

Public Knowledge Regarding Childhood Epilepsy Attending a Tertiary Care Hospital

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ABSTRACT

Objective: To evaluate the knowledge of the public regarding epilepsy in children.

Methodology: This was a cross-sectional study, conducted at the department of pediatrics, Madinah Teaching Hospital, Faisalabad, from October 2024 to December 2024. A total of 384 individuals (Parents/guardians/attendants) aged 20-60 years were included in the study after taking consent from the participants. Health care professionals and attendants of epileptics, or parents who themselves had epilepsy were excluded to exclude bias. Participants' knowledge about epilepsy was assessed, using a questionnaire, comprising of nine knowledge-based questions related to epilepsy. Knowledge was classified into 3 categories, viz. poor, moderate or good. Chi-square analysis was conducted to compare knowledge against education level and socio-economic status. P-value of <0.05 was considered significant.

Results: Overall, our population showed 34.4% with good; 51.3% with moderate and 14.3% with poor knowledge regarding epilepsy. Results of our study also showed that there was a significant association between socioeconomic status and extent of knowledge ($p=0.01$). Similarly, significant association was reported between education and extent of knowledge ($p=0.01$) and it was observed that knowledge decreased with increasing age.

Conclusion: Majority of our public has inadequate knowledge about epilepsy and the contributory factors can be the low literacy level according to our study or due to certain cultural and religious beliefs that need to be evaluated further. It is crucial to educate our society about epilepsy, empowering them to make informed decisions about treatment, without the burden of stigma and misconceptions.

KEYWORDS: Children, Epilepsy, Knowledge

INTRODUCTION

The word epilepsy comes from the root word "Epilambanein", which in Greek, means 'to be seized'.¹ Epilepsy can be defined as presence of a minimum of one unprovoked seizure in a child,

followed by another such episode or clinical and EEG findings that suggest a tendency to have a recurrence of these fits.² A seizure or fit can be defined as a patient experiencing momentary signs or symptoms from excessively abnormal, neuronal activity in the brain.² Epilepsy affects almost 50 million patients worldwide.³ Its prevalence is around 4 to 10/ 1000 people, while the incidence of this disease is around 0.05 to 0.06%.³ Epilepsy is more common in children than in adults; almost 11 million children who are less than 15 years of age develop epilepsy.⁴ In Pakistan, the prevalence of epilepsy is almost 9.99/1000 and this rate is higher in younger population, especially in rural areas.⁵ Epilepsy can be classified into 3 groups viz (1) self-limiting focal epilepsy (2) Generalized epilepsy (3)

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We come across a lot of studies worldwide regarding public awareness towards epilepsy, but the magnitude of problem regarding lack of knowledge, negative or positive attitude and perception towards epilepsy has not been probed in detail in our region and very little published data is available regarding this topic. The magnitude of this problem is immense and an end to it is nowhere in sight. The rationale behind this study is to find out the prevalent knowledge of public attending the tertiary care hospitals in our region, so that we may spread proper awareness. This may increase the likelihood that individuals seek evidence-based medical treatment and counselling, instead of relying upon widespread concepts related to spirituality and quackery, as indicated in previous studies.

METHODOLOGY

This was a descriptive cross-sectional study conducted at the department of pediatrics Madinah Teaching Hospital, Faisalabad in 3 months duration from 01-10-24 to 31-12-24. A total number of 384 individuals were included in the study by non-probability, consecutive sampling, using formula for calculating sample size for KAP studies i.e. $[N=z^2 \times p \times (1-p) / c^2]$, where N= sample size; Z= 1.96 (value at 95% confidence interval; p= prevalence of primary indicator (50% as anticipated for good knowledge from the reference study); c= standard error 0.05.⁷

The study was conducted after obtaining ethical approval through letter number TUF/UMDC /DME/23/24 dated 30th August 2024, along with informed consent from all participants. Parents, guardians and the attendants aged 20-60 years from both genders accompanying or visiting patients in the department of pediatrics with any disease apart from fits were included in the study, and the individuals who themselves belonged to healthcare fields were excluded from the study. Further the exclusion criteria were extended to the parents, guardians and attendants who had been diagnosed

with epilepsy or any mental illness leading to behavioral issues as well as parents of epileptic patients in order to minimize bias. Demographic variables included age, gender, residential area, educational status, and socioeconomic status, while the primary study variable was knowledge regarding epilepsy.

Data was collected by conducting interviews according to the questionnaire comprising of 9 questions and was entered into SPSS version 22.0 software for analysis. Descriptive statistics were applied to age. Frequencies and percentages were checked for gender, socioeconomic status (stratified according to lower, lower middle and upper middle class) and educational level. The questionnaire was designed to evaluate knowledge variable. Each question had 3 options i.e., yes, no and I don't know, in the proforma.

For the nine knowledge-based questions, each correct answer was assigned a score of 1 and was considered as adequate knowledge, whereas incorrect answers and 'I don't know' were given a score of 0 indicating lack of knowledge. Afterwards the points were added and a combined score of ≤ 3 was labelled as "poor knowledge", 4-6 as "moderate knowledge" and 7-9 as "good knowledge". This questionnaire was then piloted in 15 subjects at department of pediatrics Madinah Teaching Hospital and checked for clarity and coherence.

Chi square analysis was conducted to compare knowledge against education level and socioeconomic status. Regression analysis was applied to compare age with the extent of knowledge. A 95% confidence interval was assumed and p value of less than 0.05 considered statistically significant.

RESULTS

In our study (n=384) maximum number of the participants belonged to the age range 20-30 years (n=191, 49.7%). Thirteen percent of the sample (n=50) comprised of males while the remaining 87% were females (table I). The possible reason

for such a large number of females in our study might be because in pediatric ward, mothers or female attendants are usually allowed to stay with the patient. Most of the respondents hailed from urban areas and lower-middle socioeconomic class as shown in (table I).

Demographic feature		Number (Percentage)
Gender	Male	50 (13%)
	Female	334 (87%)
Literacy status	Illiterate	114 (29.7%)
	Primary/secondary	163 (42.4%)
	Graduation	83 (21.6%)
	Post-graduation	24 (6.3%)
Residence	Rural	140 (36.5%)
	Urban	244 (63.5%)
Socioeconomic status	Lower	126 (32.8%)
	Lower middle	230 (59.90%)
	Upper middle	28 (7.30%)

Table I shows the distribution of educational status among the 384 participants, categorized as illiterate, primary and secondary education, higher secondary, graduate, and postgraduate. Most had gained knowledge via adults in the family as a source of information (85.4%), print media (3.10%), healthcare professionals (1.8%) and some were unsure. Those with a monthly income of <10,000 Rs were classified as lower class; monthly income of 10,000 to 50,000 Rs as lower middle and >50,000 Rs as upper middle class.

Table II explains the detailed responses to questions pertaining to knowledge regarding epilepsy. These were combined (according to scores) to calculate percentage of extent of knowledge (Figure I). Association of the extent of knowledge with socioeconomic status and

education were analyzed via chi square tests (Table III). There was a significant association between socioeconomic status and extent of knowledge ($p=0.01$). Similarly, significant association was reported between education and extent of knowledge ($p=0.01$).

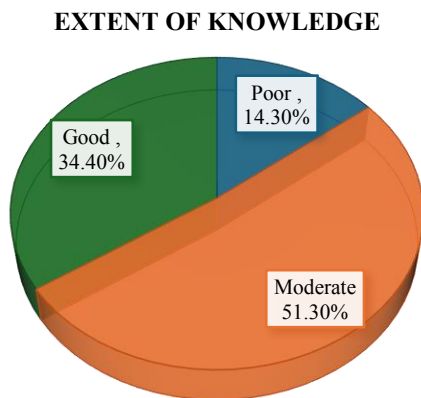
Information inquired	Adequate knowledge	No knowledge
Have you heard or read about epilepsy?	94.3%	5.7%
Is it a form of mental illness?	21.4%	78.6%
Is it associated with supernatural powers?	61.7%	38.3%
Can it affect any age group?	75%	25%
Is it contagious?	64.1%	35.9%
Is epilepsy medically treatable?	81.8%	18.2%
Is epilepsy spiritually treatable?	38.3%	61.7%
Is it caused due to possession by jinns?	69%	31%
Are there different types of epilepsy?	40.4%	59.6%

Linear regression was applied between age and extent of knowledge. No significant association was found ($p=0.080$), however the beta coefficients showed that a negative correlation existed between them, indicating that knowledge decreased with increasing age (e.g., age and knowledge -0.09).

Table III: Association of extent of knowledge with socioeconomic status and education

Variable		Extent of Knowledge			P Value
		Poor	Moderate	Good	
Socioeconomic status	Lower	23.8%	53.2%	23%	0.01
	Lower Middle	10%	51.3%	38.7%	
	Upper Middle	7.1%	42.9%	50%	
Education	Illiterate	23.7%	51.7%	24.6%	0.01
	Primary / Secondary	14.7%	55.2%	30.1%	
	Intermediate / Graduate	4.8%	45.8%	49.4%	
	Post Grad	0%	41.7%	58.3%	

*p value < 0.05 is considered significant

Figure I: Extent of Knowledge of People towards Epilepsy

DISCUSSION

Epilepsy is associated with a lot of taboo and stigma in the society worldwide and people with epilepsy face isolation and discrimination.⁸ This attitude towards epileptics is influenced by the limited knowledge and misconceptions about the condition, especially in underdeveloped and developing countries.⁸ The negative beliefs and limited knowledge was not only found among general population but also among health care professionals of certain regions; media also plays an important part in further consolidating these false beliefs due to negative reporting and misinterpretations.⁹ A study conducted in Tanzania showed that 97.7% people believed that epilepsy was caused by the witchcraft and evil spirits and 90.6% people thought it was contagious.¹⁰ Most of the people opted for traditional healing methods first, later on shifting to proper antiepileptic drugs but that too with poor compliance.¹⁰ Another such study conducted in Saudi Arabia showed that the percentage for low, intermediate and high knowledge regarding epilepsy among respondents was 23.2%, 51.6% and 25.2% respectively.¹¹ In addition, 15.7% people associated it with evil spirits and 19.9% with mental disorders; 46% preferred spiritual treatment over antiepileptic drugs.¹¹ A majority of people also showed negative attitudes towards marriage, employment and interaction with epileptic children.¹¹ A study conducted in

Pakistan showed that 36.7% people thought it was a psychiatric disorder, 51.76% thought it was due to jinns and 12.8% thought it was due to a curse from God.¹² Few among the study population (41.4%) thought it could be cured, while majority of the people resorted to traditional healing methods and spiritual healers for its cure.¹²

Childhood epilepsy is a chronic disorder and due to its signs and symptoms, there is a lot of stigmatization associated with this condition.¹³ If we take into account the knowledge and attitude of our general population towards epilepsy, there is still a large gap of correct information about this clinical syndrome.¹⁴ In our present study, when we evaluated the level of knowledge and their resource about this topic, 94.3% of respondents had heard about epilepsy and majority of these people got to know about it from their elders. A total of 78.6% respondents thought it was a mental illness; 38.3% associated it with supernatural powers; 35.9% considered it as contagious; 81.8% thought it was medically treatable; 61.7% thought it was spiritually treatable; 31% said it was due to possession by jinns. That clearly depicts the picture of inadequate knowledge of the common man regarding epilepsy as many people correlate the disease with supernatural powers and believe in spiritual treatment. These myths and false beliefs are among the major contributory factors towards inadequate treatment of the disease.

In comparison to the studies done in various regions of the world, including some developing and underdeveloped countries, we found some of the statistics similar to our study, like the number of people who had heard about the disease (81.1%); people considering it as medically treatable (80.8%) and associating it with supernatural powers (39%).^{15,16,17} However, further probing when compared, depicted a wide gap of knowledge in our region with rest of the world. Beliefs like epilepsy being considered a mental illness was a lot less in other studies (27.2%) as compared to ours¹⁶. Only 1.8% people in a study conducted by Alharthi AS et al. considered it as contagious.¹⁶ The number

of people who thought the treatment for it was spiritual and that it was due to possession by jinns was also significantly lower in these comparable studies viz 32.4% and 3.8%.¹⁸ Another study showed that 26.7% people considered demon possession as a cause of epilepsy.¹⁹

This difference of basic knowledge and misconceptions about epilepsy shows that the problem is deeply rooted in our region and hence requires more attention. The medical and social media teams can play a vital role to create awareness in this regard. The understanding of our general population can be improved via appropriate educational programs, involving healthcare professionals and media, especially in our rural areas. Further studies and surveys must be conducted to explore more factors responsible for such false and firm beliefs.

Overall, our study population had an average knowledge regarding epilepsy, 34.4% with good; 51.3% with moderate and 14.3% with poor knowledge regarding epilepsy. The negative attitudes and wrong perceptions need to be pinpointed and addressed for adequate management of epileptic patients and their families. There was a statistically significant association of knowledge with education and socioeconomic status (p value ≤ 0.01). More educated people and those belonging to upper middle class had better understanding of the disease.

CONCLUSION

Misconceptions about childhood epilepsy remain a major barrier to timely and appropriate care, largely driven by socio-cultural stigma and inadequate awareness. Our findings highlight the need for targeted educational interventions at the community level to improve understanding and reduce stigma and improve outcomes for children with epilepsy.

Limitations: This study had some key limitations including a single hospital-based sampling, cross sectional design and lack of a proper validated

questionnaire. There may be a possibility of recall bias in the study.

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