

ASSESSMENT OF KNOWLEDGE, ATTITUDE AND PRACTICE OF CAREGIVERS IN CHILDREN WITH EPILEPSY

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Abstract: Epilepsy is a chronic disorder of the brain that affects people worldwide and most common pediatric neurological disorder. The incidence of seizures is highest, 5 % of children experience convulsion during the first 5 years of life, with decreasing frequency in older age. Parent's attitude and practice towards children with epilepsy are greatly influenced by the degree of their knowledge. Seizure in childhood may interfere with familial life, sleep and social life of parents, imposing tremendous stress and anxiety of parents. **AIM:** To evaluate knowledge, attitude and practice of caregivers in children with epilepsy towards the health condition. **Methodology:** This is a cross-sectional observational study conducted for a period of 6 months in a tertiary care hospital setting. The caregivers of the patients were briefed about the study and consent was obtained to be recruited in the study. A structured 31-item questionnaire was designed to examine knowledge, attitudes and practice towards children with epilepsy. **Results:** A total of 86 caregivers were enrolled in the study based on the inclusion and exclusion criteria, out of which 52% were female and 48% were male. The mean age of our study subjects was found to be 9.30 ± 4.63 yrs. The factors like family history, birth order, type of seizure were assessed in our study. Assessment of knowledge, attitude and practice were done using self-designed questionnaire. On an average their quantum regarding the disease was found to be as knowledge 54%, attitude 69%, practice 76%. **CONCLUSION:** Most of the caregivers are unaware of the exact risks associated with epilepsy. Even though considerable respondents had satisfactory knowledge, attitude and practice regarding epilepsy, many of them don't seek appropriate preventive or corrective measures due to various factors.

Keywords: Parent; Knowledge; Attitude; Practice; Child; Pediatric; Epilepsy.

I. INTRODUCTION

Epilepsy is a chronic disorder of the brain that affects people worldwide. It is characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized), and are sometimes accompanied by loss of consciousness and control of bowel or bladder function.¹ A seizure is defined as a transient, involuntary alteration of consciousness, behavior, motor activity, sensation or autonomic function caused by an excessive rate and hyper synchrony of discharges from a group of cerebral neurons. The definition of status epilepticus refers to continuous or recurrent seizure activity lasting longer than 30 minutes without recovery of consciousness.

During a seizure, cerebral blood flow, oxygen, glucose consumption, carbon dioxide and lactic acid production will increase. Early systemic changes include tachycardia, hypertension, hyperglycemia and hypoxemia. Brief seizures rarely produce lasting effects on the brain. Prolonged seizures, however, can lead to lactic acidosis, rhabdomyolysis, hyperkalemia, hyperthermia and hypoglycemia. All of which may be associated with permanent neurologic damage.

Seizures are the most common pediatric neurologic disorder, with 4% to 10% of children suffering at least one seizure in the first 16 years of life. The incidence is highest in children younger than 3 years of age, with a decreasing frequency in

older children. Epidemiologic studies reveal that approximately 150,000 children will sustain a first-time, unprovoked seizure each year, and of those, 30,000 will develop epilepsy.² At a conservative estimate, 50 million people worldwide suffer from epilepsy. It has been shown that as much as 80% of persons with epilepsy live in the developing world.³

A KAP survey can:

- Measure the extent of a known situation; confirm or disprove a hypothesis; provide new tangents of a situation's reality.
- Enhance the knowledge, attitude, and practices of specific themes; identify what is known and done about various health-related subjects.
- Establish the baseline (reference value) for use in future assessments and help measure the effectiveness of health education activities ability to change health-related behaviors.
- Suggest an intervention strategy that reflects specific local circumstances and the cultural factors that influence them; plan activities that are suited to the respective population involved.⁴

“KAP” study measures the Knowledge, Attitude and Practice of a community. It serves as an educational diagnosis of a community. The knowledge possessed by a community refers to their understanding of any given topic. Attitude refers to their feeling towards the subject. Practice refers to the ways in which they demonstrate their knowledge and attitude through their actions.⁵ Parent's knowledge on care of children greatly influences the health status of child by reducing the mortality and morbidity rate.⁶ The caregiver has to understand the disease progress, first aid measures to treat seizures and ways to prevent their recurrence of seizure.⁷

The important components of child growth are maternal activities and socioeconomic status that promote the children's physical, intellectual and psychosocial development so that they may grow up to express their full potentials.⁸

From previous studies it was found that level of knowledge and understanding among parents of children with epilepsy needs improvement. Many parents have significant misconceptions, negative attitudes, and poor parenting practices. These correlated with their educational levels and had significant implications on the medical management. Therefore, there is a need for improving the degree of knowledge, which will help in improving their attitudes toward epilepsy. Demystification of wrong beliefs will influence the family positively and improve the relationship with their child.⁹

To measure Knowledge, Attitude & Practice in caregiver of child with epilepsy we are using KAP questionnaires: It is a self-designed questionnaire which contains, questions for the patient caregivers regarding their knowledge, attitude and practice towards the disease condition.

II. METHODOLOGY

This study was carried out for a period of 6 months between 1st November 2017 to 30th April 2018 in the out-patient pediatric Epilepsy clinic of ESIC-PGIMSR & Model Hospital, Rajajinagar, which is a 500 bedded hospital with state of art facilities for patients, Bangalore, Karnataka, India.

The hospital Research and Ethics Committee scrutinized the protocol and gave ethical approval for the study. Caregivers of epileptic child who were present in out-patient pediatric department were contacted and explained the purpose of the study and depending upon their willingness and study criteria their participation in the study was considered and informed consent was obtained from caregivers prior to the commencement of interviews. Caregiver considered in the study is either mother or father.

We included children with epilepsy aged <18 years, who were on long term AEDs, and with regular follow up visits accompanied by Caregivers who were able to read and speak English or the local language Kannada. 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 researchers was used to obtain necessary data from the parents who were then assessed for their KAP. The questionnaire had questions which were of the close ended type and comprised of yes / no / don't know variety of answers. The structured questionnaires were administered to the parents who completed them on the spot. Those who could not read and write were assisted by the researchers. The questionnaire was structured to elicit demographic information and to test the knowledge of the parents of the cause of epilepsy, the first-aid management of an epileptic attack and the attitude towards the child with epilepsy.

III. RESULTS

This study includes a total of 86 caregivers drawn from the out-patient pediatric clinic at ESIC MC-PGIMSR & Model Hospital, Rajajinagar, which is a 500 bedded hospital with state of art facilities for patients.

Majority of patients were male (52.32%), mean age of our study population was found to be 9.30± 4.63years. less than one third (5.81%) of patients were belonged to infants age group of 1 month-2 year. There was equal distribution of male and female 50% in children age group (2years-12years) followed by adolescence (12years-18years) and infants (1 month-2 year) where 60% were male and 40% were female. There were no neonates in the study. Most of the patients (90%) were found to be a case of no-hereditary. Majority of the patients were diagnosed as GTCS (Generalised tonic clonic seizure).

Table 1 : KAP questionnaire used in our study

Knowledge	Attitude	Practice
1) Do you think epilepsy is a brain disorder?	1) Does epilepsy create hindrance in normal life?	1) If you see a person with epileptic fits what you will do?
2) Do you think epilepsy is a mental disease?	2) Should a person with epilepsy not study?	2) Do you give any other medicine other than allopathy ?
3) Do you think epilepsy is a contagious disease?	3) Should a person with epilepsy not play?	3) Do you skip the drugs due to some reasons?
4) Do you think epilepsy is always hereditary?	4) Should a person with epilepsy not work?	4) What will you do if seizure are under control on treatment?
5) Is epilepsy due to supernatural powers?	5) Do you avoid upsetting your child?	5) Do you give more amount of antiepileptic medication than prescribed when your child feels seizure symptoms?
6) Is an epilepsy results of previous life sins?	6) Do you treat your affected child different, from his brothers/sisters?	6) Do you think it is better to stop taking anti-epileptic medication when your child feels Side Effects?
7) Do you think epilepsy is always curable?	7) Do you avoid punishing your child?	7) Do you supervise your child while taking medication?
8) Do you believe that always there is a state of unconsciousness during an epileptic attack?	8) Do you consider your child always vulnerable to illness and crises? No []	8) Do you inform class teacher about disease of child & Medication?
9) Does epilepsy affect the intelligence of the child?	9) Can a person with epilepsy marry? Don't know []	9) Do you inform your relative about child's condition & treatment? No []
10) What do you think causes epilepsy?	10) Do you think it is necessary to disclose your child's epileptic condition while consulting a general physician?	10) Do you avoid sending your child for vacation?

Among the total 86 responses in KAP questionnaire, Majority 70(81.4%) of caregivers thought epilepsy as a brain disorder. Where 44(51.16%) of caregivers thought epilepsy is not an mental disorder. More than two-third of caregivers 60 (69.76%) does not think of it as contagious disorder. About 43 (50%) describes it as non-hereditary. Majority of caregivers 73 (84.88%) had good knowledge and believes epilepsy is not due to supernatural powers and also not due to

result of previous life sin. About 42 (48.83%) of caregivers believe epilepsy is curable. More than half 45 (52.32%) believes there is unconsciousness during epileptic attack. Majority of caregivers 49 (56.97%) presume epilepsy does not affect the intelligence of the child. More than two-third of caregivers 50 (58.13%) does not know the cause of epilepsy. Less than one-third of caregivers 22 (25.58%) did not know the role of diet in seizure attacks. Considering the overall response of the caregivers on an average their knowledge quantum regarding the disease was found to be 54%.

Considering the attitude of caregivers regarding the epilepsy it was found that more than half of caregivers 51 (59.30%) does not think epilepsy creates hindrance. About 74 (86.04%) of caregivers believes a child with epilepsy should study. Very few caregivers 2(2.33) urges epileptic child not to play. Almost all caregivers 76 (88.37%) urges epileptic child can work. Majority of caregivers 59 (68.60%) avoided upsetting their child. About 68 (79.06%) of caregivers treated their child similar to other children. More than half of caregivers 50 (58.13%) avoided punishing their child. Majority of caregivers 65 (75.58%) considered their child vulnerable to illness. All most all of caregivers 79 (91.86%) had an positive attitude regarding marriage. Most of caregivers 56 (65.11%) considered disclosing complete health information while consulting physician. Considering the overall response of the caregivers on an average their positive attitude towards the disease was found to be 69%.

Responses regarding practice of caregivers towards epilepsy showed that majority of caregivers 50 (58.13%) would take the child to hospital in case child experience seizures. Few caregivers also considered administering medicines other than allopathy but more than two-third of caregivers 69 (80.23%) avoided administering medicines other than allopathy. Almost all of the caregivers 73 (84.88%) didn't skip administering medicine to child. Only 2(2.33%) of caregivers followed doctors order during course of treatment. More than half of caregivers 69 (80.23%) had positive practice of not administering more amount of AED. About 49 (56.87%) consulted doctor before taking decision regarding AED during course of treatment. Majority of caregivers 59 (68.60%) supervised their child while taking AED. Almost all the caregivers 80 (93.02%) informed class teacher regarding health condition of child. Some caregivers 46(53.48%) were not willing to disclose child health condition to relatives. Around 44 (51.16%) avoided sending their child to vacations. On an average caregivers had a positive practice regarding the disease 76% whereas one-third had negative practice towards disease.

IV. CONCLUSION

“KAP” study measures the Knowledge, Attitude and Practice of a community. It serves as an educational diagnosis of a community. The knowledge possessed by a community refers to their understanding of any given topic. Attitude refers to their feeling towards the subject. Practice refers to the ways in which they demonstrate their knowledge and attitude through their actions.⁵ Parent's knowledge on care of children greatly influences the health status of child by reducing the mortality and morbidity rate.⁶ The caregiver has to understand the disease progress, first aid measures to treat seizures and ways to prevent their recurrence of seizure.⁷

The duration of the study was six-months, this cross-sectional study performed in the out-patient clinic of paediatric department. A total of 86 patients were enrolled in the study, based upon the inclusion and exclusion criteria. The study was conducted at ESIC-PGIMS, Rajajinagar, Bangalore. The institution primarily serves for the labour class.

Among the responses received from caretakers there was slight preponderance was seen in female 52.32% in comparison to male 47.67%. In contrast with the studies conducted, **Teferi J et al** in Ethiopia, showed male predominance 54.1% in comparison to female 45.9% of total population.¹⁰

Birth order of the children was taken into account. Most of the children in the study were of first born (40.67%) followed by second born (38.37%) child of their parent. This result is in contrast with other two studies, conducted by **Angelillo IF et al** in Italy¹¹ and **Roodpeyma S et al** in Iran¹², both found that children of second order 41.4% and 47.2% was suffering more from the disease.

The involvement of family history to the cause of epilepsy in the study revealed that only 10.46% of children were having a positive family history whereas 89.43% not. The most common diagnosis in the study was found to be GTCS (52.32%) followed by breakthrough seizure (15.11%).

Out of the total 86 patients, the first born child suffering from the disorder was found to be 35 (40.67%) which was similar to the study conducted by **Jyoti P** “Assessment of Knowledge and Attitude of Parents regarding Childhood Seizures in Selected Hospital of Haryana” where it was 41.3% in the first born.¹³

In a total number of 86 patients, the most common diagnosis was found to be GTCS (52.32%) was similar to a study conducted by **Shaju M** "Knowledge, Attitude and Practice of parents regarding pediatric antiepileptic drug therapy" found that 60% of children were diagnosed with GTCS.¹⁴ In another study conducted by **Zaine LE** "Parent's Knowledge and Attitudes towards Children with Epilepsy" found that 60% of children with were diagnosed with GTCS.¹⁵

After the interpretation of the study, we found that 81.4% had a good knowledge about epilepsy as a brain disorder, which was similar to the study conducted by **Shaju M**. "Knowledge, Attitude and Practice of parents regarding pediatric antiepileptic drug therapy" where 79% had good knowledge.

Further in the study, 25.58% of the caregivers knew that a specific diet helped in the control of seizure attack in respect to the study conducted by **Shaju M** "Knowledge, Attitude and Practice of parents regarding pediatric antiepileptic drug therapy" where only 7% of the caregiver opted of ketogenic diet.¹⁴

Along the study, 43.02% of the caregivers believed that epilepsy could affect intelligence of a child, whereas study conducted by **Shaju M** "Knowledge, Attitude and Practice of parents regarding pediatric antiepileptic drug therapy" found 59% believed that the intelligence of the child could be affected.¹⁴

During the study, questions of KAP was compared with different studies, it was found out that 44(51.16%) of the caregivers thought of epilepsy, not a mental disease and 3(3.48%) took it as a contagious disease which when compared with the study questions conducted by **Zaini IE** "Parent's Knowledge and Attitudes towards Children with Epilepsy" showed (48%) and (2%) respectively. Also the following results were compared as according to the questions, i.e (53%) avoided upsetting the child, (44%) of believed that affected child is different, 9% thinks the epileptic child is vulnerable to illness. Which in comparison to our study showed (59%) avoid upsetting, (68%) did not think the affected child is different and (65%) thought that the child is prone to illness.¹⁵

In a study conducted by **Shaju M** "Knowledge, Attitude and Practice of parents regarding pediatric antiepileptic drug therapy", (1.16%) thought of it as a hereditary disease, (3.25%) as supernatural powers and (1.3%) as a sin in previous life. Also (69.1%) said epilepsy is curable. In our study, we found that (28%) thought of it as hereditary, (3%) as supernatural power and (6%), as sins of previous life and (42%) distribution of curability. Further in the study (85.3%) stuck with the prescribed drugs, (96.74%) continued medication even if the seizure was under control and (96.75%) did not think of stopping the drugs even if the side-effects are felt. For the same our study showed, (80.23%) stuck to prescribed drugs, (97.67%) continue as doctor advised even if it is under control and (34.88%) did not think of stopping the drug if there is any side-effect to the child.¹⁴

"Knowledge and attitudes of parents toward children with epilepsy" was conducted by **Frank-Briggs AI** which results showed (21.07%) believed there is a state of unconsciousness during epileptic attack, (11.78%) opted that it may affect intelligence of the child. Also (47.5%) of caregivers will take the epileptic patient to the hospital than that (58.1%) in our study. the cause of epilepsy was unknown to (62.7%) of the caregivers whereas in our study only (58.13%) didn't know about the cause of epilepsy.¹⁶

There are some limitations to our study. Our sample was not large; however, it was representative of children with epilepsy with variable ages. Parent's reporting bias may have affected the results since the questions on their knowledge, attitude and practice are predisposed to subjective judgments. We tried to overcome this problem by assigning one coauthor to personally assist all parents in completing the questionnaire. Finally, the questionnaire is self-structured and hence has not been used or validated in previous studies.

We conclude that the level of knowledge and understanding among parents of children with epilepsy needs improvement. Many parents have significant misconceptions, negative attitudes, and poor parenting practices. These correlated with their educational levels and had significant implications on the medical management. Therefore, there is a need for improving the degree of knowledge, which will help in improving their attitudes toward epilepsy. Demystification of wrong beliefs will influence the family positively and improve the relationship with their child. This is also true for the general public [3,4]. Therefore, educating the community about epilepsy is also essential. The media, as well as, government authorities should play a major role in increasing the public awareness. Parents, teachers, and school children should be targeted with such educational programs. Increased awareness and public educational campaigns can be successful in filling the gaps, ameliorating misconceptions, and minimizing the social stigma, and ultimately improving the quality of life of the children with epilepsy and their families.

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