

Knowledge, Attitude and Practice about Epilepsy among Attendants of Epilepsy Patients in Bangladesh: A Hospital Based Study

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Abstract

Background: Knowledge and positive attitudes are required for attendants of People With Epilepsy (PWE) to allow them to play their roles efficiently. Knowledge, Attitude and Practice (KAP) study among attendants of PWE was limited in Bangladesh. The study aimed to find KAP of epilepsy among attendants of PWE in a tertiary health center in Bangladesh.

Materials and methods: Three hundred and ninety persons accompanying visited or admitted diagnosed cases of epilepsy in different Outpatient and Inpatient Departments of Chittagong Medical College Hospital, Chattogram, Bangladesh, were selected and interviewed with a structured questionnaire.

Results: The median age of the respondents was 36 years (Range: 18-78 years), with male to female ratio of 1:1.32. The majority (66.2%) were from rural areas, and only 15.6% had educational qualifications above college level. Overall, 19.7% were knowledgeable (Having fair to good knowledge) about epilepsy, 14.1% had a positive attitude, and 64.9% observed safe practices related to epilepsy. They mostly failed to underline the physical causes of epilepsy, accepted possession as a cause and thought that epilepsy is contagious. Most of them believed that the onset of an epileptic seizure in a spouse is a sufficient reason for divorce. Only 6.7% of the respondents knew how to provide first aid during a seizure attack in the proper way, and 36.2% preferred traditional medicine or spiritual healing for the treatment of epilepsy.

Conclusions: The present study revealed poor KAP for epilepsy, which justifies a more structured grassroots-level educational program to raise awareness about different aspects of epilepsy.

Key words: Attendants; Attitude; Epilepsy; Knowledge; Practice.

Introduction

Globally, epilepsy affects approximately 70 million people of all ages.¹ Epilepsy is responsible for a 1% contribution to the global burden of diseases. Eighty percent of 50 million PWEs reside in developing countries.^{2,3} Although no national statistics are available about the prevalence of epilepsy, it is estimated that at least 1.5–2.0 million people have epilepsy in Bangladesh, i.e. about 10-12 per 1000 people and primarily expected in the most active age of life. The prevalence of epilepsy is slightly high in Bangladesh as compared to other countries.^{4,5}

Myths and misconceptions about epilepsy are deeply rooted and have resulted in considerable societal stigma and discrimination.⁶ Individuals with epilepsy may suffer from psychological issues such as depression, anxiety, and psychosis.⁷ Living with a PWE will provide some challenges, particularly at home. Studies have reported that relatives of PWE have an increased risk of anxiety.⁸ Epilepsy can burden the PWE and their family members by decreasing quality of life and productivity.⁹ Epilepsy-related KAP are essential qualities for relatives of PWE to play their role effectively.¹⁰ Studies have demonstrated that PWE and their caregivers do not have adequate basic knowledge about epilepsy, including seizure precipitants, types of seizures, and side effects of medications.¹¹ In this context, misunderstandings and misinformation should be recognized and corrected for optimal care. Despite this, there is a scarcity of studies on the information needs of caregivers of PWE. Access to and experience of epilepsy services is vital from the perspective of the person caring for PWE and needs information to carry out their caring role effectively.¹²

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Submitted on ☐ 12.11.2023

Accepted on ☐ 03.02.2024

In Bangladesh, studies regarding knowledge of PWE and their relatives about epilepsy were lacking. To delineate the magnitude and scope of this problem, the present study was conducted to assess the KAP about epilepsy among attendants of PWE in Bangladesh.

Materials and methods

A cross-sectional study was carried out in Chittagong Medical College Hospital, Chattogram, Bangladesh, from February 2017 to January 2018. Attendants of diagnosed cases of epilepsy admitted or attended to the Neurology, Neurosurgery, Medicine Inpatient and Outpatient Departments were the study participants. Ethical clearance was obtained from the Institutional Ethical Committee. Informed consent was taken from the participants, and measures were taken to maintain data confidentiality.

Relatives or accompanied persons of epilepsy patients aged 18 years and above who attended and observed seizure attacks twice or more and took part in the management were included in the study. Relatives or accompanied persons of epilepsy patients who attended and observed seizure attacks less than twice and did not take part in the management of epilepsy patients were excluded.

A pretested structured questionnaire collected data, which had four parts: Part 1 included questions regarding sociodemographic data. Part - 2 contained 15 questions asked to know the knowledge regarding epilepsy. The Knowledge scale scored 1 for correct answer and 0 for wrong or do not know. The total score on the knowledge scale ranged from 0 to 15 and was classified into three levels as follows: (According to Bloom's cut-off points): Good Knowledge (80-100%) 12-15 scores, Fair Knowledge (60-79%) 9 -11 scores, and Poor Knowledge (less than 60%) 0 - 8 scores. Part -3 included 10 questions to assess the attitude of the respondents toward epilepsy and it was evaluated by using 5-point Likert scale. The total score on the attitude scale ranged from 10 to 50 and was classified into two levels: Positive attitude < 30 scores and Negative attitude ≥ 30 scores. Part 4 had five questions on practices. The practice scale was scored 1 and 0 for positive and negative or inadequate practice, respectively. The total score on practice scale ranged from 0 to 5 and

was classified into three levels as follows: Good practice (80-100%) 4-5 scores, Fair practice (60-79%) 3 scores and poor practice (less than 60%) < 3 scores.

Categorical data were expressed as mean ± SD (Standard Deviation) or median and Interquartile Range (IQR). Frequency (%) was used for qualitative variables. Independent factors associated with good knowledge, positive attitude and good practice were determined by multivariate regression analysis and were expressed as Odds Ratio (OR) at 95% Confidence Interval (CI). Pearson's correlation estimated the correlation between attitude and knowledge, practice and knowledge. $p < 0.05$ was considered as statistical significance. Analyses were done using SPSS Statistics software version 23.0.

Results

A total of 390 attendants of PWE were interviewed to reveal the study objectives during the study period. Their median age was 36 years, ranging from 18-78 years. Age group, gender, education, occupation, and residential location of the respondents are shown in Table I. Seizure duration of the epileptic patients with accompanying persons was <1 year in 43.3% and >5 years in 36.9% of the patients. Primary generalized seizure (48.2%) was the most common, followed by focal with secondarily generalized (45.9%). The majority of the patients (98.4%) with generalized seizures had tonic-clonic patterns.

Table I Sociodemographic characteristics of the respondents (n=390)

Variables	Frequency (n)	Percentage (%)
Age in years		
≤25 years	73	18.7
26-36 years	126	32.3
37-47 years	93	23.8
≥48 years	98	25.1
Sex		
Male	168	43.1
Female	222	56.9
Education		
Illiterate to primary	156	40.0
Secondary to HSC	173	44.4
Graduate and above	61	15.6
Occupation		
Housewife	193	49.5
Service holder & retired	54	13.8
Farmer & day laborer	28	7.2
Business & others ^a	115	29.5
Residence		
Urban area	132	33.8
Rural area	258	66.2

Data are expressed as number (%) or median (Interquartile range, IQR) as appropriate.

^a: Others includes student, unemployed.

When asked about which part of the body is affected by epilepsy, the majority of participants (282; 72.3%) answered that they don't know. Only 80 (20.5%) participants knew that epilepsy is a brain disorder. 43 (11%) said that epilepsy is an infectious disease, 48 (12.3%) said that trauma to the brain is a cause of epilepsy, and 29 (7.4%) said that the cause is unknown. Of the 390 responders, 158 (40.5%) believed epilepsy to be demonic possession or of supernatural origin. When the respondents were asked about the common symptoms of epilepsy, 375 (96.2%) said repeated jerky movements of part or whole body as a symptom, 360 (92.3%) said the loss of consciousness as a symptom, 238 (61%) recognized eye rolls upward and head turn to one side as symptom and 333 (85.4%) said tongue biting, involuntary bladder and bowel movement as a symptom of epilepsy. In terms of knowledge about trigger factors for repeated seizures, the responses were as follows: sleep deprivation (69.7%), missed a dose of AED (69.7%), watching TV for a long time (11%), and inter-current infections (16.4%). 379 (97.2%) respondents knew that PWE needed to take medicine regularly for seizure control. The mean knowledge score was 6.69 ± 2.08 (Range: 2 to 13). Figure 1 shows the overall knowledge level of the respondents.

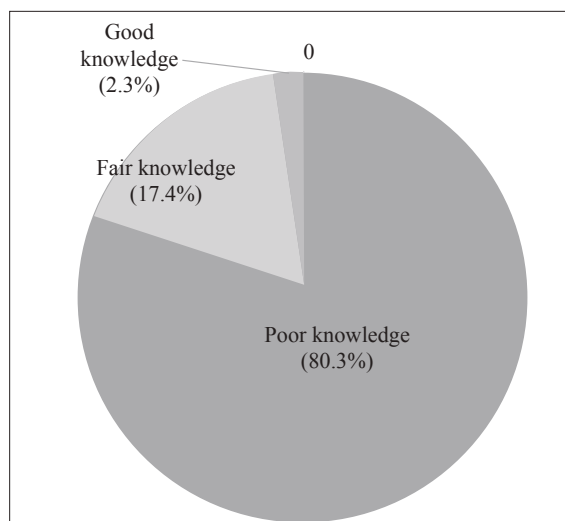


Figure 1 Respondents' level of epilepsy related knowledge

The majority of responders, 290 (74.4%), believed that children with epilepsy had a higher incidence of psychosis than normal children. Two hundred and thirty-nine (61.3%) of the 390 respondents said the onset of epileptic seizure in a spouse is a sufficient reason for divorce. 268 (68.7%) believed PWE have lower intelligence than other people. 288 (73.9%) of respondents thought that PWE is insane, and about half of the respondents believed that epilepsy is a punishment for sins or the consequence of ancestors' sins, or is the appearance of Jinn in human/demonic possession. The mean score for attitude was 35.31 ± 5.37 (range: 11 to 43). The attitude status of the respondents is shown in Figure 2.

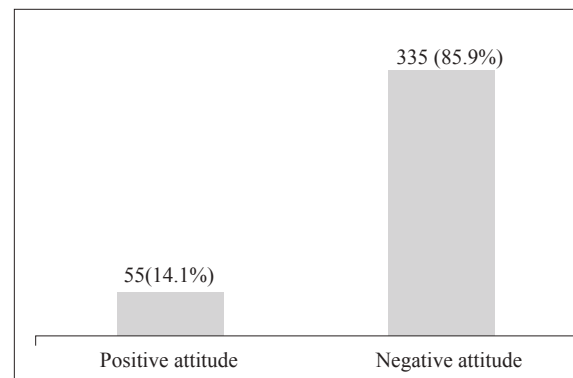


Figure 2 Respondents' attitude towards PWE

About 49% persons believe that allopathic medications are effective in the treatment of epilepsy. Traditional medicine (13.6%) and spiritual healing (22.6%) were also believed to be effective in the treatment of epilepsy. Regarding first aid treatment, about 86% of attendants manage seizure attacks in improper ways. Of them, 59.6% would put leather on the nose, 23.1% would call a doctor for help, and 11.6% would insert a spoon or gag in the mouth of the patient. However, 5.6% would sprinkle the urine of animals on their face. About 60% would prefer to send the patient to a hospital, and 14.4% seek traditional healers when the seizure attack continues. However, 6.9% would wait while the seizure attack continues. The mean score for practice was 3 ± 0.98 (Range: 1-5). The practice level of the respondents is shown in Figure 3.



Figure 3 Respondents' practice towards an epileptic attack

Multivariate analysis shows that respondents with a higher educational status and respondents with patients who had epilepsy for ≥ 1 year had good knowledge of epilepsy. Age, sex, education, occupation, and area of living of the respondents were not significantly associated with attitudes towards epilepsy. Respondents' educational status" and "duration of epilepsy of the person with epilepsy" persist as independent predictive factors for good practice of the respondents to manage a patient with epilepsy (Table II).

Table II Factors associated with good knowledge, positive attitude and good practice on epilepsy

Variables	Good knowledge		Positive attitude		Good practice	
	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value
Age						
<25 years	1		1		1	
26-36 years	0.84 (0.26-2.76)	0.778	0.69 (0.18-2.61)	0.588	1.92 (0.91-4.05)	0.087
37-47 years	3.38 (0.96-11.91)	0.058	1.61 (0.36-7.23)	0.534	1.66 (0.75-3.66)	0.211
>47 years	1.26 (0.33-4.86)	0.74	0.67 (0.13-3.39)	0.632	1.30 (0.59-2.89)	0.515
Sex						
Female	1		1		1	
Male	0.33 (0.07-1.46)	0.142	0.12 (0.02-1.60)	0.115	0.33 (0.11-1.05)	0.061
Occupation						
Farmer & laborer	1		1		1	
Service	0.81 (0.12-5.54)	0.830	0.46 (0.04-5.83)	0.549	2.21 (0.75-6.92)	0.174
Housewife	0.201 (0.02-2.02)	0.173	0.03 (0.01-1.15)	0.123	0.75 (0.18-3.11)	0.694
Business & other	0.602 (0.09-3.92)	0.596	0.19 (0.02-2.40)	0.199	1.64 (0.63-4.32)	0.311
Residence						
Rural	1		1		1	
Urban	1.38 (0.63-3.02)	0.427	1.44 (0.56-3.68)	0.452	0.89 (0.52-1.50)	0.652
Education						
Illiterate to primary	1		1		1	
Secondary to HSC	4.33 (1.17-14.79)	0.001	4.56 (1.81-15.23)	0.004	2.31 (1.44-3.93)	0.001
Graduate & above	9.74 (3.23-33.73)	<0.001	6.21 (2.33-41.22)	<0.001	2.65 (1.54-3.32)	0.007
Duration of epilepsy						
<1 year	1		1		1	
≥ 1 year	3.57 (1.51-8.41)	0.004	1.62 (0.59-4.25)	0.344	1.89 (1.17-3.04)	0.009

In the present study, a higher score in knowledge level indicates higher knowledge, a higher score in attitude level suggests a negative attitude and a higher score in practice level means good practice in the study. Knowledge was negatively correlated with attitude score, indicating good knowledge was connected with more positive attitudes ($r = -0.623$, $p < 0.001$). Knowledge score was positively correlated with practice score, indicating good knowledge is connected with more good practice ($r = 0.457$, $p < 0.001$).

Discussion

Although most PWEs manage their disease independently, attendants play a vital role in providing first aid during seizure attacks, follow-up, and treatment of patients. Few studies have been done in developing countries on the knowledge and attitudes of attendants of PWE about epilepsy and there was a scarcity of KAP-related research on epilepsy in Bangladesh. The present study showed that attendants of PWE had misconceptions and poor knowledge about epilepsy.

In our research, most of the participants did not know that epilepsy is a brain disorder or believed that it is an infectious disease or contagious. A survey conducted in the Malwa region of India showed that regarding the cause of epilepsy, 64% believe that epilepsy is an organic brain disorder. In comparison, 70% believe that epilepsy is a mental problem. Prevalent misconceptions were that epilepsy results from previous life sins, is contagious and is a hereditary disorder.¹⁴ Our respondents had less information about triggers of epilepsy, which agreed with the findings of Karimi et al.¹⁵

Of the 390 responders, 335 (85.9%) had negative attitudes about PWE. In the present study, the majority (76.5%) of responders believed that children with epilepsy had a higher incidence of psychosis than normal children. 78% of the respondents said the onset of epileptic seizure in a spouse is a sufficient reason for divorce. 68.7% believed PWE have lower intelligence than other people. 73.9% of respondents thought that PWE is insane and about half of the respondents believed that epilepsy is a punishment for sins or the consequence of ancestors' sins, or is the appearance of Jinn in human/demonic possession. The study conducted in the Malwa region of India showed that 75% of people thought epilepsy hinders patients' everyday lives. Almost half of people believe that a person with epilepsy should not marry or may not have normal sexual relations. 32% of persons were against the education of epileptic patients, while 60% believed that epileptic persons should not work.¹⁴

Though all of our study participants provided first aid service to seizure attacks of epileptic patients on at least two occasions, only 6.7% properly provided the care. Many attendants were unfamiliar with the initial procedures for attending to a person during a seizure. The initial practices adopted by some parents were inappropriate, like putting leather on the nose or sprinkling the urine of animals on the face and even inserting a spoon or gag in the mouth of the patient. 49.2% of persons believe that allopathic medications are effective in treating epilepsy. Traditional medicine (13.6%) and spiritual healing (22.6%) were also believed to be effective in treating epilepsy.

Regarding first aid treatment, 60% would prefer to take the patient to the hospital. Mutabazi et al. found that most respondents promptly moved the patient away from immediate danger.¹³ The study by Pal et al. indicated that 57% of persons believed that allopathic medications were influential in treating epilepsy.¹⁴ Holy treatment with worship (20%) and tantric (20%) were also believed to be effective in treating epilepsy. Regarding first aid treatment, 66% would prefer to take the patient to the hospital. However, 50% would sprinkle water on the face, and 23% and 20% would give a bunch of keys in hand or put shoes or onion on the nose of the patient, respectively.

The present study shows that formal 'secondary education and above,' 'age between 34-47 years', being 'male,' and 'living in an urban area' are positively associated with the level of knowledge regarding epilepsy. On the other hand, 'rural dwellers' and 'farmers' or 'day laborers' were negatively related to the level of knowledge about epilepsy. Findings were similar to Tefari et al.¹⁶ However, innumerable factors could be associated with KAP on epilepsy and study results differed in including the factors that positively and negatively affect KAP. The present study had a significant association between attitude and knowledge. This finding was similar to other studies that found good knowledge correlated with more positive attitudes.^{17,18} During patient management, if the concerned physicians consider factors revealed in this study, the treatment outcome of epilepsy patients might be better.

Limitations

The first limitation of this study was its cross-sectional design, which is unable to establish the temporal relationship between the dependent variable and its associated factors. Secondly, since face-to-face interviews collected the data, it might be prone to social acceptability bias, especially in the case of epilepsy stigma. Finally, a small sample size and sampling from a tertiary-level hospital might limit the generalizability of the study results to the community at large.

Conclusion

The level of knowledge of epilepsy among attendants of PWE was low and fraught with misconceptions and gaps with an unfavorable

attitude toward epilepsy and unsafe practices related to epilepsy. Being male, living in an urban area and having an education at or above the college level had a significant association with knowledge of epilepsy among respondents and they are also more likely to have a favorable attitude towards epilepsy. Education above college level, living in an urban area and occupational history of being a housewife had a positive association with good practices related to epilepsy.

Recommendation

Educational and mass awareness programs regarding epilepsy should be strengthened in Bangladesh. A multicentric study with a large representative sample is necessary to find out the actual parameters of KAP about epilepsy in Bangladesh.

Acknowledgement

The authors would like to acknowledge the help of the people who participated in the study.

Contribution of authors

DKDN-Conception, data collection, analysis, drafting & final approval.

RA-Manuscript drafting, interpretation of data, drafting, critical revision & final approval.

SN-Manuscript drafting, data analysis, critical revision & final approval.

RMM-Data collection, analysis, drafting & final approval.

AH-Data collection, analysis, drafting & final approval.

MH-Design, critical revision Data collection, analysis, drafting & final approval.

Disclosure

The authors declared no conflicts of interest.

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