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Research Paper

Knowledge, Attitude, And Practices of Caregivers in Pediatrics Epilepsy Management: A Questionnaire Based Study in Tertiary Care Teaching Hospital

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ABSTRACT

Background Epilepsy is a common chronic neurological disorder in children requiring long-term therapy and active caregiver involvement. Caregivers' knowledge, attitude, and practices significantly influence treatment adherence and seizure control Objectives To assess knowledge, attitudes and practices among pediatric caregivers regarding antiepileptic medication therapy, and to identify gaps requiring targeted educational intervention. Methodology A cross-sectional questionnaire-based study was conducted among 160 caregivers at a tertiary care teaching hospital during a 6-months period. Results Majority of caregivers were females (65.6%) and belonged to the 19–30 years age group (59.3%). Most had primary education (45%) and were from rural areas (55.6%). Knowledge regarding epilepsy and antiepileptic drugs was moderate, with misconceptions about long-term therapy and disease cure. Attitude was generally positive, with high trust in healthcare professionals (97.5%). Practices were mostly appropriate, including medication adherence and supervision, though some unsafe practices like overdosing were observed. Sodium valproate was the most commonly prescribed drug (63.1%), and generalized seizures were the most prevalent diagnosis. Education level showed significant association with caregiver knowledge ($p<0.001$) Conclusion Caregivers demonstrated moderate knowledge with notable gaps and misconceptions. Structured educational interventions and counselling are essential to improve epilepsy management and treatment outcomes.

INTRODUCTION

Epilepsy remains an important public health concern and highlights the need for effective

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prevention, early diagnosis, appropriate treatment, and rehabilitation to improve health outcomes and quality of life.[1] It is one of the most common neurological conditions, affecting more than 50 million people worldwide. Its prevalence varies from 2.8 to 19.5 per 1,000 people in the general population. Epilepsy can occur at any age, but it is particularly common during childhood, adolescence, and older adulthood, with the highest incidence observed during the early years of life.[2]

An epileptic seizure is a temporary episode resulting from abnormal, excessive, or synchronous electrical activity in the brain. According to the International League Against Epilepsy (ILAE), epilepsy is generally diagnosed when a person has two or more unprovoked seizures.[3] However, epilepsy may also be diagnosed after a single unprovoked seizure when the risk of having another seizure is considered high. The risk of recurrence increases substantially after two unprovoked non-febrile seizures and has been estimated to be approximately 60–90%. The ILAE and the International Bureau for Epilepsy (IBE) recognize epilepsy as a disease rather than simply a disorder, emphasizing its chronic nature and the wide range of conditions that can contribute to its development. [4]

Epileptic seizures result from excessive, synchronous neuronal discharges due to persistent neuronal hyperexcitability, which may arise from factors such as trauma, infection, tumors, metabolic disturbances, or genetic and developmental abnormalities, although no identifiable cause is found in nearly half of all cases.[5]An epileptic seizure is a transient, time-limited clinical event with a distinct onset and termination, characterized by variable sensory, motor, autonomic, cognitive, emotional, or behavioural manifestations depending on the brain region involved and patterns of neuronal activity[6].Successful epilepsy management requires individualized selection and monitoring of antiepileptic drugs (AEDs) based on the cause and type of epilepsy, with the primary goals of achieving complete seizure control, minimizing adverse effects, and improving quality of life while addressing issues such as treatment compliance and appropriate therapy selection.[7]

Adherence to anti-seizure medication is an essential part of effective epilepsy management. Consistent medication use can reduce seizure recurrence and frequency, decrease healthcare-related costs, and contribute to better treatment outcomes. Active involvement of both children and their families is therefore important in maintaining adherence and managing the condition effectively.[8] Although more than 25 anti-seizure medications are currently available, a considerable number of children with epilepsy continue to experience poorly controlled seizures because of drug resistance, inadequate treatment response, or medication-related tolerability problems.[9]

Most children with newly diagnosed epilepsy can achieve seizure freedom with appropriate anti-seizure medication. However, nearly 20% continue to experience seizures despite treatment.[10] In this context, parents play an important role in the day-to-day management of childhood epilepsy. Adequate parental knowledge can help reduce anxiety, stigma, and misconceptions about the condition and may support better care and management, ultimately improving the child's quality of life.[10] Parental knowledge and perceptions also influence decisions about seeking treatment, attitudes towards epilepsy, and the social and psychological well-being of children living with the condition. Therefore, providing accurate and understandable information to parents is an important part of addressing misconceptions and supporting effective epilepsy management.[11]

OBJECTIVES

Primary Objective

1. To assess knowledge, attitude and practice among paediatric caregivers regarding antiepileptics medication therapy.

Secondary Objective

1. To identify gaps in knowledge among caregivers about epilepsy
2. To determine the need for targeted educational or awareness program for caregivers

MATERIAL AND METHODS

Study site

The study was carried out in the Department of Pediatrics at Chigateri District Hospital, Davangere, Karnataka, India.

Study duration

The study was conducted over a 6-month period

Study design

A hospital-based Cross Sectional questionnaire-based study.

Sample size:

- A total of 160 caregivers were enrolled in the study. Sample size was determined based on eligible participants during the study period

Study criteria:

- The study was carried out by considering the following inclusion and exclusion criteria

Inclusion criteria:

- Pediatric inpatients
- Patient who are prescribed with at least one antiepileptic.
- Patient of either gender

Exclusion criteria:

- Patient having missed or insufficient data.
- OPD Patients
- No antiepileptic prescribed patients.

STUDY PROCEDURE

A cross-sectional questionnaire-based study was conducted over six months among caregivers of pediatric inpatients receiving at least one antiepileptic drug at Chigateri District Hospital, Davangere. Ethical approval and written informed consent were obtained, and demographic, clinical, and medication-related data were collected from case sheets using a structured form along with a validated Knowledge, Attitude, and Practice (KAP) questionnaire. Data were analysed using Microsoft Excel and descriptive statistics, with results presented in tables and graphs.

RESULT

A six-month study was conducted in the pediatric inpatient department, involving interviews with 160 caregivers of children diagnosed with epilepsy.

1.Participant characteristics

A total of 160 caregivers of pediatric epilepsy patients participated in the study. The majority were female (105, 65.6%), while 55 (34.4%) were male. Most caregivers belonged to the 19–30 years age group (59.4%). Primary education was the most common educational level (45.0%), and 55.6% of participants were from rural areas. Mothers constituted the largest proportion of caregivers (51.3%).

Table1: Demographic characteristics of caregivers (N=160)

VARIABLES	n (%)
Male	55 (34.375%)
Female	105(65.625%)
Age 19-30 yrs.	95(59.375%)
Age 30-40 yrs.	47(29.375%)
Age 40-50 yrs.	18(11.25%)
Primary Education	72(45%)
Secondary Education	60(37.5%)
Rural Residence	89(55.625%)
Urban Residence	71(44.375%)
Mother	82(51.25%)
Father	43(26.875%)
Others	35(21.8%)

2.Caregivers' Knowledge of Antiepileptics

Knowledge regarding epilepsy varied among caregivers. Only 30.0% correctly identified that long-term AED use may affect child growth and cognition, whereas 37.5% believed it does not and 32.5% were uncertain. More than half (58.125%) recognized the importance of regular follow-up visits. However, only 10.625% knew that antiepileptic drugs should not be discontinued without medical advice.

Table 2: Caregiver's knowledge of Antiepileptics

STATEMENTS	YES	NO	DON'T KNOW
1. Can long-term use of AEDs affect Child growth and cognitive function	48(30%)	60(37.5%)	52(32.5%)
2. Do you know that AEDs helps control seizure but don't cure epilepsy?	50(31.25%)	67(41.875%)	43(26.875%)
3. Is it safe to stop AED suddenly without doctors' advice?	17(10.625%)	112(70%)	31(19.375%)
4. Do you know that regular follow up visit is necessary for children in AEDs?	93(58.125%)	47(29.375%)	20(12.5%)
5. Do you know that certain food or life style change may help manage epilepsy?	30(18.75%)	85(53.125%)	45(28.125%)

3.Caregivers' Attitudes Towards Antiepileptics

Most caregivers (65%) believed epilepsy affects daily activities. Nearly all caregivers (97.5%) trusted healthcare professionals in prescribing AEDs, and 95.0% would recommend treatment to other caregivers.

Table 3: Caregivers Attitude towards Antiepileptics

STATEMENTS	YES	NO	DON'T KNOW
1. Does epilepsy impact person daily activity?	104(65%)	53(33.125%)	3(1.875%)
2. Is the intelligence of epileptic person lower than normal person?	69(43.125%)	86(53.75%)	5(3.125%)
3. Do you believe that children on AEDs should avoid all physical activity?	89(55.625%)	65(40.625%)	6(3.75%)
4. Would you recommend AED treatment to another caregiver if their child has epilepsy	152(95%)	6(3.75%)	2(1.25%)
5. Do you trust the healthcare professional in prescribing the right AEDs?	156(97.5%)	4(2.5%)	0(0%)

4.Caregivers Practice In Managing Epilepsy

Most caregivers (96.875%) supervised medication intake, and 89.375% stored AEDs appropriately. However, 21.25% admitted giving extra medication during seizure episodes.

Table 4: Caregivers' practice in managing Epilepsy

STATEMENTS	YES	NO	DON'T KNOW
1.Do you skip the drug due to some reasons	34(21.25%)	126(78.75%)	0
2. Do you give any other medication other than allopathy	16(10%)	144(90%)	0
3. Do you supervise your child while taking medication	155(96.875%)	5(3.125%)	0
4. Do you give more amount of antiepileptic medication than prescribed when your child feels seizure symptoms	34(21.25%)	126(78.75%)	0
5. Do you store AEDs properly to maintain their effectiveness	143(89.375%)	15(9.375%)	2(1.25%)

5.Clinical characteristics

Generalized seizures were the most common diagnosis (68.1%). Polytherapy (58.8%) was prescribed more frequently than monotherapy (41.3%). Sodium valproate (63.1%) and levetiracetam (58.8%) were the most frequently prescribed AEDs.

Table 5: Clinical Characteristics

VARIABLE	n(%)
Generalized seizures	109(68.125%)
Partial seizures	46(28.75%)
Combination seizures	5(28.75%)
Monotherapy	66(41.25%)
Polytherapy	94(58.75%)
Sodium valproate	101 (63.1%)
Levetiracetam	94(58.75%)
Phenobarbitone	23(14.375%)
Lorazepam	20(12.5%)
Clobazam	7(4.3%)

6.Association Between Knowledge of Caregivers and Level of Education

There was a progressive increase in the proportion of correct responses with increasing educational level among caregivers. Eighty percent of tertiary educated caregivers correctly identified that long-term use of antiepileptic drugs (AEDs) may affect child growth and cognition compared with 41.6% of secondary educated, 15.2% of primary educated and 16.6% of uneducated caregivers.

Table 6. Association between knowledge of caregivers and level of education

Knowledge Questions	Response	Uneducated	Primary	Secondary	Tertiary	X^2	P value
Can long-term use of AEDs affect Child growth and cognitive function?	YES NO DON'T KNOW	3(16.6%) 8(44.4%) 7(38.8%)	11(15.27%) 30(41.6%) 31(43.05%)	25(41.6%) 22(36.6%) 13(21.6%)	8(80%) 2(20%) 0(0%)	27.27	<0.001*
Do you know that AEDs helps control seizure but don't cure epilepsy?	YES NO DON'T KNOW	9(50%) 2(11.1%) 7(38.8%)	10(13.8%) 28(38.8%) 34(47.2%)	29(48.3%) 17(28.3%) 14(23.3%)	7(70%) 2(20%) 1(10%)	28.75	<0.001*
Is it safe to stop AED suddenly without doctors' advice?	YES NO DON'T KNOW	4(22.2%) 9(50%) 5(27%)	9(12.5%) 49(68.05%) 14(19.4%)	4(6.6%) 47(78.3%) 9(15%)	3(30%) 7(70%) 0(0%)	10.31	0.112
Do you know that regular follow up visit is necessary for children in AEDs?	YES NO DON'T KNOW	6(33.33%) 7(38.88%) 5(27.77%)	40(55.5%) 18(25%) 14(19.4%)	35(58.3%) 19(31.6%) 6(10%)	8(80%) 1(10%) 1(10%)	8.79	0.186
Do you know that certain food or life style change may help manage epilepsy?	YES NO DON'T KNOW	2(11.1%) 11(61.1%) 5(27.7)	19(26.38%) 30(41.6%) 23(31.94%)	19(31.6%) 30(50%) 11(18.3%)	7(70%) 1(10%) 2(20%)	14.78	0.002*

DISCUSSION

The management of pediatric epilepsy depends not only on medical treatment but also on caregivers' knowledge, attitude, and practices (KAP), which influence treatment adherence, seizure control, and the child's quality of life. In this study of 160 caregivers, females (65.6%), particularly mothers (51.3%), were the primary caregivers, and most belonged to the 19–30 years age group (59.4%), consistent with previous studies by Shahin MAH & Hussien RM and Negussie et al. Most caregivers had only primary education (45%), while 11.3% had no formal education, and 55.6% resided in rural areas, highlighting potential barriers to effective epilepsy management.

Caregivers demonstrated inadequate knowledge regarding antiepileptic drugs (AEDs). Although most knew that AEDs should not be stopped abruptly (70%) and recognized the importance of regular follow-up (58.1%), misconceptions persisted regarding their effects on growth, intelligence, and the fact that AEDs control seizures but do not cure epilepsy. Attitudes were generally positive, with most caregivers trusting healthcare professionals (97.5%) and recommending AED therapy (95%). However, many believed that children with epilepsy have

lower intelligence (43.1%) and should avoid physical activity (55.6%), reflecting persistent stigma.

Medication practices were encouraging, with 78.8% reporting good adherence and 96.9% supervising medication intake. Nevertheless, 21.3% admitted to administering higher AED doses during seizures, indicating unsafe practices requiring targeted education. Sodium valproate (63.1%) and levetiracetam (58.8%) were the most commonly prescribed AEDs, and polytherapy (58.8%) was more frequent than monotherapy. Generalized seizures were the predominant seizure type (68.1%), followed by combination (28.8%) and partial seizures (3.1%). Higher educational status was significantly associated with better knowledge of AED use and lifestyle modifications, consistent with previous studies. Overall, these findings emphasize the need for structured caregiver education, continuous counseling, and improved healthcare access to enhance treatment adherence, dispel misconceptions, and optimize pediatric epilepsy management.

CONCLUSION

The study on the knowledge, attitude, and practice of caregivers in pediatric epilepsy management highlights both strengths and gaps in caregivers' involvement. The majority of caregivers were females, particularly mothers, reflecting their primary role in child health care. Most participants were from rural backgrounds and had only primary or secondary education, which influenced their awareness and practices. Although caregivers generally understood the importance of AEDs and reported administering them regularly, misconceptions regarding the long-term use, side effects, and necessity of uninterrupted therapy were evident.

In terms of practice, while a large proportion of caregivers ensured timely medication, supervised intake, and responded appropriately during seizures, a considerable number did not administer AEDs correctly or lacked clarity on the importance of dose accuracy. Polytherapy was more common than monotherapy, and sodium valproate was the most frequently prescribed drug. Generalized seizures were the most prevalent type of epilepsy encountered in the study population.

Overall, caregivers demonstrated a moderate level of knowledge and practice that had areas of inadequate understanding, especially regarding adherence, drug effects, and seizure management. These findings emphasize the need for structured educational intervention, regular counselling, and community awareness programmes to improve caregiver competence. Strengthening caregiver knowledge and practices will directly enhance treatment outcome, reduce seizure recurrence, and improve quality of life for children living with epilepsy

LIMITATIONS

- People might not answer honestly, which can affect the results.
- The participants were chosen from one hospital, so they might not represent all caregivers.
- Its hard to measure someone's true attitude with a simple questionnaire.

Ethical Approval

The study protocol was approved by the Institutional Ethics Committee of S.C.S College of Pharmacy, Harapanahalli, Karnataka, India, on 19 March 2024 prior to commencement of the study.

Conflict of Interest

The authors declare that there are no conflicts of interest related to this study.

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