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Original Research Article

Factors associated with perceived stigma among adolescents with epilepsy attending a tertiary care hospital

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ABSTRACT

Background: Epilepsy is a chronic neurological disorder associated with substantial psychosocial burden and stigma, particularly among adolescents. Understanding the factors contributing to perceived stigma is essential to improve their quality of life. This study aimed to assess the level of perceived stigma and identify associated factors among adolescents with epilepsy.

Methods: This cross-sectional study was conducted in the Departments of Paediatric Neurology and Neurology at the National Institute of Neurosciences and Hospital, Dhaka, Bangladesh from January 2024 to December 2024. The study population comprised 206 adolescent patients aged 10 to 19 years diagnosed with epilepsy for more than one year and attended the outpatient departments during the study period.

Results: The mean age of participants was 14.9±2.6 years, with 64.1% males (male-to-female ratio 1.8:1). Generalized seizures were most common (40.8%). The mean KSSE score was 8.9±4.9, with 33% experiencing high perceived stigma. Commonly reported experiences included feeling treated as outcasts (89.8%), mistreatment (78.2%), and discrimination (71.4%). Factors significantly associated with high stigma included female gender (OR=3.73), family history of epilepsy (OR=3.09), and higher seizure frequency in the last three months (OR=1.14). Disclosure of epilepsy reduced the likelihood of high stigma (OR=0.46).

Conclusions: One-third of adolescents with epilepsy experienced high perceived stigma, which was significantly associated with gender, family history, seizure frequency, and disclosure status. Targeted interventions addressing stigma and promoting disclosure may improve psychosocial outcomes in this population.

Keywords: Epilepsy, Adolescents, Perceived stigma, Kilifi stigma scale, Seizure frequency

INTRODUCTION

Epilepsy is a chronic neurological disorder defined by the occurrence of at least two unprovoked seizures more than 24 hours apart, or by a single unprovoked seizure when the risk of recurrence is known to be high (>60%), such as in reflex seizures or specific epilepsy syndromes.[1] Globally, an estimated 50 million people live with epilepsy, with more than 80% residing in developing countries.[2] Although prevalence varies widely, the worldwide estimate is approximately 10 per 1,000 population.[3] In developed countries, the annual incidence ranges between 40 and 70 per 100,000 persons, with higher rates observed in young children and older adults.[4] A recent review of epilepsy from 23 Asian countries, including Bangladesh, reported lifetime prevalence rates ranging from 1.5 to 14.0 per 1,000 population.[5] In Bangladesh, a nationwide population-based cross-sectional survey found an overall epilepsy prevalence of 8.4 per 1,000 across all ages 8.2 among children (1 month to <18 years) and 8.5 among adults. Alarmingly, one-quarter (24.1%) of participants held false beliefs regarding the causes of epilepsy, and 58% believed that epilepsy improves with allopathic treatment.[6]

Throughout history, epilepsy has often been misunderstood and culturally devalued, contributing to persistent stigma and psychosocial burden among affected individuals in both developed and developing settings.[7] The psychological and emotional impact can be profound, especially among those with uncontrolled seizures. Unlike many other neurological disorders, epilepsy is associated with a particularly high level of stigma, which is especially problematic among adolescents. In recognition of this global challenge, the World Health Organization's global campaign against epilepsy (GCAE) "out of the shadows" initiative emphasizes the need to understand and reduce epilepsy-associated stigma.[8] Stigma represents an attribute that discredits an individual and undermines social identity, while perceived stigma refers to a person's subjective experience of discrimination or unfair treatment due to their condition.[9] Among adolescents, such stigma has been linked to low self-esteem, diminished quality of life, neurocognitive difficulties, poor academic performance, reduced healthcare-seeking behavior, and limitations in social interactions.[10-12]

A multi-country study in Europe reported that 51% of individuals with epilepsy experienced stigma, with 18% reporting high levels of stigmatization. In contrast, studies from low- and middle-income countries (LMICs) have documented perceived stigma rates ranging from 31% to 69%.[12] These disparities may reflect differences in poverty levels, access to healthcare, and prevailing cultural or traditional beliefs surrounding epilepsy. Moreover, many stigma measurement tools were developed in Western or middle-income contexts and may not adequately capture culturally grounded perceptions of stigma in low-income settings. To address this gap, the Kilifi stigma scale for epilepsy (KSSE) was developed and validated in Kilifi, Kenya. A cross-sectional study of 673 individuals with epilepsy using the KSSE found that 33% reported feeling stigmatized.[13]

Various factors have been associated with perceived stigma in people with epilepsy, including age at seizure onset, socioeconomic status, type and number of antiepileptic medications, illness duration, seizure frequency and control, and beliefs about epilepsy being contagious.[14-16] Some studies have further noted that individuals who experience seizure-related injuries or whose epilepsy becomes known within the community tend to report higher levels of stigma, while other research shows no significant association with age, gender, seizure type, or frequency.[17,18]

Despite these insights, data on stigma among adolescents in developing countries remain limited, even though these regions bear the highest burden of epilepsy. Understanding the extent of perceived stigma and identifying its associated factors among adolescents in the study center is therefore crucial.

Therefore, in this study, we aimed to assess the level of perceived stigma and identify associated factors among adolescents with epilepsy attending a tertiary care hospital in Dhaka, Bangladesh.

METHODS

This cross-sectional study was conducted in the Departments of Paediatric Neurology and Neurology at the National Institute of Neurosciences and Hospital, Dhaka, Bangladesh from January 2024 to December 2024. The study population comprised 206 adolescent patients aged 10 to 19 years who had been diagnosed with epilepsy for more than one year and attended the outpatient departments during the study period.

These were the following criteria for eligibility as study participants.

Inclusion criteria

Adolescents aged 10–19 years, and adolescents with a clinical diagnosis of epilepsy, as defined by the International League Against Epilepsy (ILAE), for more than one year were included.

Exclusion criteria

Adolescents with any neurodevelopmental disorders, including cerebral palsy, autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), metabolic disorders, or global developmental delay, and adolescents with any chronic systemic conditions such as asthma, hypertension, chronic renal failure, congenital heart disease, endocrine disorders, or other long-standing medical illnesses were excluded.

Data collection procedure

Adolescents aged 10–19 years with epilepsy, for more than one year and attending the outpatient department during the study period, were considered eligible. After screening based on the inclusion and exclusion criteria, participants and/or their legal guardians were counseled about the purpose of the study and informed of their right to withdraw at any stage. Written informed consent was obtained from adolescents aged 18 years and above, and from parents or caregivers for participants younger than 18 years. Data were collected through face-to-face interviews using a structured questionnaire that included demographic information, clinical details, epilepsy disclosure, and beliefs about the causes of epilepsy. When an adolescent with epilepsy was unable to respond, the parent or caregiver was interviewed on their behalf. All interviews were conducted in a private, secure room to ensure confidentiality, and each participant was assigned a unique identification number. Perceived stigma was assessed using the Kilifi stigma scale for epilepsy (KSSE). The original English version was translated into Bengali by a qualified translator, piloted among 10 participants, and validated before use. Stigma scores were calculated according to the operational definition. All case record forms were carefully reviewed to identify and correct any errors, ensuring quality and accuracy of the data.

Statistical analysis

Data were collected using a semi-structured questionnaire and the KSSE. Quantitative data were expressed as mean and standard deviation, and qualitative data were expressed as frequency distributions and percentages. Associations between perceived stigma and clinical factors were assessed using chi-square tests. A p value <0.05 was considered significant. Stigma scores were categorized based on the KSSE, with scores above the 66th percentile classified as high perceived stigma and scores at or below the 66th percentile as low perceived stigma. Comparisons of mean stigma scores across clinical variables were performed to identify potential predictors of perceived stigma. Stepwise multiple regression analysis was then conducted to determine the most significant factors influencing high levels of perceived stigma among adolescents with epilepsy. The data were analyzed using statistical package for the social sciences (SPSS) 26. This study was ethically approved by the Institutional Review Committee of National Institute of Neurosciences and Hospital.

RESULTS

This cross-sectional study was conducted in the Departments of Paediatric Neurology and Neurology at the National Institute of Neurosciences and Hospital, Sher-E-Bangla Nagar, Dhaka, from January to December 2024.

A total of 350 adolescents aged 10 to 19 years who had been living with epilepsy for at least one year were initially approached for interviews. After applying the inclusion and exclusion criteria, 206 participants were ultimately enrolled in the study.

Table 1 shows that the majority of the adolescents were in the 15–19-year age group, accounting for 61.2% of the study population, while 38.8% were between 10 and 14 years of age. The mean age of the participants was 14.9±2.6 years.

Table 1: Distribution of the participants according to age group (n=206).

Age group (years)	Frequency (N)	Percentage (%)
10 to 14	80	38.8
15 to 19	126	61.2
Mean±SD	14.9±2.6	

The pie chart illustrates that among the 206 participants, 132 (64.1%) were male and 74 (35.9%) were female. The male-to-female ratio was 1.8:1 in this study (Figure 1).

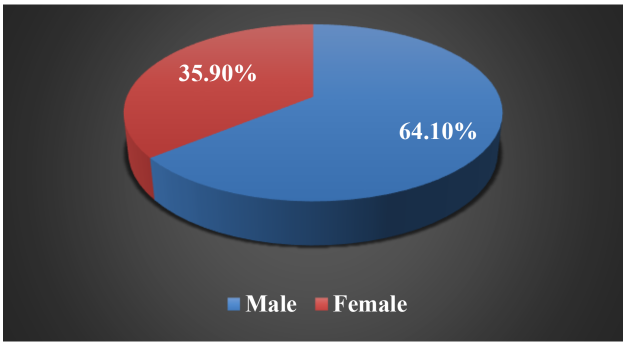

Figure 1: Distribution of the participants according to gender (n=206).

Table 2 summarizes the clinical characteristics of the participants. A family history of epilepsy was present in 28.6% of cases, and 57.8% had disclosed their condition to others. More than half of the adolescents (53.9%) perceived epilepsy as a disease, while 46.1% attributed seizures to supernatural causes. Generalized seizures were the most common type (40.8%), followed by focal seizures (26.7%) and focal to bilateral tonic–clonic seizures (26.7%); 5.8% were diagnosed with a defined epilepsy syndrome. In terms of seizure control, 35.9% reported one or no seizures in the preceding three months, whereas 64.1% experienced more frequent episodes. The average number of seizures within the last three months was 3.1±4.0. The mean age at seizure onset was 9.9±4.1 years, and the mean duration of epilepsy was 5.3±3.8 years.

Figure 2 presents the distribution of stigma scores, which shows a right-skewed pattern. Most participants reported mild to moderate levels of perceived stigma, while a smaller proportion experienced high stigma scores. Overall, the mean stigma score was 8.87 with a standard deviation of 4.9.

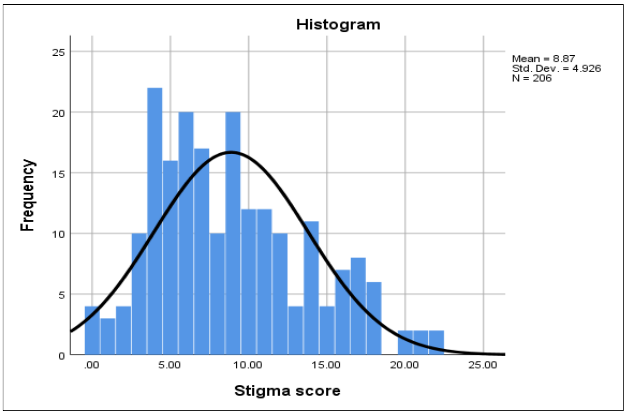

Figure 2: Histogram showing stigma score among the study participants according to Kilifi stigma scale for epilepsy (n=206).

Table 2: Distribution of the participants according to disease status (n=206).

Variables	Frequency (N)	Percentage (%)
Family history of epilepsy	59	28.6
Discloser of epilepsy	119	57.8
Belief about epilepsy		
Disease	111	53.9
Supernatural	95	46.1
Types of seizure		
Generalized	84	40.8
Focal	55	26.7
Focal to bilateral tonic clonic	55	26.7
Epilepsy syndrome	12	5.8
Seizure control		
1 or no seizure in last 3 months	74	35.9
More than 1 seizure in last 3 months	132	64.1
Frequency of seizure in last 3 months (mean±SD)	3.1±4	
Age of onset seizure in years (mean±SD)	9.9±4.1	
Duration of seizure in years (mean±SD)	5.3±3.8	

According to the 66th percentile of the KSSE, scores above 10 were classified as high perceived stigma, while scores of 10 or below were considered low perceived stigma. As shown in Table 3, 33% of participants experienced high perceived stigma, whereas 67% reported low perceived stigma.

Table 3: Proportion of perceived stigma among the study participants according to Kilifi stigma scale for epilepsy (n=206).

Perceived stigma	Frequency (N)	Percentage (%)
High	68	33
Low	138	67

Table 4 presents the relationship between various disease-related factors and perceived stigma among adolescents with epilepsy. High perceived stigma was reported by 33% (n=68) of participants, while 67% (n=138) had low perceived stigma. Significant associations were observed for family history of epilepsy (p=0.014), disclosure of epilepsy (p=0.009), difficulty in taking antiepileptic drugs daily (p=0.026), frequency of seizures in the last three months (p=0.001), age at seizure onset (p=0.005), and duration of epilepsy (p<0.001). Other factors, including belief about epilepsy, type of seizure, seizure control, difficulty attending follow-up, and injury during seizures, were not significantly associated with perceived stigma.

Table 5 summarizes the risk factors for high perceived stigma among adolescents with epilepsy. Females had 3.73 times higher odds of experiencing high perceived stigma compared to males. A positive family history of epilepsy was also associated with an increased likelihood of stigma (OR=3.09; 95% CI: 1.38–6.91; p=0.006). In contrast, disclosure of epilepsy emerged as a protective factor, reducing the odds of perceived stigma (OR=0.46; 95% CI: 0.22–0.96; p=0.037). Additionally, higher seizure frequency in the last three months was significantly associated with high perceived stigma (OR=1.14; 95% CI: 1.04–1.25; p=0.003).

Table 4: Factors associated with level of perceived stigma (n=206).

Factors	Level of perceived stigma		P value*
	High (n=68), N (%)	Low (n=138), N (%)	
Age group (years)			
10-14	25 (36.8)	55 (39.9)	0.669
15-19	43 (63.2)	83 (60.1)	
Gender			
Male	30 (44.1)	102 (73.9)	<0.001
Female	38 (55.9)	36 (26.1)	
Family history of epilepsy	12 (17.6)	47 (34.1)	0.014
Disclosure of epilepsy	48 (70.6)	71 (51.4)	0.009
Belief about epilepsy			
Disease	36 (52.9)	75 (54.3)	0.849
Supernatural	32 (47.1)	63 (45.7)	
Types of seizure			
Generalized	33 (48.5)	51 (37)	0.288
Focal	15 (22.1)	40 (29)	
Focal to bilateral tonic clonic	18 (26.5)	37 (26.8)	
Epilepsy syndrome (if defined)	2 (2.9)	10 (7.2)	

Continued.

Factors	**Level of perceived stigma**		**P value***
	High (n=68), N (%)	**Low (n=138), N (%)**	
Seizure control			
1 or no seizure in last 3 months	20 (29.4)	54 (39.1)	0.172
More than 1 seizure in last 3 months	48 (70.6)	84 (60.9)	
Difficulty to attend follow-up	32 (47.1)	151 (54.7)	0.164
Difficulty to take AEDs daily	32 (47.1)	43 (31.2)	0.026
Injury during epilepsy attack	21 (30.9)	36 (26.1)	0.469
Frequency of seizure in last 3 month (mean±SD)	4.4±5.3	2.5±3	0.001
Age of onset seizure in years (mean±SD)	8.9±4.7	10.5±3.6	0.005
Duration of seizure in years (mean±SD)	6.4±4.7	4.3±3	<0.001

*P value was determined by Chi-square test

Table 5: Risk factors analysis of high perceived stigma by logistic regression analysis (n=206).

Risk factors	**Odds ratio**	**95% CI**	**P value***
Female	3.726	1.857-7.474	<0.001
Family history of epilepsy	3.088	1.380-6.908	0.006
Disclosure of epilepsy	0.461	0.223-0.955	0.037
Difficulty to take AEDs daily	0.727	0.362-1.457	0.368
Frequency of seizure in last 3 month	1.141	1.044-1.246	0.003
Age of onset seizure in years	1.019	0.898-1.155	0.774
Duration of seizure in years	1.101	0.958-1.266	0.177

*P value was determined by multivariate logistic regression analysis

DISCUSSION

The present study aimed to assess perceived stigma and its associated factors among adolescents with epilepsy. Among the 206 participants, 61.2% were aged 15–19 years, with a mean age of 14.9±2.6 years. This finding is consistent with a previous study reporting a mean age of 13.8±3.6 years, and a meta-analysis of 42 studies that also indicated a higher prevalence of epilepsy among older adolescents.[19,20]

A male predominance (64.1%) was observed in the study population, similar to Rani et al, where 66.7% of children with epilepsy were male.[21] Other studies have also reported higher prevalence among males, although some found nearly equal gender distribution.[16,22] Biological factors, including steroid hormones, as well as cultural influences and healthcare-seeking behaviors, may contribute to this disparity, as males often receive preferential access to medical care in certain societies.[23]

Regarding seizure types, generalized seizures were the most common (40.8%), followed by focal (26.7%) and focal to bilateral tonic-clonic seizures (26.7%), aligning with previous findings that generalized seizures predominate in adolescent epilepsy patients.[24] Only 5.8% of participants were diagnosed with a defined epilepsy syndrome, highlighting potential gaps in diagnostic capabilities or awareness among healthcare providers. Notably, 46.1% of participants attributed epilepsy to supernatural causes, underscoring the need for culturally sensitive educational interventions.

Stigma remains a significant concern for adolescents with epilepsy, impacting quality of life and social integration. In this study, the mean Kilifi stigma scale score was 8.9±4.9, with 33% of participants experiencing high perceived stigma. Female participants were significantly more likely to report high stigma than males (p<0.001), consistent with prior research showing higher stigma among females.[16] Another study reported a prevalence of high perceived stigma of 34%, with older children and females experiencing higher levels, though differences were not always statistically significant.[22] Gender-based societal norms and expectations likely contribute to this disparity, as females may face greater scrutiny and discrimination.

High perceived stigma was associated with greater disclosure of epilepsy, difficulty taking antiepileptic drugs daily, increased seizure frequency over the past three months, and longer duration of epilepsy. Conversely, participants with a family history of epilepsy and higher age at onset were more likely to report lower stigma. Adolescents without a family history may feel more isolated, whereas those with affected family members often have greater knowledge and experience, enabling them to view epilepsy as a manageable condition.

Previous studies support these findings. A family history of epilepsy and early onset have been identified as barriers to social acceptance, contributing to stigma.[25] Disclosure of epilepsy can raise awareness but may also exacerbate stigma in communities with limited understanding of the condition.[26] Similarly, individuals with more frequent or severe seizures experience higher societal and self-imposed stigma, likely due to disruptions in daily functioning and reinforcement of negative stereotypes.[22] Yeni et al reported that 34% of patients felt stigmatized, with almost half experiencing high stigma, and identified factors such as education, income, age at onset, seizure frequency, social support, and knowledge and attitudes toward epilepsy as significant determinants of stigma scores.[16]

Overall, these findings highlight the multifactorial nature of perceived stigma in adolescents with epilepsy and emphasize the need for targeted interventions addressing both clinical and socio-cultural determinants.

Limitations

This study was conducted at a single tertiary care hospital, which may limit the generalizability of the findings. Additionally, the pilot study for the Bangla translation and modification of the KSSE questionnaire included only a small number of participants and may not fully represent the diverse geographic and ethnic populations of the country.

CONCLUSION

This study demonstrated that one-third of adolescents with epilepsy experienced high perceived stigma. Perceived stigma was significantly lower among participants with a family history of epilepsy. Factors significantly associated with increased stigma included female gender, earlier age at seizure onset, higher seizure frequency, longer duration of epilepsy, and disclosure of epilepsy. Further multi-center studies with a prospective and longitudinal study design, including a larger sample size, are recommended to validate these findings and to explore additional factors influencing perceived stigma among adolescents with epilepsy.

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