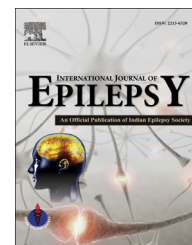


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## Original Article

# Knowledge, attitude and practice of parents regarding pediatric antiepileptic drug therapy



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## ARTICLE INFO

## Article history:

Received 30 April 2014

Accepted 11 November 2014

Available online 12 December 2014

## Keywords:

Awareness

Antiepileptic drugs

Counseling

Pediatric epilepsy

## ABSTRACT

**Objectives:** To evaluate the parental knowledge, attitude and practice (KAP) regarding the antiepileptic medication therapy in childhood.

**Methods:** This study was carried out over a period of 10 months in the division of Pediatric Neurology of Amrita Institute of Medical Sciences. The cohort of patients was selected randomly meeting the inclusion and exclusion criteria. Parents' KAP regarding epilepsy and antiepileptic drug therapy was assessed using a questionnaire prepared by the authors and patient adherence towards antiepileptic drug therapy by using Pediatric Epilepsy Self-Management Questionnaire (PEMSQ).

**Results:** A total of 123 patients were selected and enrolled in the study. Seventy eight percent of the respondents knew that epilepsy is a brain disorder, while only 6% of them were aware about all the treatment options. The scoring in the domain of "Disease and Treatment Knowledge & Expectations of parents" was found to be significantly low (69.07%) when compared to other domains in the PEMSQ. Although socioeconomic status did not correlate with knowledge score of the parents ( $p = 0.216$ ), it was significantly related to adherence ( $p = 0.042$ ).

**Conclusion:** In this cohort, even though the parents had a fair knowledge about the nature of epilepsy, they were found to be less aware about its characteristics, causes and prognosis. The awareness about the nature and duration of treatment, its objectives, use of drugs, their side effects and importance of adherence to drug regimen was found to be significantly low with a potential for affecting the therapeutic outcome. Special awareness programs for parents of children with epilepsy may be needed to reduce the knowledge gaps in the management of epilepsy and to ensure compliance and optimal therapeutic outcomes.

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Epilepsy is a chronic medical condition, which requires long term management. Adherence to antiepileptic drugs (AEDs) is crucial for preventing the risk of recurrent seizures. Knowledge about the disease condition and medications can

influence the compliance towards antiepileptic drug therapy.<sup>1,2</sup> Recently conducted knowledge, attitude and practice (KAP) studies from developed countries had shown an emergence of a positive attitude toward epilepsy.<sup>3–5</sup> However,

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<http://dx.doi.org/10.1016/j.ijep.2014.11.002>

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epilepsy still continues to be a highly stigmatizing disease in most developing countries.<sup>6–8</sup> Prior evidence showed that parents have inadequate knowledge regarding disease and pharmacotherapy of their children with epilepsy.<sup>9,10</sup> Lack of knowledge and inappropriate beliefs are the major obstacles to successful epilepsy management. Quality of life will be significantly affected by non adherence to AEDs due to the occurrence of frequent breakthrough seizures and also by increased hospital admissions. It may also lead to serious consequences like status epilepticus and sudden unexpected death in epilepsy (SUDEP).<sup>11–13</sup>

The medication management of pediatric patients with epilepsy largely depends on the attitudes of their parents and caregivers.<sup>14</sup> Good drug compliance can be achieved by imparting health education to both patient and family.<sup>15</sup> Counseling and communication between health professionals and parents of children with epilepsy regarding nature of disease, its characteristics, medications used, benefits of AEDs, dosage adjustments, potential drug interactions, adverse effects and need for adherence to therapy is essential.<sup>16</sup>

In the current study, an attempt has been made to assess Knowledge, Attitude and Practice (KAP) of the parents regarding epilepsy and antiepileptic medication therapy and also patient adherence towards antiepileptic drug therapy using Pediatric epilepsy medication Self-Management Questionnaire (PEMSQ).

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## 1. Methods

This study was carried out for a period of 10 months between 1st September 2012 to 30th June 2013 in the Epilepsy clinic of the Division of Pediatric Neurology, Department of Neurology of Amrita Institute of Medical Sciences, Kochi, Kerala, India. The hospital Research and Ethics Committee scrutinized the protocol and gave ethical approval for the study. An information leaflet describing the study pattern was given to the parents and informed consent was obtained from respondents prior to the commencement of interviews.

Patients who satisfied the inclusion and exclusion criteria were selected randomly and enrolled in the study. We included children with epilepsy aged <18 years, who were on long term AEDs, and with regular follow up visits accompanied by parents who were able to read and speak English or the local language Malayalam. We excluded parents who were not willing to participate in the study or not ready to give an informed consent. A standardized data collection form prepared by the investigators was used to obtain necessary data from the parents who were then assessed for their KAP and adherence to medications.

Two questionnaires were administered to the parents: KAP questionnaire and PEMSQ. KAP questionnaire prepared by the first author with 34 questions designed in English and local language Malayalam was used to assess KAP of the parents regarding pediatric antiepileptic drug therapy. It included questions that dealt with the disease condition, symptoms, management of seizures, different treatment options for epilepsy, proper use and storage of medications, beliefs about medication efficacy, need for adherence to AED therapy and

its side effects. The initial 10 questions were related to general awareness about epilepsy and the remaining 24 questions about the general practice and knowledge of epilepsy treatment. The questionnaire was reviewed in detail by the second author, and two other senior neurologists with vast clinical and research experience in epilepsy for the clinical appropriateness of the questions and modifications were made according to their suggestions. Then a pilot study was conducted on the proposed study population to decide on the reliability and the clinical applicability of the questionnaire. It was planned to view the responses qualitatively. However, an arbitrary scoring was also given as +1 and –1 depending on the perceived impact of the responses in the overall quality of life of children with epilepsy.

The second questionnaire used, the PEMSQ is one of the initial scales used in assessing aspects that are salient to a pediatric epilepsy population.<sup>17</sup> It is a 27 item measure consisting of four sections: Epilepsy and Treatment Knowledge and Expectations, Adherence to Medications and Clinic Appointments, Beliefs about Medication Efficacy and Barriers to Medication Adherence. It evaluates caregivers' perceptions of their understanding of epilepsy, antiepileptic drug therapy and its management, adhering to the prescribed treatment regimen, how well they believe the medication will work to treat seizures and barriers that make it difficult for their child to take medications as prescribed. Two response sets were used on the questionnaire: "Strongly disagree" to "Strongly agree" or "never" to "always". These scales together make up a total self-management score ranging from 27 to 135 which refers to all the activities required to control seizures and to reduce side effects, including taking AEDs, engaging in healthy lifestyle behaviors, active participation in decision making with the healthcare team and managing stress. Higher scores represent better self-management.

All the data were tabulated, analyzed and compared with data from other studies. The collected data were compiled using Microsoft excel. Statistical analysis was performed using SPSS Version 20. The significance of the study results were assessed using Fisher's exact test, paired sample t-test, analysis of variance (ANOVA) and correlation analysis.

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## 2. Results

A total of 123 children were recruited for the study, which included 62 males and 61 females. Their mean age was  $4.74 \pm 4.38$  years. The demographic data of the patients are shown in [Table 1](#).

Twenty-eight children (22.76%) depended previously on various alternative systems of medicines. Among them, 23 (18.69%) used ayurveda, 2 (1.63%) were on homeopathy and acupuncture respectively, and one person used Unani system (0.81%). The remaining 95 (77.24%) children solely used AEDs as polytherapy or monotherapy in which polytherapy dominated over monotherapy. Out of the 123 children, 26 (21.14%) were on ketogenic diet while the rest 97 children were managed with AEDs (78.86%). The various drugs prescribed in this study population are illustrated in [Table 1](#).

Majority of the parents were found to be less knowledgeable about the nature of epilepsy, its characteristics,

**Table 1 – Demographic data of the study population.**

Characteristics	No: Of patients	%
<b>Gender</b>		
Males	62	50.41
Females	61	49.59
<b>Mode of delivery</b>		
NVD <sup>a</sup>	66	53.66
LSCS <sup>b</sup>	57	46.34
<b>Term period of delivery</b>		
Full (37–40 weeks of gestation)	110	89.43
Early (<37 weeks of gestation)	13	10.57
<b>Gestational complications</b>	35	28.46
<b>Neonatal complications</b>	57	46.34
<b>Associated medical conditions</b>	66	53.66
<b>Family history of seizures</b>	41	33.33
<b>Educational status of parents</b>		
Post Graduates	10	8.13
Graduates	36	29.27
Intermediate	49	39.84
High School	23	18.7
Middle School	4	3.25
Illiterate	1	0.81
<b>Socioeconomic status of parents</b>		
Upper	11	8.95
Upper middle	44	35.77
Lower middle	27	21.95
Upper lower	40	32.52
Lower	1	0.81
<b>Seizure frequency (no:of times/day)</b>		
<5	66	53.66
5–10	39	31.71
10–15	4	3.25
>15	14	11.38
<b>Drugs prescribed</b>		
Polytherapy	61	49.59
Monotherapy	35	28.45
<b>Conventional AEDs</b>		
Valproic acid	70	56.91
Phenytoin	30	24.39
Clonazepam	23	18.69
Phenobarbitone	17	13.82
Carbamazepine	10	8.13
<b>Newer AEDs</b>		
Levetiracetam	67	54.47
Clobazam	55	44.72
Topiramate	24	19.51
Oxcarbazepine	10	8.13
Lamotrigine	7	5.69
Lacosamide	2	1.63
Zonisamide	1	0.81
<b>Ketogenic diet</b>	26	21.14

<sup>a</sup> Normal vaginal delivery.  
<sup>b</sup> Lower segment caesarean section.

causes and prognosis, nature and duration of treatment, its objectives, proper use and storage of drugs, their side effects and importance of adherence to drug regimen. The mean KAP score of the respondents was found to be  $19.58 \pm 3.78$  (–34 to +34). About 97 (79%) of the parents knew that epilepsy is a brain disorder and 2 (1.16%) believed that it is always hereditary. Nearly 112 (91%) of them were aware that symptoms and severity of epileptic attacks vary from patient to patient. According to 68 (55%) respondents, febrile seizures could not be labeled as epilepsy. Only 7 (6%) parents were

aware of all the treatment options other than AEDs. 29 (24%) of them believed that ketogenic diet has a role in controlling seizure attacks. 35 respondents (28%) were aware that blood samples can be used to measure the concentration of AEDs in the body. Almost 122 (99%) knew correctly about the proper use and storage of drugs. Among 123 participants, 16 (13%) did not know that a complete seizure free period is absolutely essential for stopping AEDs. Six (4.8%) of them believed that AEDs are addictives and therefore it would be difficult to stop taking it at a later date. Seventy-three (59%) parents thought that some AEDs can affect memory and concentration of the child, even though 26 (21%) of them reported that AED therapy won't have any side effects. The parental response to each of the KAP questionnaire is listed in Table 2.

**Table 2 – Response of parents' KAP regarding anti epileptic drug therapy of their children.**

Questions	No: Of respondents (%)
<b>1. Do you think epilepsy is a brain disorder?</b>	
Yes	97 (78.86)
No	5 (4.07)
Don't know	21 (17.07)
<b>2. Do you think epilepsy is a mental disease?</b>	
Yes	3 (2.44)
No	118 (95.93)
Don't know	2 (1.16)
<b>3. Do you think epilepsy is always hereditary?</b>	
Yes	2 (1.16)
No	116 (94.3)
Don't know	5 (4.07)
<b>4. Do you think epilepsy is a contagious disease?</b>	
Yes	0
No	123 (100)
Don't know	0
<b>5. Do you think epilepsy is always curable?</b>	
Yes	85 (69.1)
No	19 (15.45)
Don't know	19 (15.45)
<b>6. Is epilepsy due to supernatural powers?</b>	
Yes	4 (3.25)
No	118 (95.93)
Don't know	1 (0.81)
<b>7. Can febrile seizures be labeled as epilepsy?</b>	
Yes	29 (23.58)
No	68 (55.28)
Don't know	26 (21.14)
<b>8. Do you believe that always there is a state of unconsciousness during an epileptic attack?</b>	
Yes	13 (10.57)
No	98 (79.67)
Don't know	12 (9.76)
<b>9. Do you believe that symptoms and severity of epileptic attacks vary from patient to patient?</b>	
Yes	112 (91.06)
No	7 (5.69)
Don't know	4 (3.25)
<b>10. Do you think it is necessary to disclose your child's epileptic condition while consulting a general physician?</b>	
Yes	119 (96.75)
No	3 (2.44)
Don't know	1 (0.81)

(continued on next page)

**Table 2 – (continued)**

Questions	No: Of respondents (%)
11. Do you know any epilepsy treatment options other than with drugs?	
Yes	7 (5.7)
No	116 (94.3)
Don't know	0
12. Do you know that specific dietary therapy has a key role in controlling seizure attacks?	
Yes	29 (23.58)
No	93 (75.61)
Don't know	1 (0.81)
13. Do you know that about 75–80% of people with epilepsy can be managed easily with one drug?	
Yes	19 (15.45)
No	94 (76.42)
Don't know	10 (8.13)
14. Do you know that blood samples can be used to measure the concentration of antiepileptic drugs in the body?	
Yes	35 (28.46)
No	86 (69.91)
Don't know	2 (1.63)
15. Do you know that blood investigations are needed in patient on prolonged antiepileptic therapy?	
Yes	49 (39.84)
No	68 (55.28)
Don't know	6 (4.88)
16. Do you think it is essential to check the expiry date of the medicine while purchasing it?	
Yes	122 (99.19)
No	1 (0.81)
Don't know	0
17. Do you think it is important to keep medicines in proper storage conditions (air tight container & proper temperature)?	
Yes	122 (99.19)
No	1 (0.81)
Don't know	0
18. Do you believe that it is necessary to take medicines as advised by your doctor?	
Yes	123 (100)
No	0
Don't know	0
19. Do you believe that the time at which the medication taken will influence its effectiveness?	
Yes	118 (95.93)
No	5 (4.07)
Don't know	0
20. Do you think that disappearance of seizures means that treatment is no longer necessary?	
Yes	2 (1.63)
No	119 (96.74)
Don't know	2 (1.63)
21. Do you think it is desirable to take more amount of antiepileptic medication than prescribed when your child feels seizure symptoms?	
Yes	1 (0.81)
No	121 (98.38)
Don't know	1 (0.81)
22. Do you think that antiepileptic drugs must be taken life long?	
Yes	3 (2.44)
No	96 (78.05)
Don't know	24 (19.51)

**Table 2 – (continued)**

Questions	No: Of respondents (%)
23. Do you think that antiepileptic drugs can be stopped abruptly?	
Yes	1 (0.81)
No	113 (91.87)
Don't know	9 (7.32)
24. Do you think that complete seizure freedom for a period is absolutely essential for stopping antiepileptic drugs?	
Yes	99 (80.49)
No	8 (6.5)
Don't know	16 (13.01)
25. Do you think it is suitable to take any other drugs during fever, cold or other diseases, without doctor's advice?	
Yes	5 (4.07)
No	114 (92.68)
Don't know	4 (3.25)
26. Do you think it is better to stop taking antiepileptic medication when your child feels ill?	
Yes	3 (2.44)
No	119 (96.75)
Don't know	1 (0.81)
27. Do you know that the antiepileptic drug therapy may not have an immediate effect?	
Yes	90 (73.17)
No	25 (20.33)
Don't know	8 (6.5)
28. Do you know that the dose of medication is determined by your child's body weight?	
Yes	87 (70.73)
No	25 (20.33)
Don't know	11 (8.94)
29. Do you think that missing doses and/or taking them late or incorrectly will affect the treatment response?	
Yes	112 (91.06)
No	9 (7.32)
Don't know	2 (1.63)
30. Do you think it is wise to use any other alternative systems of medicine while on antiepileptic drugs?	
Yes	8 (6.5)
No	105 (85.37)
Don't know	10 (8.13)
31. Do you believe that it is advisable to change frequently the brands of the drug?	
Yes	8 (6.5)
No	105 (85.37)
Don't know	10 (8.13)
32. Do you believe that by taking antiepileptic medication the user will become addicted and therefore be unable to stop taking it?	
Yes	6 (4.88)
No	113 (91.87)
Don't know	4 (3.25)
33. Do you think that the some antiepileptic drugs can affect memory and concentration of your child?	
Yes	73 (59.35)
No	31 (25.20)
Don't know	19 (15.45)
34. Do you think that antiepileptic drug therapy will have side effects?	
Yes	91 (73.98)
No	26 (21.14)
Don't know	6 (4.88)

Among the total 123 responses in PEMSQ, 9 (7.32%) parents had some basic knowledge about the treatment related side effects whereas 114 parents (92.68%) were not aware of any adverse effects of AEDs. About 104 (84.55%) were confident enough to manage side effects if they occur, in partnership with the health care team whereas 19 of them (15.45%) were not. Ninety-nine of them (80.49%) were conscious about the risks of discontinuing their child's medication before he/she has been seizure free for a minimum period of two years while 24 (19.51%) were unaware of that. Over 121 of the participants (98.37%) informed that they usually followed the medical advice and treatment plans prescribed for their children. 122 parents (99.19%) felt it is important for their child to receive his/her treatment as directed and 121 of them (98.37%) stressed the importance to assure that their child takes his/her medication on a daily basis. 120 parents (98%) believed that medication treatment is necessary for their child's epilepsy whereas 20 (16%) said that the medication chosen had not controlled their child's seizures. Medications are easy to fit into the daily schedule of 120 children (98%). Sixty-six of them (54%) said that their child often dislikes the taste of the medication, 75 (61%) mentioned that the medication is difficult for the child to swallow and 81 of them (66%) reported that the child sometimes refused to take his/her medication. Nearly six of the respondents (5%) had run out of their AEDs occasionally and 20 (16%) often found difficulty in getting their medication from the pharmacy. Table 3 denotes the details of PEMSQ scoring of the respondents in different subsections.

Most of the participants identified medication related factors as the major reason for non adherence to AEDs. The primary reason for non adherence mentioned by 105 (85.36%) respondents was fear of side effects. While 34 (27.64%) parents found it difficult due to polypharmacy, other reasons reported were increased frequency of dosing by 23 (18.6%), cost of medications by 22 (17.89%) and prolonged duration of therapy by 17 (13.82%) parents. Ten (8.13%) and 12 (9.76%) of them ranked patient related factors like forgetfulness and travel respectively as other reasons for non adherence to antiepileptic drug therapy.

A statistically significant association was observed between socioeconomic status of the parents and adherence score ( $p = 0.042$ ). No significant relationship was found between socioeconomic status of the parents and their knowledge score ( $p = 0.216$ ).

### 3. Discussion

We investigated the Knowledge, Attitude and Practice (KAP) of parents regarding the antiepileptic drug therapy of their children with epilepsy in a tertiary care hospital setting. Most of our patients were on polytherapy and some were on ketogenic diet which suggests that the study population included a significantly high proportion of children with refractory epileptic syndromes with relatively high seizure burden. So the findings of this study may not be directly applicable to the general population. However even in such a cohort, we found clear knowledge gaps, mainly concerning medications and therapy of epilepsy. It was found that even though the parents of children with epilepsy were knowledgeable regarding the

**Table 3 – PEMSQ scoring of the respondents.**

PEMSQ	Mean score (range)
Disease and treatment knowledge & expectations	27.63 ± 4.23 (8–40)
Adherence to medications & clinic appointments	32.72 ± 5.63 (8–40)
Beliefs about medication efficacy	12.48 ± 1.79 (3–15)
Barriers to treatment (reverse scored)	34.32 ± 5.09 (8–40)
Total score	107.15 ± 12.69 (27–135)

nature of epilepsy, its characteristics, causes, and prognosis, they were less aware about the nature of treatment, its objectives, use of drugs, importance of adherence to the drug regimen, potential side effects and interactions of drugs, and duration of treatment. They were concerned about the seizures and their effect on various aspects of the lives of children, and also about long term side effects of AEDs.

According to existing literature awareness about epilepsy is generally poor,<sup>18–21</sup> particularly with regard to certain aspects of epilepsy<sup>18,22,23</sup> like etiology, use and administration of AEDs,<sup>24</sup> and emergency management of seizures.<sup>25</sup> The findings of our study is at variance with a Sudanese KAP study in which only 30% of the respondents knew epilepsy as a brain disorder.<sup>26</sup> An earlier population based KAP study from Kerala in which 27% of participants reported epilepsy as supernatural.<sup>27</sup> In this group, only 4 parents considered a supernatural causation for epilepsy. The difference in the study setting might be the primary reason for this discordance. This study concurs with the studies from Sudan<sup>28</sup> and Brazil<sup>29</sup> reporting that the awareness of epilepsy as a curable disease by a majority of respondents. It was encouraging to note that unlike some other populations,<sup>26,27,30</sup> none of our respondents considered epilepsy being contagious. The study by Joshi et al<sup>31</sup> in which 77% of the study population thought that epilepsy needed lifelong treatment correlates with our findings.

Medication adherence in epilepsy is mainly related to the knowledge regarding the importance of regular drug intake. However, Dawkins et al<sup>21</sup> reported that many patients were worried about the side effects of medications and risk of drug dependence. In our study group also, many parents were worried about the effects of long term administration of drugs and the chance of drug dependence. Another KAP survey from rural Gujarat demonstrated the lack of awareness about the proper usage of drugs, storage of medicine and their expiry dates.<sup>32</sup> This low level of knowledge was consistent with the findings of many other studies.<sup>33,34</sup> Our results showing the inadequate knowledge of parents about AEDs and their side effects did not support the study from Turkey<sup>35</sup> and Nigeria<sup>36</sup> in which the parents of children with epilepsy of 8–17 years of age who knew about epilepsy were found to be more aware about AEDs used and their side effects. Hirfanoglu et al<sup>35</sup> reported that both maternal education and employment were correlated with better knowledge of epilepsy ( $p = 0.004$ ). However, there was no correlation between the knowledge about epilepsy and AEDs and educational qualifications ( $p = 0.216$ ). The difference in the characteristics of the study population may explain these variations.

Several studies have shown that parents with low family income were more likely to have less knowledge about

epilepsy and its treatment.<sup>35,37</sup> Our study underlines that adherence pattern is significantly associated with socioeconomic status ( $p = 0.042$ ) which is identical to previous studies.<sup>38–40</sup> Lower socioeconomic status of parents was usually associated with higher non adherence ( $p < 0.001$ ). Previous studies suggested that adherence to medications among patients with epilepsy is sub-optimal.<sup>41,42</sup> In spite of better knowledge, high costs of medication and forgetfulness were the most frequent reasons given for poor compliance.<sup>43,44</sup> Our study also shows the same pattern. A similar trend was observed in a study from New York,<sup>45</sup> which also revealed that forgetfulness was the most often cited reason for noncompliance.

This study showed that a significant proportion of parents of children with epilepsy are unaware about the implications of antiepileptic drug therapy of their children. Improving the understanding about epilepsy and its management along with the overall medical care may ultimately enhance adherence, which will help to improve the therapeutic outcomes and overall quality of life in children with epilepsy. The present study also highlights a significant impact of low socioeconomic status on drug compliance, suggesting the necessity of improved social support in such population. There is also a need for improving the parental awareness as they play a pivotal role in the management of children with epilepsy. Educational efforts directed at parents may have a significant beneficial effect on the well being of children with epilepsy by ensuring optimal therapeutic outcome.

### Conflicts of interest

All authors have none to declare.

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