents about the broader impacts of epilepsy. Nearly all respondents (99.4%) agreed that epilepsy can cause an economic burden, reflecting an understanding of the potential financial implications of managing the disorder. All participants (100%) recognized that epilepsy can significantly affect daily routines, indicating high awareness of its disruptive nature on everyday life. Additionally, a large majority (91.8%) agreed that fully immunized children can still develop epilepsy, suggesting a realistic perception of the condition's etiology that is not solely dependent on immunization status. These results suggest that most parents have a well-grounded perception of the social, functional, and health-related implications of pediatric epilepsy.

FIGURE 3: DISTRIBUTION OF VARIOUS OPINIONS AMONG



PARENTS REGARDING EPILEPSY(PERCEPTION)

TABLE : 1.6 : RANGE, MEAN, MEDIAN AND STANDARD DEVIATION OF KNOWLEDGE, AWARENESS AND PERCEPTION SCORE REGARDING PEDIATRIC SEIZURE

VARIABLE	RANGE	MEAN	MEDIAN	S.D
KNOWLEDGE SCORE	1-7	5.76 ± 1.06	6.00	6
AWARENESS SCORE	2-7	5.92 ± 0.94	6.00	6
PERCEPTION SCORE	1-3	2.57 ± 0.55	6.00	3

Table - 1.6 shows that the mean knowledge score was 5.76 ± 1.06 (out of 7), awareness was 5.92 ± 0.94 (out of 7), and perception was 2.57 ± 0.55 (out of 3) .

TABLE : 1.7 : CORRELATION BETWEEN KNOWLEDGE, AWARENESS AND PERCEPTION OF PARENTS REGARDING PEDIATRIC SEIZURE

COMPARISON	MEAN DIFFERENCE	T - VALUE	DF	P-VALUE	SIGNIFICANCE
KNOWLEDGE VS AWARENESS	-0.16	-2.27	170	0.024	Significant
KNOWLEDGE VS PERCEPTION	3.18	28.94	170	< 0.001	Highly significant
AWARENESS VS PERCEPTION	3.34	31.59	170	< 0.001	Highly significant

***p <0.05 indicates statistical significance**
***p <0.001 indicates high statistical significance**

Table 1.7 shows that the mean knowledge score was 5.76 ± 1.06 (out of 7), awareness was 5.92 ± 0.94 (out of 7), and perception was 2.57 ± 0.55 (out of 3). Paired sample t-tests revealed a statistically significant difference between knowledge and awareness scores ($t(170) = -2.27$, $p = 0.024$), and highly significant differences between knowledge and perception ($t(170) = 28.94$, $p < 0.001$) and awareness and perception ($t(170) = 31.59$, $p < 0.001$). These findings indicate that although both knowledge and awareness scores were high, perception scores were significantly lower. The statistically significant differences highlight the importance of addressing attitudes and beliefs through targeted educational programs.

4. Discussion

This purpose of this study aimed to assess the knowledge, awareness, and perception of parents regarding pediatric seizures using a structured questionnaire. In our study, majority of patients were in the group of 1-6 years. Similar results found in the study conducted by Minumaria shaju et al.,(2014) and Raidah albaradie showed that men are most affected by epilepsy than women.

Of 171 parents , 98.83% of parents agreed that 'Epilepsy can be a hereditary disorder'. The studies done in Nepal, Malaysia and Canada found that there were more people (almost 50-60%) who believed epilepsy to be hereditary[6][12][15].However, a study done in delhi showed a more favorable results as 97% persons with epilepsy considered that ' Epilepsy was not hereditary'.According to our study, the result was not similar with the study conducted by Gourie Devi M et al (2010).

Majority of parents (98.20%) agreed that 'Epilepsy in pregnant women can affect the fetus' and 'Epilepsy can relapse'. About(97.60%) of parents agreed that ' Epilepsy does not cause death'. Most of parents (6.40%) were agreed that ' Epilepsy cannot be prevented'. In our study showed that 70.20% of parents were agreed that 'Epilepsy can be treated with allopathic medicine, but it can't be cured', which was contrast to the study conducted in Nepal and Delhi by Thapal et al(2017) [4][5]. People believing in ayurvedic medicine as a treatment for epilepsy was less in PWE of Delhi as compared and this result was not similar in this study.

According to study of Zainy et al(2013), upto 29% of parents admitted to using non-medical treatment (i.e. using traditional herbs and also religious practices).This result also not similar with this study.

The study conducted by Kim et al and Kaushal et al., found that most probable contributive factor in forming negative attitude toward epilepsy was ‘ Epilepsy cannot be cured’. Like our study shows 47.90% of parents agreed that ‘ Epilepsy is not curable’.But this result was contrast with the studies from Sudan[9] and Brazil [11] reporting that Awareness of ‘ Epilepsy as a curable disease’.

Majority of parents (99.40%) agreed that ‘epilepsy can cause an economic burden’. Even though epilepsy is an eminently preventable and treatable condition, it still remains a major public health due to high stigma, wide socio economic inequity, huge treatment gap, and the poor epilepsy healthcare Delivery system in India. Similar results found in study conducted by H.M.De Boer et al and Amudhan et al.

According to the study of Angelina Maphula et al(2023) four point likert scale were used in this study to assess the KAP of parents/ caregivers. But in our study three point likert scale were used. From the people interviewed, 58.47% believe that the major complaints of epilepsy is uprolling of eyes and Involuntary movements. This result was not similar with the study conducted by Phougat Jyoti et al(2015).

Majority of parents also said that, Giving keys or iron ,materials in hand can help is easing that seizure attack and may not require any medical attention. Studies from other authors also reported such mythical concepts and related to the observed more frequently in developing countries that lack educational practices[10].

Conclusion

This study highlights the disparity between parental knowledge, awareness, and perception regarding pediatric seizures. The knowledge, Awareness and practice among parents of children with epilepsy need improvement and proper counselling regarding the disease and its management. Many of them have significant myths and misconceptions associated; hence there is an alarming need to improve the degree of knowledge, which can help in improving their awareness and positively influence the wrong belief and practices, in order to enhance the relationship with the child. Hence educating the whole community, improving the awareness through street plays regarding the disease is essential. Parents , teachers, health government sectors should target educational program to increase the awareness and should fill the gap in minimizing the social stigma associated, in order to improve the Quality of life of the children and their families. Not only to improve the QOL and also to prevent the further complications. Based on the results of our study, suggest that there is a critical need to enhance epilepsy education and improve awareness towards epilepsy beyond seizure.

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