

Socio-Demographic Determinants of Perceived Stigma among Adolescents with Epilepsy

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Abstract

Background: Epilepsy is a prevalent neurological condition in childhood that carries multifaceted consequences, affecting not only physical and neurological health but also social functioning, academic performance, and quality of life. The purpose of the study is to assess socio-demographic determinants influencing perceived stigma among adolescents living with epilepsy.

Methods: This cross-sectional study at the Department of Paediatric Neurology and Neurology, National Institute of Neurosciences and Hospital, Dhaka, included 206 adolescents (10–19 yrs) with epilepsy >1 year, excluding those with neurodevelopmental or chronic disorders. Socio-demographics and perceived stigma (KSSE, 66th percentile) were assessed. Data were collected via structured interviews with ethical approval and informed consent, and analyzed in SPSS 26 using descriptive statistics, chi-square, t-tests, ($p < 0.05$).

Results: Among 206 adolescents (mean age 14.9 ± 2.6 years), 64.1% were male, 88.8% Muslim, and 60.7% urban residents. High perceived stigma was reported by 33%, significantly more in females than males (55.9% vs 44.1%, $p < 0.001$), while other socio-demographic factors showed no significant associations.

Conclusion: Female gender is a significant socio-demographic determinant of perceived stigma among adolescents with epilepsy, while other factors showed no strong association

Keywords: Socio-Demographic, Perceived Stigma, Adolescents.

1. INTRODUCTION

Epilepsy is a prevalent neurological condition in childhood that carries multifaceted consequences. The definition of epilepsy is complex, encompassing not only seizures but also febrile seizures and those induced by medications [1, 2]. It represents the most frequent serious neurodevelopmental disorder in children, affecting roughly 0.9% of children and adolescents worldwide [3]. Compared with young individuals living with other chronic conditions, adolescents with epilepsy (YWE) have higher rates of additional medical and neurological comorbidities, behavioral health issues such as anxiety, depression, and ADHD, as well as lower academic performance, impaired social functioning, and reduced health-related

quality of life (HRQOL) [4]. Globally, epilepsy poses a significant public health challenge among children and adolescents, with prevalence estimates ranging from 3.2–5.5 per 1000 in developed nations to 3.6–44 per 1000 in developing countries [5, 6].

Perceived stigma in epilepsy can be understood as having two main aspects: the internalized shame associated with having the disorder and the apprehension of facing enacted stigma, which may lead parents to conceal their child's condition [3]. Stigma itself is a socially constructed concept, defined as an attribute that marks an individual as different and discredited, and it may manifest as either enacted or perceived stigma. Among people with epilepsy (PWE), enacted stigma refers to actual discriminatory

behavior from others, while perceived stigma reflects the internal adoption of these negative social attitudes, producing feelings of embarrassment, shame, and fear of being treated differently [7-9]. The presence of stigma has a considerable impact on overall quality of life, affecting emotional health, psychosocial well-being, and self-esteem [10-12]. In children, epilepsy-related perceived stigma can restrict social engagement, thereby negatively influencing academic performance, social relationships, and future life outcomes [11-13].

Most prior studies on perceived stigma in epilepsy have predominantly focused on adult populations or mixed samples of children and adults, often without clearly separating age-specific outcomes. Adolescence has been recognized as a crucial developmental period during which important competencies that influence lifelong health trajectories are established [14]. This stage is characterized by heightened self-consciousness and uncertainty, with identity formation strongly shaped by interactions with peers. While parental influence remains significant, peers gain increasing importance, serving as a benchmark for social comparison. For adolescents living with epilepsy, stigma can interfere with these normative developmental processes [15]. Despite this, there remains limited evidence on the prevalence and impact of epilepsy-related perceived stigma among children and adolescents in developing countries, where the condition is more widespread.

Although some studies have explored stigma in people with epilepsy, research focusing specifically on adolescents is limited, particularly in developing countries where epilepsy prevalence is higher and sociocultural factors may influence experiences of stigma. Existing literature often emphasizes clinical and psychological aspects, while socio-demographic determinants—such as age, gender, residence, parental education, and family income—remain underexplored in this population. Understanding these determinants is essential for identifying adolescents at higher risk of perceived stigma and for designing targeted interventions to improve their social and psychological well-being. The purpose of the study is to assess socio-demographic determinants influencing perceived stigma among adolescents living with epilepsy.

2. OBJECTIVE

- To assess socio-demographic determinants influencing perceived stigma among adolescents living with epilepsy.

3. METHODOLOGY & MATERIALS

This cross-sectional study was conducted at the Department of Pediatrics Neurology and Neurology, National Institute of Neurosciences and Hospital, Dhaka, Bangladesh, between January 2024 and December 2024. A total of 206 adolescents aged 10–19 years, diagnosed with epilepsy for more than one year, were included to assess the socio-demographic determinants influencing perceived stigma among adolescents living with epilepsy.

3.1. Inclusion Criteria

- Adolescents aged 10–19 years.
- Diagnosed with epilepsy according to ILAE criteria for more than 1 year.

3.2. Exclusion Criteria

- Neurodevelopmental disorders (Cerebral Palsy, Autism Spectrum Disorder, ADHD, developmental delay, metabolic disorders).
- Chronic systemic conditions (Asthma, hypertension, chronic renal failure, congenital heart disease, endocrine disorders).

Socio-demographic factors (age, gender, religion, residence, socioeconomic status, parental education, family history, and epilepsy disclosure) were assessed as dependent variables, while perceived stigma, measured using the Kilifi Stigma Scale for Epilepsy (KSSE), was the independent variable. Poor seizure control was defined as >1 seizure in the last 3 months. Stigma scores were categorized as high or low based on the 66th percentile of KSSE scores. The study protocol was approved by the Institutional Ethical Review Committee, and written informed consent was obtained from participants aged ≥ 18 years or from guardians for participants <18 years. Data were collected through structured face-to-face interviews with participants or caregivers, and confidentiality was maintained using unique identification numbers. The KSSE was translated into Bengali, piloted, and validated before use. Data were coded, entered, and analyzed using SPSS version 26. Descriptive statistics summarized participant characteristics, and chi-square and independent t-tests assessed associations between socio-demographic factors and perceived stigma. A significance threshold of $p < 0.05$ was applied for all statistical tests.

4. RESULTS

Table 1. Socio-Demographic Characteristics of the Study Population (n = 206)

Variable		Frequency (n)	Percentage (%)
Age group (In years)	10–14	80	38.8
	15–19	126	61.2
	Mean ± SD	14.9 ± 2.6	
Gender	Male	132	64.1
	Female	74	35.9
Religion	Muslim	183	88.8
	Hindu	19	9.2
	Christian	4	2.0
Residence	Urban	125	60.7
	Rural	81	39.3
Monthly Family Income (Taka)	Below 10,000	17	8.3
	10,000–20,000	83	40.3
	20,000–40,000	64	31.1
	Above 40,000	42	20.4
Father’s Education	Illiterate	38	18.4
	Below SSC	65	31.6
	SSC	24	11.7
	HSC	38	18.4
	Graduate and above	41	19.9
Mother’s Education	Illiterate	34	16.5
	Below SSC	77	37.4
	SSC	32	15.5
	HSC	40	19.4
	Graduate and above	23	11.2

Table 1 presents the socio-demographic profile of the study participants. Among the 206 adolescents, 61.2% were aged 15–19 years, with a mean age of 14.9 ± 2.6 years. Males comprised 64.1% of the cohort. The majority were Muslim (88.8%) and resided in urban areas (60.7%).

Most participants’ monthly family income ranged from 10,000 to 20,000 Taka (40.3%). Regarding parental education, 50% of fathers had education at SSC level or above, whereas 53.9% of mothers had education below SSC or were illiterate.

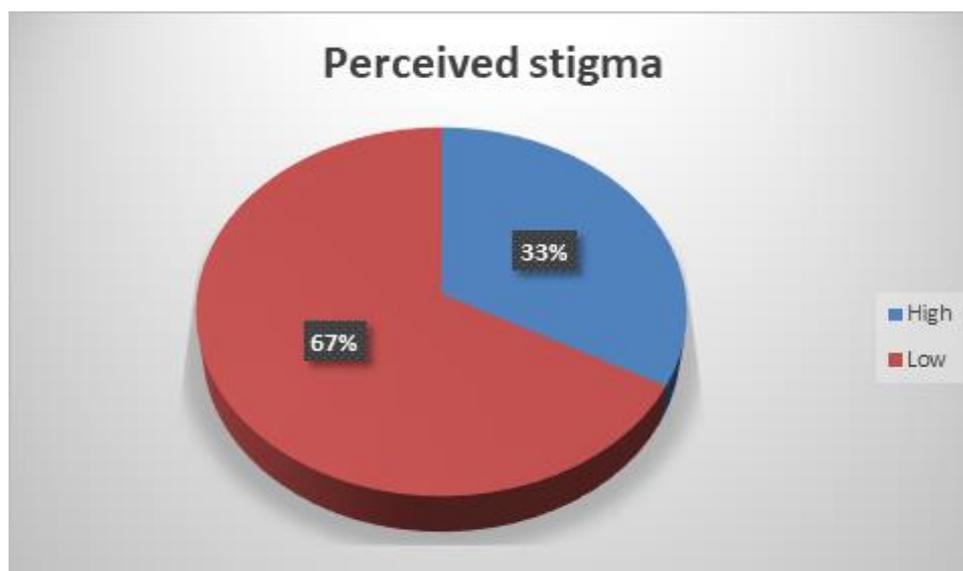


Figure 1. Distribution of Perceived Stigma in the Study Population (n = 206)

Figure 1 illustrates the distribution of perceived stigma among the study population. Among the 206 adolescents, 33% reported high levels of

perceived stigma, while 67% reported low levels, as measured by the Kilifi Stigma Scale for Epilepsy.

Table 2. Association of Socio-Demographic Factors with Level of Perceived Stigma in the Study Population (n = 206)

Variable	High Stigma (n = 68) n (%)	Low Stigma (n = 138) n (%)	p-value*
Age group	10–14	25 (36.8)	0.669
	15–19	43 (63.2)	
Gender	Male	30 (44.1)	<0.001
	Female	38 (55.9)	
Religion	Muslim	55 (80.9)	0.038
	Hindu	2 (2.9)	
	Christian	11 (16.2)	
Residence	Rural	26 (38.2)	0.823
	Urban	42 (61.8)	
Monthly family income	< 40,000	50 (73.5)	0.128
	≥ 40,000	18 (26.5)	
Father’s education	HSC or below	54 (79.4)	0.863
	Graduation or above	14 (20.6)	
Mother’s education	HSC or below	12 (17.6)	0.257
	Graduation or above	24 (35.3)	

Table 2 presents the association between socio-demographic variables and perceived stigma among the study population. Among the 206 adolescents, female participants were significantly more likely to report high perceived stigma compared to males (55.9% vs 44.1%, $p < 0.001$). No significant associations were observed for age group, residence, monthly family income, or parental education. Religion showed a borderline significant association, with a higher proportion of Christians reporting high stigma (16.2%) compared to Muslims (80.9%) and Hindus (2.9%, $p = 0.038$).

5. DISCUSSION

Perceived stigma is a significant psychosocial concern among adolescents living with epilepsy, affecting their emotional well-being, social interactions, and quality of life. The findings of this study demonstrate that certain socio-demographic factors, particularly gender and religion, are associated with variations in perceived stigma, with female adolescents and participants from minority religious groups reporting higher levels of stigma. These results highlight the importance of identifying adolescents at greater risk of experiencing stigma to inform targeted interventions, promote social inclusion, and support the overall psychosocial development of young people with epilepsy.

The socio-demographic profile of the study population highlights a predominance of older adolescents, with 61.2% aged 15–19 years and a mean age of 14.9 ± 2.6 years, reflecting a focus on mid-to-late adolescence. A notable male predominance was observed (64.1% males vs.

35.9% females), consistent with findings by Sawafta et al.[16], where 67.2% of pediatric epilepsy patients were male and adolescents comprised 38% of the cohort, and similarly supported by Memon et al.[17], who reported more males among school-attending adolescents with epilepsy. The majority of participants were Muslim (88.8%), reflecting the local demographic context, and 60.7% resided in urban areas, suggesting higher healthcare access or reporting from urban centers.

Socio-economic indicators showed that most families had a monthly income between 10,000–40,000 Taka, broadly aligning with observations by Russ et al. [18], who reported higher epilepsy prevalence among children from lower-income families. Parental education levels varied, with a substantial proportion of fathers and mothers having education below or up to SSC, while 19.9% of fathers and 11.2% of mothers had graduation-level education or higher, a pattern consistent with previous studies indicating that adolescents with epilepsy often come from families with varying education levels, potentially influencing health literacy, treatment adherence, and stigma perception. Overall, the socio-demographic characteristics of this cohort are comparable to international findings, reinforcing the relevance of these variables in understanding adolescent epilepsy populations.

In this study, 33% of adolescents with epilepsy reported high levels of perceived stigma, while 67% reported low levels. This finding is consistent with previous studies, highlighting the persistent nature of stigma among adolescents with epilepsy across different contexts. Farghaly

et al. [19] reported that 35.6% of children and adolescents (8–18 years) experienced felt stigma in a multicenter study, closely mirroring the prevalence observed here. Similarly, Kirabira et al. [20] found a 34% prevalence of high perceived stigma among 6–18-year-old adolescents, and in a separate study involving 191 children/adolescents, high stigma was associated with poorer school attendance [21]. These parallels indicate that approximately one-third of adolescents with epilepsy are likely to experience significant stigma, underscoring the global relevance of stigma as a psychosocial concern and the need for targeted interventions to mitigate its impact.

Analysis of the association between socio-demographic factors and perceived stigma revealed several noteworthy patterns. Female adolescents reported significantly higher levels of high perceived stigma compared to males (55.9% vs. 44.1%, $p < 0.001$), aligning with findings by Aydemir et al. [22], where females consistently experienced more felt stigma than males. Age group, residence, monthly family income, and parental education did not show statistically significant associations with stigma in this cohort, although religion demonstrated modest significance ($p = 0.038$), with minority religious groups reporting higher stigma. These results are comparable to Zhao et al. [23], who found that felt stigma in children and adolescents (8–18 years) was influenced by place of residence, academic performance, and social support, although not all classical socio-demographic variables were significant. Collectively, these findings highlight that while gender is a robust predictor of perceived stigma across diverse adolescent epilepsy populations, other socio-demographic factors may exert more subtle or context-dependent effects, emphasizing the multifactorial nature of stigma and the importance of tailored interventions to address its psychosocial impact.

6. LIMITATIONS OF THE STUDY

The study had a few limitations:

- The study was limited to a single tertiary care hospital, which may affect the generalizability of the findings.
- The pilot study for the Bangla translation and modification of the KSSE questionnaire involved a small number of participants, limiting its representation of the wider population across different regions and ethnic groups.

7. CONCLUSION

This study demonstrates that among adolescents with epilepsy, one-third experience high perceived stigma, with female gender emerging as a significant socio-demographic determinant. Other factors, including age, residence, family income, and parental education, were not significantly associated, while religion showed a borderline effect. These findings highlight the importance of gender-sensitive approaches in addressing stigma and underscore the need for targeted interventions to reduce psychosocial burden among adolescents living with epilepsy.

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