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Original Article

Drug compliance in children with epilepsy: Cross-sectional study, New Delhi

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ABSTRACT

Background: For individuals with epilepsy, adherence to medication is crucial in preventing or minimizing seizures and their cumulative impact on everyday life. Compliance studies in adult patients are many, but few in children with epilepsy. **Objective:** This study tries to find the prevalence of noncompliance in children with epilepsy and causes leading to it. **Method:** The study was conducted in a tertiary care super specialty children hospital of New Delhi. Children, age 1-12 years, who were already diagnosed cases of epilepsy and were all on drug therapy for at least 3 months were included in the study. After obtaining clearance from the hospital's Ethical Committee, a total of 100 parents of epileptic children were interviewed as per the prepared questionnaire. **Results:** Out of 100 children (63 males, 37 females) with epilepsy, 71% were compliant. Most of the noncompliant parents (82.7%) felt that there is the harmful effect of long-term anti-epileptic drugs. They believed in stopping medications on their own once signs and symptoms disappear and did not like to give medication to their child in public place. No significant association of noncompliance could be seen with etiology of epilepsy, monotherapy versus polytherapy, and duration of disease, mother's age and parental education ($p>0.05$). **Conclusion:** Compliance in this study group of children with epilepsy was 71%. Further improvement of health and well-being of children with epilepsy can be attempted by education of parents, distribution of written instructions in the form of pamphlets, counseling, group discussions, and exchange of personal experience. Public awareness drive should help in reducing the associated taboos.

Key words: *Children, Epilepsy, Drug compliance, Questionnaire*

Children with epilepsy are a source of huge concern to their parents irrespective of their educational status. They have fears, notions, misconceptions, and varying level of commitments to handle the special child. The role of medical personnel handling the family is extremely crucial. The health-care providers be it doctors, nurses or paramedical staff coming in their contact adds to their information and belief in ways more than one. Among the various factors affecting antiepileptic drug usage, the major determinants are age and gender of patients, side effect profile and availability of drugs, finances of patients, and behavior and influence of the treating physician [1]. For individuals with epilepsy, adherence to medication is crucial in preventing or minimizing seizures and their cumulative impact on everyday life. As many as 30-50% of persons with epilepsy are noncomplaint in following the treatment and more than half of epilepsy patients have poor seizure control due to non-adherence to medication [2]. This study aims at finding the various causes which affect drug compliance in these children.

METHODS

The study was conducted in tertiary care children hospital of North India. The questionnaire-based study proposal was ethically cleared by hospital's Ethical Committee. The patients were informed before the interview about their inclusion in this study, and their consent was taken for the same. A total of 100 children with epilepsy and their parents were interviewed during the study period. All children aged 1-12 years with diagnosis of epilepsy (irrespective of any medical cause), on drug therapy for at least 3 months were included in the study.

No drug intervention, diet modification or any blood sampling was done. The study was stopped where it was inconvenient and interfering with the routine care of the patient. The questionnaire included sex and age of child, duration of disease, treatment regimen, age and educational level of parents, information on compliance for medication taken, and the reason for noncompliance. Drug compliance was considered as satisfactory if the patient took the medication in correct dosage, regularly and as planned for him/her based on their yes/no response to the questions about the above-mentioned items. The data was entered in MS excel, descriptive statistical analysis was performed using appropriate formulas and Student t-test was used for calculating p value ($p<0.5$ was considered significant).

RESULTS

A total 100 children with epilepsy (63 males and 37 females) and their parents were interviewed. 52% of these children

were in the age group of 1-4 years. The age of onset of seizure was <1 year in 52% of the cases. Valproate monotherapy was given to 83% cases, and combination therapy (Table 1) was given to 17% cases. The patients came mostly from parts of North India including 63% from Delhi, 22% from Uttar Pradesh, 8% from Haryana, and 7% from others states. Parents of 37% children were at least 10th pass. Basic or no formal education was received by 63% parents. Only 10% were graduates. Family history of an affected parent in 5% cases, affected sibling in 4% and of a neurological disorder in anyone in the family in 56% cases was observed. More than one seizure episode per day was seen in 48% of the children (Table 2).

Out of total patients, 29% were non-compliant. No significant association of noncompliance was found with etiology of epilepsy, monotherapy versus polytherapy, and duration of disease, mother's age and parental education ($p>0.05$). Costly medication and unavailability in drug stores was reported by 24.1% of non-compliant patients. The study also found that 41.3% of noncompliant patients suffered from higher seizures frequency due to lack of timely medication. Misconceptions and lack of effective communication with doctor were reported by 82.7% of noncompliant parents. The common misconceptions were that antiepileptic drugs when taken for the long term may result in harmful side effects. Many also believed that it is correct to stop the drug therapy on their own once the sign and symptoms settle down. Some also found it embarrassing to administer drugs to the child in front of others.

DISCUSSION

Compliance is the extent to which a person's behavior coincides with medical or health advices [3]. The reasons for non-compliance may include discomfort resulting from treatment, expense of treatment, decisions based on personal judgments about the effectiveness of the proposed treatment, maladaptive coping styles (e.g., denial of illness), or mental disorders [4]. Several methods are used to measure therapeutic adherence. Indirect methods like self-reports and interviews with the patient are simplest and most common method for measuring medication adherence [5]. Questionnaire-based studies usually overestimates compliance [6].

The compliance studies in adult patients with epilepsy show good compliance because a neglect of medical treatment may cause epileptic seizures. Studies in adolescents with epilepsy showed poor compliance [7]. In children, compliance studies have given varying result; 72.4% in children attending Motahary Clinic of Shiraz [8], 42% in Cincinnati Children's Hospital [9], 86% in Pediatric University Hospital in Riyadh [10]. Despite our recent economic progress, a wide treatment gap is very much a reality and a big challenge for health care provider. This has been reported as high as 78% and 71% in Indian studies [11,12].

A study showed that compliance improved when patient was satisfied with the consultation process and was asked to recall the information [13]. Multiple visits to doctor enhanced the communication and thus compliance. Studies have also found that adherence to medication is good when health care provider are emotionally supportive, giving reassurance and respect to the patient and regularly interact with the patient to discuss how to live with the disease [14].

Caring for a child with epilepsy involves facing multiple challenges simultaneously. A majority of these children will have associated learning and behavior disorders leading to significant difficulties at school [15]. In this study, 48 (20.8%) school going children were irregular in school, 18% were weak in studies, and 41.6% were not socially interactive with their peers. Around 43.7% parents stated that they are unable to send their children to school due to high seizures frequency. Our study has limitations due to small sample size as this study was a part of ICMR-STS project in which data collection had to complete in a period of 2-month. Therefore, a larger study would be more useful to assess the causation of non-compliance.

Table 1: The various drug combinations used in children (n=17) with epilepsy

Drugs are given for treatment	Number of patients
Valproate+topiramate	1
Epitoin+valproate	4
Valproate+clobazam	6
Valproate+levetiracetam	2
Epitoin+clobazam+carbamazepine	1
Valproate+clobazam+topiramate	1
Valproate+levetiracetam+epitoin	1
Phenobarbital+levetiracetam+phenytoin	1
Total	17

Table 2: Frequency of seizure episodes in the patients (n=100)

Frequency	Number of cases
Only 1-2 episodes till date	2
One in 1 year gap	7
One in>1 month gap	28
One in>1 week gap	15
More than one episode daily	48

CONCLUSION

Assessment of adherence should be part of routine management of epilepsy. Noncompliance in the present study was 29%. As the noncompliance is not significantly associated with any usual causative factor, improvement in compliance by paying attention to psychological health of the child, group education, medication education for parents, especially through written information, and support from other affected parents and physicians maybe important and useful. Awareness campaigns in general public about epilepsy should be done frequently to reduce the associated taboo.

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