



KNOWLEDGE, ATTITUDE AND PRACTICE AMONG PARENTS TOWARDS CHILDREN WITH EPILEPSY

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ABSTRACT

Parent's attitude towards their children with epilepsy can be influenced by their knowledge on disease. Myths and misconceptions associated with disease should be identified for optimally care in children with epilepsy. We aimed to assess the knowledge, attitude and practice of parents towards children with epilepsy using a questionnaire and to educate parents, the correct practice involved about disease and its management. We conducted study on 150 parents whose child had seizures and attended department of paediatrics. Specially designed questionnaire was used, the questions were asked to the parent of child with epilepsy. Questionnaire included 3 parts knowledge, attitude and practice. Of the total 150 interviewed, 60% were mothers. Majority of them had not heard about epilepsy, until their child was diagnosed with the disease. Majority of parents believed that epilepsy is not a hereditary disease. They believed that their child inspite of childhood epilepsy can achieve a lot in future and lead independent life. While majority said they donot discriminate the affected child between his/her siblings. They believed that medication adherence and compliance is very important in controlling the seizures. Majority said that they follow age old myth associated during the seizure i.e., giving keys or iron material in the hand, while only 35.3% of parents said that they seek immediate medical attention. The knowledge, attitude and the practices among parents of children with epilepsy is not adequate and need improvements. In order to improve the quality of life of the children and their families' proper awareness, guidance and educational programmes are necessary.

INTRODUCTION

Epilepsy being one of the most common neurological disorders is characterized by recurrent and unprovoked seizures. These epileptic seizures are generated from excessive and abnormal cortical nerve cell activity in the brain. Most cases of epilepsy are idiopathic whereas some cases may be a result of brain injury, stroke, brain tumour, alcohol/drug abuse or due to genetic mutation.^[1] The overall aim in treating epilepsy should be complete control of seizures without causing any inappropriate reaction due to the medication.^[2] Epilepsy is the most common neurological disorder in children.^[3] A large number of drugs are currently available for the treatment of epilepsy.^[4] There are several anti-epileptic drugs (AEDs) available and are broadly classified as conventional AEDs and new AEDs.^[5] One of the greatest challenges in pediatrics is the age related pharmacokinetic changes in the particular drug and considering the wide variety of adverse events with the AEDs. Polytherapy is a common practice for the

management of epilepsy despite of significance increase in side effects.^[6]

With all these it becomes very important that there is awareness among parents regarding the disease and its treatment. In India, lot of myths and misconceptions are associated with the disease. Several studies have demonstrated lack of awareness.^[7] The lack of awareness regarding epilepsy among the general population and even among health care professionals has to be considered as it influences the children with epilepsy. The culture background and educational level are known to influence one's attitude towards epilepsy. Knowledge about epilepsy is associated with less perceived stigmatization and social isolation, as well as fewer depressive symptoms and misconceptions. Moreover, parent's degree of knowledge and misconceptions regarding epilepsy affect their attitude towards their epileptic children. Adequate education is the corner stone in managing the patients and their families. Therefore, to optimally care for epileptic children, all misconceptions

and misinformation should be identified and corrected.^[1] Considering these issues, we aimed to assess the knowledge, attitude and practice of parents towards children with epilepsy using a questionnaire and to educate parents the correct practice involved about the disease and its management.

METHODOLOGY

This prospective, questionnaire based study was conducted in a tertiary care hospital in Bangalore, Karnataka, India, after obtaining ethical committee clearance. We conducted study on 150 parents whose child was having seizures and attended outpatient or inpatient department of paediatrics. The study was conducted from April 2018 to June 2019. Children younger than 18 years, with confirmed cases of epilepsy, receiving anti-epileptic drugs were enrolled in the study only after obtaining consent from the parents or the legal guardians. Children with severe systemic disorders like chronic kidney disease, chronic liver disease, neurological conditions like mental retardation, global development delay, autism etc were excluded from the study.

Data was entered in a Microsoft excel sheet, where demographic details was collected according to the modified Kuppuswamy scale. Specially designed questionnaire was used and the questions were asked to the parent of the child with epilepsy. This questionnaire included 3 parts - knowledge, attitude and practice, among which we had 22 questions for knowledge and 21 questions for attitude, and questions were asked regarding the practice followed during and after attack. This was noted from each parent to understand the myth and misconceptions associated with the disease. All the data were entered and kept confidential.

RESULTS

A total of 150 parents were interviewed, of which 60% were mothers. The families interviewed had high school education [42%], among which either of the parent was a skilled worker [35.33%]. When we analyzed the socioeconomic status of the family as per kuppuswamy scale, 49.3% of the family belonged to lower middle class family. Majority of the children with epilepsy had their age ranged between 0m to 4years [56.6%], and were mostly females [60.6%].

When we analyzed the knowledge about epilepsy among the parents, as shown in table 1, we observed that, majority of them never heard about the disease [64.86%] before their child was diagnosed and got to know either by a friend or a neighbour or a relative or by a medical professional. Answers to the key knowledge has been summarized under table 1, where we observe that majority of the parents had myths and misconceptions associated with the disease. Majority of the parents believed that epilepsy is not a hereditary disease [70.27%] and said that malnutrition is not the cause for epilepsy [77.7%]. Parents also believed that childhood

seizures can have impact of their future employment [71.6%]. Most of the parents agreed that seizure in childhood leads to financial problem in the family [71.6%]. About 82.4% of the parents trusted that medications/ surgery can help in treating their child with epilepsy.

On analyzing the parent's attitude on epilepsy as shown in table 2, we noticed that majority of the parents had positive attitude regarding the disease and its treatment. They believed that their child inspite of childhood epilepsy can achieve a lot in the future [80.4%], lead independent life [71.6%]. While majority of the parents said that they donot discriminate the affected child between his/her siblings [63.5%]. A parents understanding with regards to the treatment and compliance was positive. They believed that medication adherence and compliance is very important in controlling the seizures [72.9%].

When we asked the parents, what they do during or after seizure, majority of them said that they follow age old myth associated during the seizure i.e., giving keys or iron material in the hand [50.6%], which helps in easing down the attack. While only 35.3% of parents said that they seek immediate medical attention. While few of them believed that rubbing hands or legs or sprinkling water on the face, holding hands and legs firmly [6%] can help the situation. Those parents who believed that epilepsy is associated with evil, sought help from a faith healer [5.3%], while few of them tried treating the child with ayurvedic or homeopathy medications before shifting to allopathic medications [2.6%]. We did not find any correlation with regards to parent's knowledge and attitude with their socioeconomic status.

DISCUSSION

In our study we documented that, parents of children with epilepsy were not aware about the disease before diagnosis, which was similar to the study results conducted by Jyothi and her colleagues.^[8] A study was conducted by Azhar Daoud and his colleagues, reported that 81% of the parents knew or read about the disease which was in contrast to our study.^[9] Parents of children with epilepsy were well informed with significant knowledge and positive attitude, while they exhibited poor practices with regards to disease. Though parents felt informed about the disease and other treatment aspects, still many believed that epilepsy is a mental and a hereditary disorder. Other authors reported contrast results where parents mentioned that evil spirit was considered to be the cause of the disease.^[10] Such myths and misconceptions can cause significant negative impact on medical treatment with greater risk of non compliance.^[7] Some of the parents thought that a child with epilepsy needs special school and considered them as vulnerable to the disease. Such misconceptions are more commonly reported from developing countries¹¹⁻¹³ due to limited educational practices. We also observed that few of the parents were over protective and treated

their child differently from his/her siblings. They avoided upsetting or punishing the affected child. Such practices should be discouraged to a great extent as it can lead to predisposed problems like adaptation, relationships, difficulty to socialize and at school.

As most of the parents believed that epilepsy is a mental disorder and admitting to use non medical treatment like faith healer and ayurvedic or homeopathic mode of treatment. This has been mostly the practice in our region. While majority of the parents also said that, giving keys or iron materials in hand can help is easing the seizure attack and may not require any medical attention. This correlation with the belief that disease is a mental disorder or can be associated with the evil, they reverted to these type of non medical treatment until the condition of the child was severe and brought to the hospital. We reported few other inappropriate and harmful procedures like burning the forehead with a heated glass bangle can help to overcome the disease. Such myths associated with the disease can make the condition worse and may require long term treatment with drugs and if untreated, can face severe consequences. Studies from other authors also reported such mythical concepts and related to the have observed more frequently in developing countries that lack educational practices.^[10]

CONCLUSION

We conclude that, the knowledge, attitude and the practices among parents of children with epilepsy is not adequate and need improvement and proper counselling regarding the disease and its management. Many of them have significant myths and misconceptions associated; hence there is an alarming need to improve the degree of knowledge, which can help in improving their attitude and positively influence the wrong belief and practices, in order to enhance the relationship with the child. Hence educating the whole community, improving the awareness through street plays regarding the disease is essential. Parents, teachers, health government sectors should target educational program to increase the awareness and should fill the gap in minimizing the social stigma associated, in order to improve the quality of life of the children and their families.

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