

## COMPLIANCE TO ANTIEPILEPTICS AMONG CHILDREN WITH EPILEPSY

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### ABSTRACT

The aim of the study was to evaluate the barriers to access to treatment and compliance to medication among children with epilepsy and to explore the influencing factors. **Methods:** It was a descriptive cross-sectional study; data were collected from 100 children aged 6-14 years attending Amrita Hospital, Kochi, who had been on antiepileptic medications for a minimum of six months. Data collection tools included a structured questionnaire for caregivers covering demographic details, adherence levels, and influencing factors, supplemented by medical record reviews. According to the brief adherence rating scale, only 67% of the population showed 100% adherence. These findings suggest that a considerable proportion of children are not consistently following their medication schedules. Barriers to treatment suggest more diverse experiences among respondents regarding obstacles in treatment access or compliance. Analysis shows that education and socio-economic status play an important role in shaping knowledge and expectations about disease treatment. Results also suggest that better understanding and expectations around disease treatment may be associated with fewer seizure episodes in children. **Conclusion:** Adherence to antiepileptic medications among children with epilepsy was found to be suboptimal, with only two-thirds showing complete compliance. Parental education and socioeconomic status influenced treatment knowledge but did not guarantee consistent adherence. Targeted interventions are needed to address barriers and improve treatment outcomes.

**KEYWORDS:** According to the brief adherence rating scale, only 67% of the population showed 100% adherence.

### INTRODUCTION

Epilepsy in children is a neurological disorder characterized by recurrent seizures resulting from abnormal electrical activity in the brain. It is one of the most common neurological conditions affecting the pediatric population. A seizure occurs when part(s) of the brain receives a burst of abnormal electrical signals that temporarily interrupts normal electrical brain function. Epilepsy affects people of all ages, races, and ethnic backgrounds. According to the CDC, almost three million Americans live with epilepsy, and nearly 200,000 people in the U.S. are newly diagnosed each year. Globally, it affects approximately 50 million people, with a significant portion being children.<sup>[1]</sup>

The cornerstone of epilepsy management is the consistent use of antiepileptic medications. Studies suggest that carefully selected medical therapy, guided by seizure type and AED characteristics, is effective in more than two-thirds of children with epilepsy. Adherence (compliance) is the degree to which a patient follows a treatment regimen. For medications, adherence requires that the prescription be obtained promptly and the medication be taken as prescribed in terms of dose, dosing interval, duration of treatment, and any additional special instructions.<sup>[2]</sup> However, adherence to antiepileptic medications among children remains suboptimal, leading to increased seizure frequency, decreased quality of life, and higher healthcare costs.

Epilepsy is the second most common and frequently encountered neurological condition that imposes a heavy burden on individuals, families, and healthcare systems. As per a recent study, 70 million people have epilepsy worldwide, and nearly 90% are found in developing regions. The study also estimated a median prevalence of 1.54% (0.48–4.96%) for rural and 1.03% (0.28–3.8%) for urban areas in developing countries. With a conservative prevalence estimate of 1%, there are more than 12 million persons with epilepsy (PWE) in India, accounting for nearly one-sixth of the global burden.<sup>[3]</sup> In Kerala alone, epilepsy affects nearly 600,000 children under 14 years of age. The incidence is highest in very young and elderly populations. Moreover, the stigma surrounding epilepsy often prevents individuals from leading a normal life.<sup>[4]</sup>

Studies examining medication adherence among children with epilepsy have reported varying prevalence rates, generally ranging from 30% to 70%, depending on the methodology and population studied. Cross-sectional studies estimate nonadherence rates between 12% and 35%. Antiepileptic drugs have variable efficacy and the potential for both short- and long-term adverse effects. In India, the issue of nonadherence is multifactorial, influenced by socio-cultural beliefs, economic status, and healthcare accessibility.

A cross-sectional study conducted at the Children's Hospital of Nanjing Medical University between February and August 2022 assessed medication compliance among 156 children with epilepsy. The study found that 37.18% of participants had poor compliance.<sup>5</sup> Factors such as age, duration of epilepsy, parental education level, household income, and the number of drugs taken were found to affect adherence. These findings suggest the need for targeted nursing and medical interventions to improve medication compliance in children.

Nonadherence to AED therapy can result in breakthrough seizures, increased risk of injury, hospitalizations, emergency department visits, poor academic performance, and psychosocial issues. It can also lead to treatment failure and the development of drug-resistant epilepsy. Therefore, studying medication adherence in children with epilepsy is essential for optimizing treatment outcomes, improving quality of life, and reducing the burden of epilepsy on families and healthcare systems.

## STATEMENT OF THE PROBLEM

Study to assess compliance to anti-epileptics among children with epilepsy attending a tertiary care Hospital, Kochi.

## OBJECTIVES

### Primary objective

1. To find the level of adherence to antiepileptic medication among children with epilepsy attending a tertiary care hospital Kochi.

### Secondary objective

1. To find the factors associated with level of adherence to antiepileptic medication among children with epilepsy attending a tertiary care hospital Kochi.  
2. To find the association between level of adherence to anti-epileptic medications and selected socio-demographic variables among children with epilepsy attending a tertiary care hospital Kochi.

## MATERIALS AND METHODS

### 1. Study Design

This study employed a descriptive cross-sectional design to assess the level of adherence to antiepileptic medications and the associated factors among children with epilepsy. Data were collected over a two-weeks period.

### 2. Study Population

The study involved children aged 6 to 14 years diagnosed with epilepsy, attending Amrita hospital in Kochi. The inclusion criteria were children who had been on antiepileptic medications for minimum six months. Children with significant cognitive disabilities or those under inpatient care were excluded. A total of 100 participants were selected using a convenience sampling

### 3. Study Area/Setting

The study was conducted at Amrita Hospital, a tertiary care centre in Kochi. This facility provides specialized care for children with epilepsy and has access to a variety of antiepileptic medications.

### 4. Data Collection Tools

Data were collected using a Semi-structured questionnaire on socio-demographic data, Brief adherence rating scale and Pediatric Epilepsy Medication Self-Management Questionnaire. The questionnaire used to assess the sociodemographic data. Brief Adherence rating scale<sup>[6]</sup> was used to assess compliances to antiepileptics. Pediatric Epilepsy Medication Self-Management Questionnaire<sup>[7]</sup> were used to assess the factors affecting medication adherence Medical records were also reviewed to verify prescription details and seizure control.

### 5. Data Collection Procedure

Caregivers were approached during routine clinic visits, and written informed consent was obtained. Data collection was conducted by co-investigators, and all information was anonymized to protect participant privacy.

## 6. Data Analysis

The collected data were analysed. Descriptive statistics were used to summarize demographic data and adherence levels. Chi-square and Sherman's correlation were employed to identify factors associated with adherence.

## RESULTS

### SECTION I

Frequency and percentage distribution of the socio-demographic variables.

**Table 1: Frequency and percentage distribution of demographic variables according to baseline characteristics.**

Socio – demographic variable		Frequency	Percentage
Age of the child	6-8 years	48	48.0
	8-10 years	28	28.0
	10-12 years	24	24.0
Gender of the child	Male	64	64.0
	Female	36	36.0
Type of family	Joint family	48	48.0
	Nuclear family	51	51.0
	Extended family	1	1.0
Educational status of father	Illiterate	3	3.0
	Primary school	28	28.0
	Middle school certificate	44	44.0
	High school certificate	25	25.0
Educational status of mother	Illiterate	1	1.0
	Primary school illiterate	28	28.0
	Middle school completion	39	39.0
	High school certificate	29	29.0
	Diploma	2	2.0
	Graduate	1	1.0
Occupation of father	Government employee	19	19.0
	Non-government employee	45	45.0
	Self employed	35	35.0
	Unemployed	1	1.0
Occupation of mother	Government employee	15	15.0
	Non-government employee	18	18.0
	Self employee	7	7.0
	Unemployed or Housewife	60	60.0
Socioeconomic status	Upper class	28	28.0
	Upper middle class	34	34.0
	Lower middle class	34	34.0
	Lower class	4	4.0
Number of seizure episodes in child during last 6 months	None	38	38.0
	1-2 times	47	47.0
	3-4 times	5	5.0
	4 and above	10	10.0
Number of hospital admissions of child in last 6 months due to seizure	None	63	63.0
	1-2 times	31	31.0
	3 -4 times	3	3.0
	4 and above	3	3.0

N=100

The study included children aged 6–12 years, with the nearly half (48%) between 6–8 years. Most were males (64%) and from nuclear families (51%). Fathers were mostly educated up to middle school (44%) and employed in non-government sectors (45%), while mothers were mainly middle school educated (39%) and unemployed (60%). Socioeconomically, 68% of the children belonged to the middle class. Regarding seizure history, 47% experienced 1–2 episodes with in past 6

months, and 63% had no hospital admissions related to seizures during this period.

### SECTION II

Analysis of compliance to anti-epileptics among children with Epilepsy based on brief adherence rating scale.

**Table 2: Frequency and percentage distribution based on Brief Adherence Rating Scale.**

Items		Frequency	Percent
Number of pills per day	1	3	3.0
	2	96	96.0
	3	1	1.0
Over the month, number of times child not take pills	few<7	97	97.0
	7 to 13	3	3.0
Over the month, number of times child taken less than prescribed number of pills	Some times	19	19.0
	Never	81	81.0
Out of prescribed doses, the proportion of antiepileptic medication taken in a month	80%	2	2.0
	90%	31	31.0
	100%	67	67.0

**N=100**

The analysis showed that 96% of children were taking 2 pill a day, 3% of them takes one pill a day and 1% takes 3 pills a day. Over the month 3% children missed 7 to 13 tablets and 97% missed less than 7 tablets. 19% of children took less than prescribed number of pills and 80% took all prescribed tablets. Only 67% of children 100% of tablets prescribed, 31% of children missed 10% of tablets and 2% missed 20% of tablets. These findings suggest that a considerable proportion of children are not consistently following their medication schedules.

### SECTION III

Assessment of factors associated with medication adherence among children with epilepsy.

#### 1. Disease knowledge and expectation

The majority of caregivers reported a strong understanding of epilepsy and high confidence in managing their child's condition. Nearly all participants stated that the healthcare team explained epilepsy and seizures clearly, with 99% of them feeling equipped to handle medication side effects and 100% of them know whom to contact in case of concerns. Additionally, all caregivers expressed belief in achieving seizure freedom and awareness of the risks involved in stopping medications. Most (97%) of them felt listened to by the care team, and only 1% reported difficulty in accessing healthcare providers. These results indicate a highly informed and engaged caregiver population regarding disease management.

#### 2. Adherence to Medications and Clinic Appointments

The data showed that most caregivers are actively engaged in their child's epilepsy management. About 68% of them ensure that the child takes medication as prescribed, and 79% follow medical advice. Transportation was not a major barrier, with 75% reporting easy access to clinics. However, gaps in adherence were observed. 16% of caregivers reported that the child did not consistently receive medication, 25% did not strictly prioritize treatment, and 11% did not consider daily medication essential. Additionally, while 75% of families reported agreement with the treatment plan, 24% were neutral and 1% disagreed. These findings highlight areas where

caregiver understanding and commitment can be further strengthened through education and support.

#### 3. Beliefs about medication efficiency

The data suggests that caregivers strongly believe in the necessity and effectiveness of the antiepileptic medication. A majority (89%) strongly agreed that the treatment is necessary for managing the child's condition, while 11% agreed. Similarly, 86% strongly believed that the medication would control the seizures, and 14% agreed with this statement. These findings indicate a high level of confidence among caregivers regarding the efficacy of the prescribed treatment. Most caregivers reported that incorporating the medication schedule into daily life was manageable. Specifically, 79% stated it is "always easy" to fit medications into the daily routine, 19% said it is "often easy," and only 2% reported it as "sometimes easy." None of the caregivers indicated it was rarely or never easy. This suggests that for most families, medication timing is not a significant burden.

#### 4. Barriers to treatment

Caregivers reported several barriers that affect treatment adherence. Regarding medication taste, 4% of children always disliked it, while 6% disliked it sometimes. Forgetfulness was an issue for some families, 2% of parents sometimes forgot to give the medication, and 36% occasionally forgot. Difficulties in swallowing pills were reported always by 4% and occasionally by 15% of children. Social embarrassment was also a minor concern, with 5% of children occasionally and 1% always feeling embarrassed to take medicine in front of others. Medication refusal was reported always by 1%, sometimes by 2%, and occasionally by 34% of children. Interference from other activities was noted in 11% of children. Additionally, 13% of families occasionally ran out of medication, and 9% faced difficulty obtaining it from the pharmacy. These findings point to specific areas where caregiver support and system-level interventions can be beneficial.

## SECTION IV

**Association between sociodemographic variables and factors associated with medication adherence among children with epilepsy**

Table 3 presents chi-square test results for the associations between demographic variables (age of child, type of family, parental education and occupation,

and socio-economic status) and four areas in the paediatric medication self-management questionnaire: Disease Treatment and Knowledge Expectations, Adherence to Medication and Clinic Appointments, Beliefs about Medication Efficacy, and Barriers to Treatment.

**Table 3: Association between sociodemographic variables and factors associated with medication adherence.**

Demographic variable	Factors associated with medication adherence			
	Disease treatment and knowledge expectations	Adherence to medication and clinic appointments	Beliefs about medication efficiency	Barriers to treatment
Age of child	$\Sigma^2$ -0.443 df-2 <b>P=0.801</b>	$\Sigma^2$ -0.598 df-2 <b>P=0.742</b>	$\Sigma^2$ -0.573 df-2 <b>P=0.751</b>	$\Sigma^2$ -0.576 df-2 <b>P=0.750</b>
Type of family	$\Sigma^2$ -2.538 df-2 <b>P=0.281</b>	$\Sigma^2$ -2.580 df-2 <b>P=0.275</b>	$\Sigma^2$ -1.442 df-2 <b>P=0.486</b>	$\Sigma^2$ -2.137 df-2 <b>P=0.344</b>
Educational status of father	$\Sigma^2$ -17.530 df-3 <b>P=0.001</b>	$\Sigma^2$ -3.349 df-3 <b>P=0.341</b>	$\Sigma^2$ -3.924 df-3 <b>P=0.270</b>	$\Sigma^2$ -1.986 df-3 <b>P=0.575</b>
Educational status of the mother	$\Sigma^2$ -15.511 df-4 <b>P=0.004</b>	$\Sigma^2$ -1.541 df-4 <b>P=0.819</b>	$\Sigma^2$ -2.199 df-4 <b>P=0.699</b>	$\Sigma^2$ -3.155 df-4 <b>P=0.532</b>
Occupation of father	$\Sigma^2$ -14.511 df-3 <b>P=0.002</b>	$\Sigma^2$ -2.381 df-3 <b>P=0.497</b>	$\Sigma^2$ -1.807 df-3 <b>P=0.613</b>	$\Sigma^2$ -1.720 df-3 <b>P=0.633</b>
Occupation of the mother	$\Sigma^2$ -5.626 df-3 <b>P=0.131</b>	$\Sigma^2$ -7.527 df-3 <b>P=0.057</b>	$\Sigma^2$ -0.711 df-3 <b>P=0.871</b>	$\Sigma^2$ -7.126 df-3 <b>P=0.068</b>
Socio-economic status	$\Sigma^2$ -20.086 df-3 <b>P&lt;0.001</b>	$\Sigma^2$ -2.865 df-3 <b>P=0.413</b>	$\Sigma^2$ -0.875 df-3 <b>P=0.831</b>	$\Sigma^2$ -1.094 df-3 <b>P=0.779</b>

$\chi^2$  -Chi-square, df – degree of freedom

The Chi-square test was conducted to examine the association between selected sociodemographic variables and four domains of pediatric medication adherence: disease treatment and knowledge expectations, adherence to medication and clinic appointments, beliefs about medication efficacy, and barriers to treatment. The analysis revealed no significant association between the child's age, type of family, or mother's occupation and any of the four domains ( $p > 0.05$ ).

However, significant associations were found between certain demographic variables and the domain of disease treatment and knowledge expectations. Specifically, the

educational status of the father ( $\chi^2 = 17.530$ ,  $p = 0.001$ ), educational status of the mother ( $\chi^2 = 15.511$ ,  $p = 0.004$ ), occupation of the father ( $\chi^2 = 14.511$ ,  $p = 0.002$ ), and socioeconomic status ( $\chi^2 = 20.086$ ,  $p < 0.001$ ) were all statistically associated with higher scores in disease treatment knowledge and expectations. These findings suggest that caregivers with higher levels of education and better socioeconomic status tend to demonstrate a greater understanding and higher expectations regarding epilepsy treatment. No significant associations were observed between any demographic variable and the domains related to adherence behavior, beliefs about medication, or treatment barriers.

**Table 5: Association between seizure episodes and factors associated with medication adherence.**

Spearman's rho (r)	Disease treatment and knowledge expectations	Adherence to medication and clinic appointments	Beliefs about medication efficiency	Barriers to treatment
Number of seizure episodes in the child during the last 6 months	$r = -.215$ $p = .031$	$r = -.091$ $p = .367$	$r = -.095$ $p = .348$	$r = .038$ $p = .707$
Number of hospital admissions of children in the last 6 months due to seizures	$r = -.025$ $p = .801$	$r = -.142$ $p = 0.158$	$r = .043$ $p = 0.672$	$r = .071$ $p = 0.483$

N=100



There is a significant, weak negative correlation between Disease Treatment and Knowledge Expectations and the number of seizure episodes ( $r = -0.215$ ,  $p = 0.031$ ), suggesting that a better understanding and expectations around disease treatment may be associated with fewer seizure episodes in children. Other factors, including adherence, beliefs about medication efficacy, and barriers to treatment, show no significant correlations with either the frequency of seizures or hospital admissions.

## DISCUSSION

The analysis of the data revealed that the majority of children in the study were males (64%), and nearly half (48%) were between 6 to 8 years of age. More than half (51%) belonged to nuclear families. Most of the fathers had completed middle school education (44%) and were employed in non-governmental sectors (45%), while 39% of mothers had a similar educational background. Socioeconomically, the majority (60%) of families fell into either the upper or lower middle-class categories. Nearly half (47%) of the children had experienced one to two seizure episodes in the past six months, and 63% had no hospital admissions related to seizures during that period.

The primary objective of the present study was to assess the level of adherence to antiepileptic medications among children with epilepsy, and the findings indicate a clear concern. According to the Brief Adherence Rating Scale, only 67% of children achieved 100% adherence to their prescribed medication. Notably, 19% had missed doses in the past month, and 3% had missed between 7 to 13 doses. Additionally, 31% took only 90% of their prescribed doses, and 2% took 80%, pointing to suboptimal adherence in nearly one-third of the study population. While most of the children were on relatively simple regimens (e.g., taking two pills daily), a small percentage on more complex regimens may face additional challenges, contributing to inconsistency in adherence.

These findings are consistent with a study conducted at Government Medical College and Rajindra Hospital, Patiala, where poor adherence was observed in 50% of children taking antiepileptic drugs. That study also identified the importance of demographic and treatment-related factors in influencing compliance.<sup>[8]</sup> Similarly, another large cross-sectional study from West China Second Hospital of Sichuan University reported high levels of treatment access barriers among caregivers, which were significantly associated with difficulties in adherence—especially in families facing financial constraints, dealing with comorbidities, or caring for younger children.<sup>[9]</sup>

A quantitative study conducted on parents depicts the importance of implementing an education programme for parents of children with epilepsy, as it would help to improve knowledge on home care management and

follow healthy practices.<sup>[10]</sup> In the present study, although caregivers generally demonstrated good knowledge and understanding of the disease and treatment—as indicated by high scores in disease treatment expectations and beliefs about medication efficacy—this did not always translate into consistent medication-taking behavior. The paediatric medication self-management assessment showed that while parents had a positive attitude toward treatment, barriers such as forgetting doses, difficulty accessing medications, and occasional refusal by children were still reported.

Further analysis revealed that certain sociodemographic factors, particularly the educational status and occupation of parents, as well as socioeconomic status, were significantly associated with caregivers' knowledge<sup>10</sup> and expectations about treatment. However, these factors did not show a strong association with actual medication adherence, beliefs about efficacy, or perceived treatment barriers. This suggests a gap between awareness and practice—while caregivers may understand the importance of the medication, practical or behavioral challenges continue to hinder full adherence.

Overall, the study highlights that poor adherence remains a significant issue among children with epilepsy, despite caregivers' awareness and supportive healthcare environments. The findings point to the urgent need for targeted interventions—beyond education alone—that address behavioral, logistical, and systemic challenges faced by families.

## CONCLUSION

The findings of this study reveal a significant issue with medication adherence among children with epilepsy. Although antiepileptic drugs are essential for seizure control, only 67% of children in the study adhered fully to their prescribed treatment, while the remaining one-third missed doses or took less than the prescribed amount. This level of non-adherence poses a serious challenge to effective epilepsy management and increases the risk of uncontrolled seizures, hospitalizations, and reduced quality of life.

Despite caregivers reporting good knowledge, positive beliefs about treatment, and supportive healthcare interactions, these factors did not consistently translate into optimal adherence behavior. Barriers such as forgetfulness, medication refusal by children, and logistical issues like running out of medicine or difficulty obtaining it from pharmacies continue to affect consistent medication intake. Furthermore, while caregiver education and socioeconomic status were significantly associated with better knowledge and expectations, they had limited influence on actual adherence practices.

These findings highlight the urgent need for targeted interventions aimed specifically at improving adherence. Educational programs alone may not be sufficient;

instead, comprehensive strategies that include behavioral counseling, reminder systems, caregiver support, and structural solutions to reduce access barriers are essential. Addressing poor adherence is critical to improving clinical outcomes and ensuring better long-term management of epilepsy in children.

### Recommendations

#### 1. Parental Education Programs

Healthcare providers should implement structured educational initiatives for parents and caregivers to enhance their understanding of the critical importance of consistent antiepileptic medication adherence. These programs should also address how to identify and manage common side effects to reduce treatment interruptions.

#### 2. Medication Management Support

Hospitals and clinics should establish systems for regular follow-up with families. This may include appointment reminders, medication schedule alerts, and platforms for reporting and managing drug-related concerns, thereby promoting sustained adherence.

#### 3. Tailored Interventions for At-Risk Groups

Special attention should be directed toward children from lower socioeconomic backgrounds or with less-educated parents. Tailored strategies such as home visits, community-based support, and simplified medication routines may be effective in addressing unique barriers within these groups.

#### 4. Counseling on Side Effects

Physicians and healthcare staff should provide proactive counseling to families on managing and reporting side effects. Early identification and intervention can prevent discontinuation of treatment and improve adherence outcomes.

### Implications for nursing

#### Nursing Administration

Nursing administrators should formulate and implement policies that emphasize family education and ongoing support for managing chronic conditions such as epilepsy. This includes creating frameworks for regular follow-up, adherence monitoring, and staff training to ensure high-quality care delivery.

#### Nursing Education

Nursing curricula should integrate detailed training on the importance of medication adherence in chronic pediatric conditions. Students should be equipped with the skills to counsel families, identify adherence barriers, and communicate effectively with caregivers from diverse backgrounds.

#### Nursing Practice

In clinical settings, nurses play a vital role in ensuring medication adherence. They should provide personalized education to families, identify individual challenges, and

collaborate with caregivers to develop practical and sustainable adherence plans.

### Nursing Research

Further research is essential to explore innovative, family-centered strategies that enhance medication adherence. Studies should evaluate the effectiveness of interventions such as mobile-based reminders, community health outreach, and nurse-led counseling programs in improving adherence outcomes.

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