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The pattern of knowledge, attitude, and practice of epilepsy in Bengali-speaking literate epilepsy patients in Kolkata

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ABSTRACT

Background: A good knowledge, attitude, and practice (KAP) are lacking among epilepsy patients and the general public (even literates) across the world. As a result, a treatment gap is generated, and drug-resistant cases rise. **Aims and Objective:** This study aims to understand the misconceptions in KAP in the Eastern Indian Subcontinent among the local literate Bengali population and compare with other parts of India. **Materials and Methods:** A consecutive 104 epilepsy patients were enrolled in Kolkata city in 2017–2018 and interviewed with a validated Bengali KAP questionnaire, and their responses were noted and analyzed. **Results:** About 27% believe that epilepsy is a familial disease, whereas 26% believe that epilepsy is a mental problem. Misconceptions like epilepsy is a result of previous life sin (19.23%), contagious (7.6%) are prevalent. 78% thought epilepsy affects education of a person and 36% said that epilepsy patients cannot be employed. 76% thought that epilepsy creates a hindrance to normal life functioning. 76% believe that a person with epilepsy can have a normal married life, and 86% believe that people with epilepsy can have normal sexual relations. 60% thought that epilepsy patients are discriminated against in society. 89% would sprinkle water on the face, and even 18% would give a bunch of keys to the patient. 98% would allow their child to play with a child with epilepsy. **Conclusion:** We found regional differences in KAP misconceptions among epilepsy patients. The data emerging from this study can be incorporated to plan epilepsy awareness programs and formulate better management strategies.

Key words: Epilepsy knowledge attitude and practice; Bengali; Literate; India; Public health

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INTRODUCTION

Of the 70 million persons with epilepsy (PWE) worldwide, nearly 12 million PWE reside in India, which contributes to nearly one-sixth of the global burden. The overall prevalence (3.0–11.9/1,000 population) and incidence (0.2–0.6/1,000 population/year)[1] data from recent studies in India on the general population are comparable to the rates of high-income countries (HICs) despite marked variations in population characteristics and study methodologies. There is a differential distribution of epilepsy among various sociodemographic and economic groups, with higher rates reported for the male gender, rural population, and low socioeconomic status. A changing pattern in the age-specific occurrence of epilepsy, with a preponderance toward the older age group, is noticed due to sociodemographic and epidemiological transition. Neuroinfections, neurocysticercosis, and neurotrauma, along with birth injuries, have emerged as major risk factors for secondary epilepsy.[2-4] Despite its varied etiology (unknown and known), majority of the epilepsy are manageable.

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Although it has existed for centuries and has been well-known for more than 2,000 years (as described by Hippocrates), it is only in recent years that epilepsy has attracted the attention of the medical community. Consequently, efforts are being made for a better understanding of the disease and also to organize comprehensive services. To organize preventive, promotive, curative, and rehabilitative services for PWE (the public health approach), understanding the burden, distribution, risk factors, and determinants of epilepsy through epidemiological approaches becomes crucial.

The knowledge, attitudes, beliefs, and practices of individuals with epilepsy, their families, and society have a major influence on the recovery and quality of life of PWE. Poor knowledge and attitude towards epilepsy were observed among the general public, school children, and teachers, even though a majority of them had heard or read about epilepsy.[5-11] Even among the primary healthcare doctors, overutilization of EEG, improper prescription of antiepileptic drugs (AEDs), and inadequate skills in the management of AED-resistant epilepsies have been reported.[12] A significant number of the general public in Kerala believed in other traditional medical practices for treating epilepsy.[11] Among the PWE who attended a tertiary hospital, 7.7% reported the additional use of complementary and alternative medicine.[13] Das et al. found that a significant number of patients in India had discontinued epilepsy treatment within 1 year because of poor knowledge regarding the outcomes after discontinuation.[14] In the large population-based studies, Radhakrishnan et al., in Kerala, found that a considerable number of people still believed epilepsy was a form of insanity, while Sureka and Sureka in Rajasthan found that nearly one-fourth of the subjects thought epilepsy was a disease of evil spirits.[5,11]

Even though there has been a shift in the perceived knowledge and attitudes about epilepsy in HICs, the situation is far from satisfactory in many of the low-income countries, including India. There is a need for capacity strengthening of healthcare providers and creating awareness among students, teachers, and other educational institutions, besides the general community. A recent study evaluating the impact of a comprehensive epilepsy education program for school teachers in Chandigarh has highlighted the need for regular workshops to improve and reinforce the knowledge and skills of the teachers about epilepsy.[15] It is equally important to address the secondary treatment gap among those patients who discontinued the initiated treatment. Cost of AEDs, unemployment, frustration, and marital disharmony were found to be the important causes for the secondary treatment gap besides stigma. Das et al., from West Bengal, reported a secondary treatment gap as high as 42.8%.[14] A recent review of medical records from tertiary care hospitals in Karnataka has revealed polytherapy as a major cause for non-compliance with AEDs.[16]

Aims and objectives

We aimed to generate data about the knowledge attitude and practice of epilepsy among the epileptic patients in the ethnic people of Eastern India, so that the data emerging from this study can be incorporated to plan awareness programs and formulate better management strategies to enhance the public understanding of the nature of the disorder and focus on eliminating the negative attitudes toward people with epilepsy. Kolkata is near Bangladesh, a Bengali-speaking country, with a large population of Bengali literate people. Hence, geographically, the results could be implicated there also. We aim to fill the region-specific gap in the epilepsy knowledge, attitude, and practice (KAP) data in our country.

MATERIALS AND METHODS

This is a cross-sectional observational study done on consecutive epilepsy patients attending the neuromedicine OPD and epilepsy clinic of a tertiary-level medical college and hospital in Kolkata, Eastern India. A total of 104 patients were enrolled following the inclusion and exclusion criteria in the years 2017 and 2018 (Institutional Ethics Committee [IEC] certificate no IPGME&R/IEC/2017/170 dated March 27, 2017).

Inclusion criteria

- Male and female epileptic patients in the age group of 19–40 years.
- Patients with epilepsy for more than 2 years.
- Patients who can read, write, and understand the Bengali language.

Exclusion criteria

- illiterate people
- Patients with other neurological disorders (e.g., static encephalopathy, stroke) along with epilepsy.
- Patients with mental subnormality and psychiatric disorder, along with epilepsy.
- Patient with systemic disease along with epilepsy.

We made a set of KAP questionnaire for epilepsy disease from the already published studies on epilepsy KAP in various parts of India,[9,17,18] which were aligned with our research goals. Authors JG and SKS did the translation from English to Bengali. Author JM reviewed both English and Bengali versions and finalized one Bengali draft. Two independent translators PG and SM translated the Bengali

draft back to English. The IEC, with multi-disciplinary expert members, evaluated all versions of the questionnaire with the original one and ensured conceptual equivalence. Author GG administered the Bengali version to ten epilepsy patients to ensure the understanding, clarity, and cultural appropriateness. Finally, IEC approved the study.

After obtaining the required consent, the patients have been provided with the KAP questionnaire. The answer sheets have been collected and analyzed statistically later on. Statistical tools were employed for the evaluation of the findings. A descriptive statistics was done with SPSS software version 22. Patients' demographic parameters (age, gender, education, etc.,) were noted. Patients were asked about various KAP questions. Their responses were noted as "Yes," "No," and "I don't know." The "Yes" responses are noted as positive responses and their percentage was calculated and compared it other similar studies.

RESULTS

In our study, we interviewed one hundred and four people with epilepsy who fulfilled the inclusion and exclusion criteria of our study and tried to assess their KAP of epilepsy. They comprised thirty-three males and seventy-one females. Age ranged from 19 to 40 years. Forty-five people are in the 19–25 years of age group, 43 people are 26–35 years of age group, and the rest 16 people are in the 36–40 years of age group. Twenty-two are unmarried and 77 are married. Eighty-three of them are Hindu, and twenty-two are Muslim by Religion. Thirty-five persons have primary education, forty-eight persons have secondary education, and twenty-one have tertiary education. Forty-four persons are homemakers, fifteen are unemployed, and forty-five are employed. In the employed category, seventeen people are in business, eight are in agriculture, nine are students, seven are in private and public services, and four are laborers. Income-wise, twenty-nine people earn <Rs. 5000, fifty-nine people earn Rs. 5000 – 10000, and sixteen people earn above Rs. 10000/month. By number of seizure attacks, thirty-six people had 0–5 attacks, fifty-seven people had 6–20 attacks, and eleven people had more than 20 attacks in the previous year. The demography is depicted in Table 1, and the response to the KAP questionnaire is summarized in Table 2.

Table 1: Socio-demographic profile of subjects with epilepsy

Parameter	Category	Frequency	Percentage
Age (in years)	19–25	45	43.28
	26–35	43	41.34
	36–40	16	15.38
Sex	Male	33	31.73
	Female	71	68.26
Marital status	Unmarried	27	25.96
	Married	77	74.04
Religion	Muslim	21	20.19
	Hindu	83	79.8
Education	Primary	35	33.64
	Secondary	48	47.8
	Tertiary	21	20.19
Occupation	1. Home Maker		44
	2. Employed	45	43.27
	a. Business	17	16.34
	b. Agriculture	8	7.69
	c. Student	9	8.65
	d. Service	7	6.73
	e. Labourer	4	3.84
	3. Unemployed	15	14.42
Monthly income (rupees)	≤5000	29	27.88
	5000–10000	59	56.73
	≥10000	16	15.38
No. of attacks in last year	0–5	36	34.61
	20-Jun	57	54.8
	>20	11	10.57

Knowledge

The majority of persons (97%) had heard about epilepsy. Regarding the cause of epilepsy, 27% believe that epilepsy is a familial disease, while 26% believe that epilepsy is a mental problem. Misconceptions such as epilepsy is a result of previous life sin (19.23%), contagious (7.6%) are prevalent. Seventy-eight percent thought epilepsy affects education of a person and 64% said that epilepsy patients can be employed.

Attitude

Seventy-six percent thought that epilepsy creates a hindrance to normal life functioning. Seventy-six percent believe that a person with epilepsy can have a normal married life, and 86% believe that people with epilepsy can have normal sexual relations. Eighty percent said they will reveal the epilepsy of their daughter, and 82% of their son before marriage. Sixty percent thought that epilepsy patients are discriminated against in society.

Practice

Regarding first aid treatment, 68% would prefer to take the patient to a hospital. However, 89% would sprinkle water on the face, and even 18% would give a bunch of keys to the patient. Ninety-four percent would allow their child to play with a child with epilepsy.

DISCUSSION

Similar studies have already been done in other parts of India on the KAP of epilepsy. However, India is a big country, and it is often referred to as a subcontinent. Hence, different states have different socioeconomic and cultural backgrounds, which are unique to their population. In a big metropolis like Kolkata, the population is heterogeneous.

Table 2: Response to knowledge attitude and practice of epilepsy questionnaire

S. No	Questions	Yes	No	Don't Know	Positive response percentage
1	Have you heard/read about epilepsy?	101	3	0	97.11
2	Is epilepsy a mental illness?	27	56	21	25.96
3	Is epilepsy known to occur in families?	26	52	26	25
4	Is epilepsy the result of previous life sins	20	77	7	19.23
5	Can epilepsy spread by contact?	8	83	13	7.69
6	Whether Epilepsy create a hindrance in a normal, happy life?	79	19	6	75.96
7	Whether a person with epilepsy marry?	76	17	11	73.08
8	Whether a person with epilepsy have normal sexual relations?	7	89	8	14.43
9	Whether Epilepsy hamper study?	79	13	12	75.96
10	Whether a person with epilepsy be employed?	64	19	21	61.53
11	Should society behave differently with a person with epilepsy?	60	34	10	57.69
12	Would you like to object to playing/studying with an epileptic child?	3	97	4	6.73
13	Can epilepsy be treated by allopathic medicines?	90	5	9	86.53
14	Is Ayurveda treatment an option for epilepsy?	84	7	13	80.76
15	If you see a person with an epileptic fit, what will you do?				
	A. will go to hospital	89	2	13	85.57
	B. will give bunch of keys in hand	23	74	7	22.11
	C. will put some water on his face	97	3	4	97

People from different ethnic and cultural backgrounds reside, who have their own beliefs and values, and attitudes to life. In our study, we have included a subgroup of people attending the outpatient department and epilepsy clinic of a tertiary care medical college and hospital, who can understand spoken and written Bengali (the local language). Hence, we are targeting mainly a section of people who are from the urban and suburban areas around Kolkata and from surrounding rural Bengal who are literate and belong to the Bengali ethnicity, to find their situation regarding the KAP of epilepsy. Epilepsy is not only a disease but also a social problem, and it has its influence on not only the life of the patient but also on their families and society.

The analysis of data conforms to other Indian studies, though regional variation exists due to variation in the composition of rural and urban populations, literacy rate, and other differences in regional attitudes. The patients are, in general, better informed than the general population. There are still certain misconceptions that are found to be prevalent in all studies (Table 3). In all Indian studies, most of the people had heard about epilepsy (94–97%). Epilepsy is a mental disease thought by 26% of people in our study, in the study by Gourie-devi et al. also showed similar results (14.9%),[19] but in other Indian studies, this misconception is much higher (59–74%).[9,17,18] In our study, 25% thought that epilepsy is a familial disease, which is much lower in Gourie-devi's study (3%),[19] but higher in other Indian studies (31–43%).[9,17,18] In our study, 19% thought that epilepsy is caused by previous life sins, which is also much lower in Gourie-devi's study (5.2%),[19] but higher in other Indian studies (11–21%). 7.69% in our study thought that epilepsy is a contagious disease, which is also much less in Gourie-devi's study (0.8%),[19] but higher in other Indian studies (4.7–23%).[9,17,18] 75% of our study population thought that epilepsy is a hindrance to a normal, happy life, which is also similar in other studies (61–72%).[9,17,18] 73% of people in our study opine that a person with epilepsy can marry, and 85.7% thought they can have normal sexual relations. In other Indian studies, 54–90% of people opine positively that PWE can marry, and 7–75% thought that they cannot have a normal sexual relationship.[20] 96% of people thought epilepsy hampers study in other studies, ranging from 18.30% to 72.5%. In our study, 63% thought that PWE can be employed, which is 29–90.8% in other studies. 57% of our participants thought that PWE are discriminated against in society, which is 26.59–56% in other studies.[9,17,18] 6.73% of persons said that they will not allow their child to be with a child who has epilepsy, whereas 5–18.90% in other studies opine similarly. It has also been seen that 80.76% people in our study believe that Ayurvedic treatment is effective in epilepsy, which is much lower in Gourie-devi's study (2.8%),[19] whereas 59–75.8% in others and 97% believe that sprinkling of water is beneficial for the patient during the fits which is 23.2–49.50% in other studies.[9,17,18] Although this is a small study, the data emerging should guide us to plan future studies to find the problems in this population for management of misconceptions and betterment of attitude and practice toward the disease.

If we go through the various studies done in different parts of India during the past 20 years, we see different KAP in the study populations varying due to regional customs, beliefs, and practices. The pouring of water is almost universal in and around Kolkata, which is reflected in almost universal assertion in the questionnaire, which may not be so in other parts of India. Epilepsy runs in families is a notion seen in all the studies except in Gouri-devi. Epilepsy is a mental disease that is negated by 74%

Table 3: Comparison of knowledge, attitude, and practice from various studies in India

S. No	Questions	Kankane et al., Jhanshi-2015 (percentage) (n=400)	Pandian et al., Kerala-2006 (percentage) (n=1213)	Gourie-Devi et al., New Delhi-2010 (percentage) (n=120)	Goel et al., Uttarakhand-2011 (percentage) (n=219)	Current study, Kolkata (percentage) (n=104)
1	Have you heard/read about epilepsy?	94	97.7	94.2	97.6	97.11
2	Is epilepsy a mental illness?	64	59.3	14.2	74.9	25.96
3	Is epilepsy known to occur in families?	43.5	34.1	3.3	31.8	25
4	Is epilepsy the result of previous life sins	21.5	11.2	20.9	5.2	19.23
5	Can epilepsy spread by contact?	23	13.9	0.8	4.7	7.69
6	Whether Epilepsy create a hindrance in a normal, happy life?	61	62.4	-	72.5	75.96
7	Whether a person with epilepsy can marry?	54	58.1	89.2	76.3	73.08
8	A person with epilepsy will not have normal sexual relations.	58	43.2	7.5	75.3	14.43
9	Whether Epilepsy hampers study?	62	40.8	18.3	72.5	75.96
10	Whether a person with epilepsy can be employed?	64	29	90.8	74.4	61.53
11	Whether society should behave differently with a person with epilepsy?	53	45.1	-	26.5	57.69
12	Would you like to object to play/study with an epileptic child?	18.9	13	5	15.6	6.73
13	Can epilepsy be treated by allopathic medicines?	69.5	55.4	91.7	61.10	86.53
14	Is Ayurveda treatment is a option for epilepsy?	58	59	2.5	75.8	80.76
15	If you see a person with an epileptic fit, what will you do?					
	A. Will go to hospital	68	62.3	96.7	49.8	85.57
	B. Will give bunch of keys in hand	25.5	7.5	5.8	1.4	22.11
	C. Will put some water on his face	49.5	23.9	-	23.2	97

of our study population, but most of the other studies have the opposite answer, except Gouri-devi. It has been found that most of the study populations do not believe that epilepsy is caused by previous life's sins or that epilepsy is spread by contact. It is a universal perception that epilepsy hinders a normal, happy life. It hampers study and can be treated by modern medicines, though a substantial population thinks that Ayurvedic medicines are also effective. These regional variations indicate the inhomogeneity of the Indian population regarding their language, socioeconomic status, urban, suburban, or rural location, educational status, and cultural diversity. These diversities determine the ultimate outlook of the disease, its treatment and outcome, and its effect on the person concerned, his or her family, and society.

Strength of the study

This study fills the gap in the region-specific epilepsy KAP data in our country, India. This study also noted that literate people, too, have many misconceptions about epilepsy. This necessitates increasing epilepsy awareness programs targeting even the literate people and other members of the community to reduce the huge social and economic burden on our country.

Limitation of study

This is a hospital-based cross-sectional study of a population for whom normative data are not known, so the results cannot be extrapolated to the community. The small sample size is another limitation.

CONCLUSION

The present study provides valuable insights into the knowledge, attitudes, and practices (KAP) related to epilepsy among literate Bengali-speaking patients attending a tertiary care center in Kolkata. Despite a generally high level of awareness and better-informed status compared to the general population, significant misconceptions persist. A substantial proportion of respondents incorrectly associated epilepsy with mental illness, familial inheritance, or believed it resulted from past-life sins or contagiousness. However, these misconceptions were generally lower compared to other Indian regions, highlighting unique regional variations.

The perception of epilepsy as a social hindrance remains prevalent, significantly impacting educational pursuits,

employment opportunities, marital prospects, and social interactions. Notably, a majority of respondents believed epilepsy hampers normal life activities, but a positive outlook was observed regarding marriage and sexual relationships. This indicates evolving attitudes among the literate urban and suburban populations.

Traditional practices, such as the widespread belief in the effectiveness of Ayurvedic treatment and the universal practice of sprinkling water during seizures, underscore deeply rooted cultural practices and beliefs. These practices require targeted educational interventions to enhance awareness of evidence-based management.

Regional disparities reflected in our findings emphasize India's sociocultural diversity, influencing epilepsy perceptions and practices. Future research must address these diversities comprehensively, incorporating larger, representative samples to facilitate culturally appropriate health education and intervention programs. Tailored educational initiatives aimed at reducing stigma and misconceptions will contribute significantly towards improving patient quality of life, societal integration, and overall management outcomes for epilepsy in Bengal and similar communities.

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