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A Descriptive Study to Assess the Knowledge and Attitude of Caregivers Regarding Care of Children Receiving Antiepileptic Drugs (AEDs) at a Selected Tertiary Care Hospital

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Abstract:

Introduction: Epilepsy is one of the most common neurological disorders in children, requiring long-term management with antiepileptic drugs (AEDs). Effective care largely depends on caregivers' knowledge and attitude regarding medication adherence, seizure management, and follow-up care. Inadequate knowledge may lead to poor treatment outcomes and increased complications. Therefore, this study was undertaken to assess the knowledge and attitude of caregivers regarding the care of children receiving AEDs.
Objective: 1. To assess the level of knowledge & attitude among caregivers regarding care of children receiving antiepileptic drugs. 3. To determine the association between caregivers' knowledge and attitude.
Methods: A descriptive cross-sectional study was conducted among 100 caregivers selected using convenient sampling at a selected tertiary care hospital. After permission & ethical approval data were collected using structured questionnaire consisting of demographic variables, knowledge, and attitude questionnaires(tool validation done by experts). Descriptive statistics (frequency, percentage, mean, standard deviation) and inferential statistics (Fisher's exact test) were used for data analysis.
Results: The findings revealed that 68% of caregivers had good knowledge, while 32% had moderate knowledge, with a mean knowledge score of 7.96 ± 1.188. Regarding attitude, 81% of caregivers demonstrated a moderate attitude, 16% had a good attitude, and 3% had a poor attitude, with a mean score of 32.92 ± 4.601. The association between knowledge and attitude was not statistically significant (p = 0.4219), indicating that caregivers' attitude did not significantly depend on their level of knowledge.
Conclusion: The study concluded that although caregivers possess adequate knowledge their attitude remains predominantly moderate & there is no significant association between knowledge and attitude, suggesting the influence of other factors. The findings highlighted need for continuous health education, counselling, and supportive interventions for quality care and treatment outcomes in children with epilepsy.

Keywords: *Epilepsy, Antiepileptic drugs (AEDs), Caregivers, Knowledge, Attitude, Pediatric epilepsy, Medication adherence.*

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I. INTRODUCTION

Epilepsy is characterized by recurrent, episodic, paroxysmal, involuntary clinical events associated with abnormal electrical activity from the neurons. The patient may present with motor, sensory or psychomotor phenomena, often with alteration in sensorium[1] The manifestation of seizure depends on the region of the brain in which they originate and may include unconsciousness or altered consciousness, involuntary movements and changes in perception, behaviour, sensations, and posture.[2]

A 2025 epidemiological analysis using Global Burden of Disease (GBD) data reports that in 2021 the global incidence rate of childhood epilepsy was about 61.0 per 100,000 children per year (i.e., ~0.061%) with approximately 1,227,191 new cases of childhood epilepsy worldwide that year[3] The overall prevalence of pediatric epilepsy in India is about 0.8 % (95 % CI: 0.6–1.0 %). This means roughly 8 in every 1,000 children are estimated to have epilepsy in India[4]Children depend entirely on caregivers for medication administration and safety during seizures.[5] Poor caregiver knowledge has been associated with increased seizure frequency, emergency admissions, and psychosocial stress.Understanding caregivers' baseline knowledge is crucial for improving continuity of care in children with epilepsy. [6]

Therefore, assessing caregivers' knowledge and attitude regarding AED therapy is essential to identify existing gaps and to improve the quality of care provided to children with epilepsy.

II. REVIEW OF LITERATURE

Epilepsy is one of the most common pediatric neurological disorders in children characterized by recurrent, involuntary clinical events associated with abnormal electrical activity from the neurons requiring long-term treatment with antiepileptic drugs (AEDs).[7]Literature suggests that caregivers often have inadequate knowledge regarding antiepileptic drug therapy, seizure precautions, and medication adherence. Several Indian studies have reported misconceptions regarding epilepsy and antiepileptic drugs amongcaregivers, Caroline J et al. (2024) conducted a study among 30 caregivers and found that although 77% knew epilepsy is a brain disorder, only 57% were aware of treatment options other than drugs, indicating the need for caregiver education.[8]A cross-sectional study among 418 caregivers by Sinha R et al. (2023) reported that 36.6% missed doses of anti-seizure medications and significant gaps existed in knowledge, attitude, and practice regarding epilepsy care.[9]Similarly, Reddy HV (2019) reported overall knowledge, attitude, and practice scores of 54%, 69%, and 76% respectively among 86 caregivers, showing moderate awareness with persisting misconceptions.[10]Another study by Minumaria S (2014) among 123 parents revealed that only 6% were aware of treatment options apart from antiepileptic drugs, despite 78.86% identifying epilepsy as a brain disorder.[11]These studies indicate the importance of assessing caregiver knowledge and attitude to plan effective educational interventions and improve the quality of care provided to children with epilepsy.

III. METHODOLOGY

A descriptive cross-sectional research design was adopted to assess the knowledge and attitude of caregivers regarding care of children receiving antiepileptic drugs (AEDs).

Study Setting

The study was conducted in the Pediatric Outpatient and Inpatient Department of a selected tertiary care hospital. The setting was chosen due to the availability of children diagnosed with epilepsy receiving antiepileptic drug therapy along with their caregivers attending for treatment and follow-up.

Study Population

The study populationfor the study were caregivers of children diagnosed with epilepsy and receiving antiepileptic drug (AED) therapy.

Sample Size and Sampling Technique

A total of 100 caregivers was included in the study using a non-probability convenience sampling technique. Caregivers who meet the inclusion criteria and were available during the data collection period were recruited.

Inclusion Criteria

1. Caregivers of children receiving antiepileptic drugs.
2. Caregivers who were willing to participate in the study and provide informed consent.
3. Caregivers who understood and responded in Hindi, English, or local language.

Exclusion Criteria

1. Caregivers who were healthcare professionals.
2. Caregivers who were unwilling to participate in the study.

Data Collection Tools

Data was collected using aself-structured questionnaire which consisted of:

- Demographic Variable proforma to assess socio-demographic characteristics of caregivers and children.
- Self-Structured Knowledge Questionnaire to assess caregivers’ knowledge regarding epilepsy, antiepileptic drug administration, medication adherence, side effects,andseizuremanagement.
- Self-Structured Attitude Questionnaireto assess caregivers’ attitude towards epilepsy care and antiepileptic drug therapy.

Data Collection Procedure

After obtaining ethical clearance and administrative permission, participants were approached in the selected setting. The purpose of the study was explained and written informed consent was obtained. Data was collected through self-administration or interview method depending upon the literacy level of the caregivers. Confidentiality and anonymity of participants was maintained throughout the study.

Data Analysis

Data was coded andanalysed using descriptive and inferential statistics. Frequency, percentage, mean, and standard deviation was used to describe demographic variables, knowledge, and attitude scores. Chi-square test was used to determine the association between knowledge and attitude among caregivers. A p-value of <0.05 was considered statistically significant.

Ethical considerations

Ethical clearance was obtained from the Institutional Ethics Committee. Participation was voluntaryand informed consent was obtained from all participants. Confidentiality and privacy were maintained throughout the study.

Informed consent was obtained, participants were free to withdraw anytime from study and debriefing was done telephonically after study results compilation.

IV. RESULTS

A. Socio- demographic Profile

Table 1 Demographic characteristics of Caregivers n=100

Age of caregiver	Frequency	Percentage
20 – 30 years	42	42%
31 – 40 years	56	56%
41 – 50 years	2	2%
Gender	Frequency	Percentage
Female	77	77%
Male	23	23%
Relationship	Frequency	Percentage
Father	22	22%
Grandparent	1	1%
Mother	77	77%
Education	Frequency	Percentage
No formal education	2	2%
Primary education	4	4%
Secondary education	24	24%
Higher secondary	43	43%
Graduate and above	27	27%
Duration	Frequency	Percentage
Less than 1 year	4	4%
1 – 3 years	42	42%
3 – 5 years	24	24%
More than 5 years	30	30%
Family history of epilepsy	Frequency	Percentage
No	80	80%
Yes	20	20%

Overall, the findings indicated that most of the caregivers were females accounting for 77%, whereas 23% were male. Among care givers, maximum were mothers (77%), followed by fathers (22%) in the age group of 31–40 years. 1% were grandparents. Most of the mothers had higher secondary education, (43%) and 2% were without any formal education. About the duration of receiving antiepileptic drugs, most of the children were receiving for more than one year (42%). Only 20 % had relevant family history of seizures, where 80% were with other causes.

B. Assessment of Level of Knowledge among Caregivers regarding Care of Children Receiving Antiepileptic Drugs

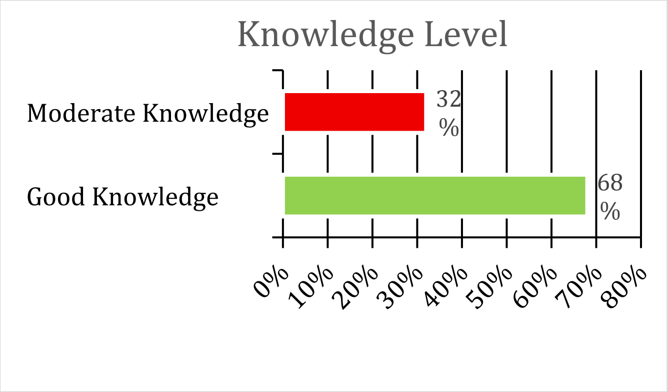

Fig..1 Distribution of Knowledge level of caregivers regarding care of children receiving antiepileptic drugs

The knowledge level of caregivers revealedthat majority of caregivers 68% had good knowledge regarding care of children receiving antiepileptic drugs, while 32% had moderate knowledge. None of the caregivers were found to have poor knowledge. This indicates that most of the caregivers had adequate understanding about medication administration, adherence, side effects, and general care required for children receiving antiepileptic therapy.

Table 2: Mean and standard deviation of knowledge score of caregivers regarding care of children receiving antiepileptic drugs n=100

Average Knowledge Score	Std Deviation
7.96	1.188

The mean knowledge score of caregivers was 7.96 with a standard deviation of 1.188, which indicates that the overall knowledge level of caregivers was relatively high with less variation among the scores. Overall, the results suggest that most caregivers possessed good knowledge regarding the care of children receiving antiepileptic drugs, although a considerable proportion still had only moderate knowledge, indicating the need for continued education and guidance to improve their understanding further.

C. Assessment of level of attitude among caregivers regarding care of children receiving antiepileptic drugs

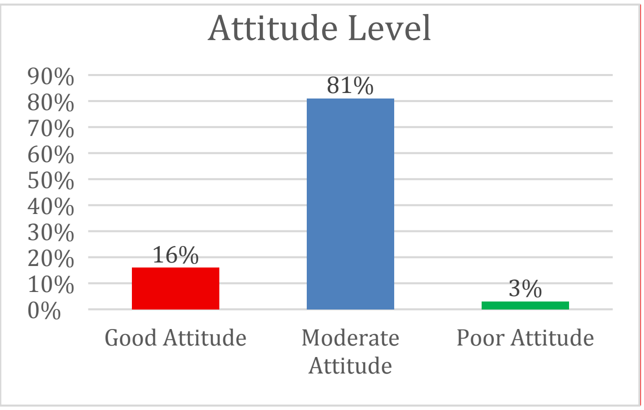

Fig. 2 Distribution of attitude level of caregivers regarding care of children receiving antiepileptic drugs

The distribution of attitude level of caregivers revealedthat most caregivers 81% had a moderate attitude towards the care of children receiving antiepileptic drugs, while 16% had a good attitude, and only 3% had a poor attitude. These results indicate that most caregivers had an acceptable but not highly positive attitude towards the care and management of children receiving antiepileptic therapy.

Table.3: Average attitude score and standard deviation of caregivers regarding care of children receiving antiepileptic drugs.

Average Attitude Score	Std Deviation
32.92	4.601

The mean attitude score of caregivers was 32.92 ± 4.601, indicating a predominantly moderate level of attitude. Majority of caregivers (81%) had moderate attitude, while only 3% demonstrated poor attitude regarding the care of children receiving antiepileptic drugs. These findings suggest the need for health education and counselling to improve caregivers' attitude and promote better treatment adherence and care.

D. Association between Knowledge and Attitude of Caregivers regarding Care of Children Receiving Antiepileptic Drugs

Table.4: Association between Knowledge and Attitude of Caregivers regarding Care of Children Receiving Antiepileptic Drugs **n=100**

	Attitude Level			Fisher Exact p-value
Knowledge Level	**Good Attitude**	**Moderate Attitude**	**Poor Attitude**	
Good Knowledge	11	56	1	0.4219 (not significant)
Moderate Knowledge	5	25	2	

Fisher exact test was used to determine the association between the level of knowledge and the level of attitude among caregivers regarding the care of children receiving antiepileptic drugs. The obtained p-value was 0.4219.Since the p-value was greater than 0.05, the result was not statistically significant at the 5% level. Hence, the null hypothesis was accepted, indicating no significant association between the level of knowledge and attitude among caregivers regarding the care of children receiving antiepileptic drugs. Therefore, caregivers' attitude did not significantly depend on their level of knowledge in the present study.

V. DISCUSSION

The present study assessed the knowledge and attitude of caregivers regarding the care of children receiving antiepileptic drugs. The findings revealed that most caregivers possessed adequate knowledge regarding medication administration, adherence, seizure management, and adverse effects of antiepileptic therapy. The satisfactory level of knowledge observed among caregivers may be attributed to regular interaction with healthcare professionals, follow-up visits, and increased access to health information. Nevertheless, the presence of caregivers with only moderate knowledge indicates the need for continuous educational interventions to strengthen understanding and promote effective home-based care.

Despite the overall adequate knowledge, the majority of caregivers demonstrated only a moderate attitude towards the care of children receiving antiepileptic drugs. This finding suggests that knowledge alone may not be sufficient to foster a highly positive attitude towards caregiving. Caregivers may continue to experience concerns related to long-term medication use, fear of seizure recurrence, treatment burden, social stigma, and uncertainty regarding the child's future. These factors may influence attitudes irrespective of their level of knowledge.

The present study also found no statistically significant association between caregivers' knowledge and attitude regarding the care of children receiving antiepileptic drugs ($p > 0.05$). This finding indicates that attitude is likely influenced by multiple factors beyond knowledge, including personal experiences, emotional responses, cultural beliefs, family support, and caregiving burden. Therefore, improving knowledge alone may not necessarily result in a corresponding improvement in caregiver attitude.

The findings of the present study are comparable with those reported by Caroline J et al. (2024), who observed that caregivers possessed adequate knowledge regarding epilepsy management; however, gaps remained in attitude and caregiving practices. Similarly, the present study demonstrated satisfactory knowledge among caregivers, while attitudes remained predominantly moderate. Both studies emphasize that educational interventions should focus not only on improving knowledge but also on addressing psychosocial concerns and promoting positive caregiving attitudes.

The findings are also consistent with those of Reddy HV (2019), who reported moderate knowledge among caregivers along with persisting misconceptions regarding epilepsy care. Although the present study demonstrated comparatively higher levels of knowledge, a proportion of caregivers still exhibited only moderate understanding. These findings suggest that continuous health education remains essential for strengthening caregivers' competence and confidence in managing children receiving antiepileptic therapy.

Similar observations were reported by Minumaria S (2014), who found that although parents were aware of epilepsy, their knowledge regarding treatment options, medication use, adverse effects, and treatment adherence remained inadequate. In the present study, the predominance of moderate attitudes despite adequate knowledge further supports the notion that awareness alone does not guarantee positive perceptions or confidence in caregiving. Both studies highlight the need for ongoing educational and supportive interventions to bridge the gap between knowledge and attitude.

The present findings also correspond with those of Sinha R et al. (2023), who reported substantial emotional, social, and financial burden among caregivers of children with epilepsy. While the current study did not directly assess caregiver burden, the predominance of moderate attitudes may reflect underlying emotional concerns, anxiety, and challenges associated with long-term disease management. These findings underscore the importance of integrating psychosocial support, counselling, and family-centred interventions into routine epilepsy care.

Overall, the study highlights that effective management of children receiving antiepileptic drugs extends beyond medication administration and seizure control. Addressing caregivers' emotional concerns, beliefs, and confidence is equally important for promoting treatment adherence and improving the quality of care. Therefore, continuous health education, counselling, and supportive interventions should be incorporated into routine clinical practice to enhance caregiver preparedness and improve health outcomes among children receiving antiepileptic therapy.

VI. CONCLUSION

The present study concludes that caregivers of children receiving antiepileptic drugs generally possess good knowledge regarding medication administration, adherence, seizure precautions, and overall child care. However, despite adequate knowledge, the attitude of caregivers was predominantly moderate, indicating the presence of concerns, misconceptions, and lack of confidence related to long-term epilepsy management.

The findings further revealed that there was no statistically significant association between knowledge and attitude among caregivers, suggesting that factors other than knowledge may influence caregivers' attitude towards the care of children receiving antiepileptic drugs.

Overall, the study emphasizes that caregiving in childhood epilepsy is a multidimensional process influenced by educational, emotional, and psychosocial factors. Therefore, continuous health education, counselling, caregiver support, and structured awareness programs are essential to improve caregivers' attitude, enhance treatment adherence, and ensure better health outcomes and quality of life for children receiving antiepileptic therapy.

VII. RECOMMENDATIONS

Based on the findings of the present study, it is recommended that structured health education and counselling programs should be regularly conducted for caregivers of children receiving antiepileptic drugs to improve their knowledge, attitude, and confidence in managing the child's condition. Continuous guidance regarding medication adherence, seizure precautions, side effects, and long-term management should be integrated into routine pediatric care. Healthcare professionals, especially nurses, should provide emotional support and address misconceptions related to epilepsy and antiepileptic therapy. Educational materials in simple language and local dialects may help caregivers better understand the treatment process. Future studies with larger sample sizes and interventional approaches are recommended to assess the effectiveness of educational and counselling interventions on caregivers' knowledge and attitude.

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