Factors Associated with Internalized Stigma in People with Epilepsy: A Hospital-based Study in Medan, Indonesia

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Abstract

Objective: Stigma toward epilepsy is associated with a negative self-concept and has a negative impact on people with epilepsy (PWE) and their families, especially in low-to middle-income countries in which the majority of PWE live. This study aimed to assess and identify factors associated with internalized stigma in PWE.

Methods: A cross-sectional study was conducted among patients with epilepsy at two university teaching hospitals in Medan, North Sumatra, Indonesia, from December 2022 to May 2023. Participants (n=81) with generalized or focal epilepsy, aged >18 years, literate in Bahasa Indonesia, and without psychiatric comorbidities were included. We used Internalized Stigma of Epilepsy (ISEP), which was validated in Bahasa Indonesia, to measure stigma across five subscales.

Results: The mean age was 34.7±14.5 years with an approximately equal gender distribution. Most participants (79%) demonstrated moderate internalized stigma, with a mean ISEP score of 57.96±9.90. Males exhibited higher ISEP scores than females [62.5 (36.0-71.0) vs. 59.0 (36.0-79.0)]. A statistically significant difference in stigma scores was noted between males and females ($p=0.039$, $p<0.05$). Additionally, patients with generalized tonic-clonic seizures displayed lower stigma scores than those with absence seizures [59.5 (36.0-71.0) vs. 71.0 (65.0-79.0)].

Conclusion: This study highlights the need to improve knowledge and raise awareness regarding epilepsy to decrease the stigma associated with the condition.

Keywords: Epilepsy, stigma, Indonesia

INTRODUCTION

Epilepsy is a neurological disorder that can affect individuals of diverse ages, races, social backgrounds, and geographical locations.[1] The disease exerts a significant impact on the global disease burden, with approximately 50 million people worldwide experiencing epilepsy. Annually, approximately 5 million new cases are diagnosed, and an estimated 4-10 out of a thousand individuals live with persistent epilepsy, necessitating ongoing therapy. Notably, the prevalence of epilepsy is highest in low- and middle-income countries, accounting for approximately 80% of cases, particularly affecting 12.7 out of 1000 people in developing countries.[2,3] In Indonesia, a developing country with a population of around 260 million, the incidence of epilepsy ranges from 1.1 to 1.8 million individuals. Research conducted in 15 Indonesian cities in 2013 identified 2,288 cases of epilepsy, including 487 new cases.[3,4]

Epilepsy is a neurological disorder characterized by either two or more unprovoked or reflex seizures occurring more than 24 hours apart, a single unprovoked or reflex seizure in an individual with a 60% risk of another seizure within the next 10 years, or an epilepsy syndrome.[5] Epileptic seizures often induce anxiety and fear in individuals and those around them, leading to social exclusion. Consequently, individuals with epilepsy frequently encounter challenges in education, at home, and in the workplace.[6]

Stigma encompasses societal perceptions marked by labeling, stereotyping, and discrimination that arises from discrediting differences. It is typically categorized into "enacted stigma", involving real instances of discrimination by the public, and "self-stigma", representing internalized stigma experienced by individuals with feelings of inferiority, shame, secrecy, or withdrawal.[4,7,8] Self-stigma significantly impacts the treatment of epilepsy patients, influencing treatment adherence and potentially delaying diagnosis, leading to heightened risks of uncontrolled seizures. Stigma is also a risk factor for somatic disorders and mental health issues in patients with epilepsy, influencing therapy outcomes, prognosis, and quality of life. Several studies have identified factors contributing to stigma in patients with epilepsy,

including age, gender, seizure frequency and type, knowledge about epilepsy, treatment received, and perceptions of those around them. According to the International League Against Epilepsy Task Force on Stigma in Epilepsy (2022), stigma arises from inadequate information about epilepsy, low educational levels, economic disparities, residing in underdeveloped environments, and biased beliefs.[9-11] The Internalized Stigma of Epilepsy (ISEP) serves as a scale to quantify stigma in patients with epilepsy. Adapted from the Internalized Stigma of Mental Illness,[12] ISEP has undergone various studies and validations in multiple countries, including Indonesia. The instrument is recognized as valid and reliable for assessing stigma perceptions, making it applicable for use in the context of epilepsy in Indonesia.[4]

METHODS

Study Design and Participants

This observational analytical cross-sectional study was conducted at the neurology outpatient clinic of two university teaching hospitals in Medan North Sumatra Indonesia, Adam Malik General Hospital and Universitas Sumatera Utara Hospital, from December 2022 until May 2023. Using a non-random consecutive sampling method, we recruited literate people with epilepsy (PWE) with epilepsy older than 18 years who were able to communicate fluently in Bahasa Indonesia and who had no psychiatric comorbidities. Informed consent was obtained from each patient.

Procedures

We collected demographic data, including age, sex, occupation, and education level. The ISEP was assessed using the ISEP validated in Bahasa Indonesia. The ISEP comprises 29 items on perceived stigma. It consists of five subscales measuring Alienation" with 6 items, "Stereotype Endorsement" with 7 items, "Discrimination Experience" with 5 items, "Social Withdrawal" with 6 items, and "Stigma Resistance" with 5 items. Each item has four response options scored using Likert scale from 1 to 4. The "Alienation" subscale measures the subjective experience of being less than a full member of society. The "Stereotype Endorsement" subscale measures the degree to which respondents agreed with common stereotypes regarding PWE. The "Discrimination Experience" subscale is composed of five items intended to capture respondents' perception of how they are being treated by others. The "Social Withdrawal" subscale consists of statements like "I don't talk about myself much because I don't want to burden others with my epilepsy". The "Stigma Resistance" subscale measures the degree of resistance toward being stigmatized or remain unaffected by internalized stigma. The maximum score is 116 and the minimum score is 29. Based on these scores, the perception of stigma was classified as low (<50.75), medium (50.75-94.25), and high (>94.25).[4,12]

MAIN POINTS

- This study assessed the internalized stigma among individuals with epilepsy in Medan using the Internalized Stigma of Epilepsy scale.
- Gender and type of seizures influenced stigma levels; men experienced higher stigma than women, and those with absence seizures reported more stigma than those with generalized tonic-clonic seizures.
- The findings of this study suggest increased educational efforts and support to mitigate internalized stigma and improve the quality of life of people with epileps

Statistical Analysis

Data were coded and entered Statistical Package for Social Sciences windows version 25 for analysis. Descriptive statistics were used for the sociodemographic and clinical variables. Data are presented as mean value±standard deviation for normally distributed continuous variables, median (minimum-maximum) for continuous variables with non-normal distribution, or frequency (%) for categorical variables. We used Mann-Whitney and Kruskal-Wallis tests to compare the mean stigma score with demographic variables. The significance level was set at $p<0.05$.

RESULTS

The study involved 81 patients with epilepsy, with a mean age of 34.7±14.5 years and an almost equal gender distribution. Most patients had university education (51.9%) and were college students (32.1%). The majority of subjects experienced generalized tonic-clonic seizures (96.3%), whereas 3.7% experienced absence seizures. Although we initially intended to include patients with both focal and generalized epilepsy, we ultimately did not identify any individuals with focal seizures. The mean seizure duration was 94.2±101.5 months. In terms of treatment, most subjects used antiepileptic drug (AED) monotherapy (63%), whereas the remaining 37% used polytherapy. The subject characteristics are presented in Table 1.

The majority of subjects exhibited a moderate level of internalized stigma (79%), whereas 21% displayed a low level of internalized stigma. The mean ISEP score was 57.96±9.90. The breakdowns of scores by subscale were as follows: Alienation subscale, 3.7±3.1; Stereotype Endorsement subscale, 13.3±2.7; Discrimination Experience subscale, 9.4±2.8; Social Withdrawal subscale, 12.1±3.1; and Stigma Resistance subscale, 9.4±2.7. The detailed responses to the questionnaire items are presented in Tables 2 and 3.

In this study, we observed that males exhibited higher ISEP scores than females [62.5 (36.0-71.0) vs. 59.0 (36.0-79.0)]. A statistically significant difference in stigma scores was noted between males and females ($p=0.039$, $p<0.05$). Additionally, patients with generalized tonic-clonic seizures displayed lower stigma scores than those with absence seizures [59.5 (36.0-71.0) vs. 71.0 (65.0-79.0)], with a significant difference in stigma scores between those two types ($p=0.012$). However, there were no significant differences in stigma scores according to education level, occupation, and the use of AEDs (Table 4).

DISCUSSION

This study aimed to assess stigma and identify factors associated with internalized stigma in individuals with epilepsy. The study involved 81 patients from neurology outpatient clinics at two university teaching hospitals in Medan, Indonesia. The mean age of the patients was 34.7±14.5 years, with an approximately equal gender distribution. Age is related to epilepsy prevalence and incidence, with a lower prevalence in children, increasing prevalence in adolescents and young adults, and decreasing prevalence after 30 years.[13,14] Older age at epilepsy diagnosis is

correlated with a poorer quality of life, potentially due to better emotional control when diagnosed at a younger age.[15] Studies have reported a peak prevalence of epilepsy around 30-34 years, reinforcing the notion that epilepsy is generally a disease of the young.[16] Previous research indicates a slightly higher prevalence in men than in women, which is attributed to differences in brain development and social effects.[17,18]

Bifftu et al.[19] (2015) found that among the 408 patients examined, 71.8% experienced seizure frequencies of 1-11 times per year. Most participants (76%) received monotherapy, and 67.2% had a history of non-adherence to AEDs. Another study in Sudan reported that generalized tonic-clonic seizures were the most prevalent type, accounting for 68% of cases, followed by focal seizures at 11%.[20] Another study involving 431 patients with epilepsy showed that 25.3% had generalized seizures and 8.9% had focal seizures. Discrepancies in seizure type classification may result from early misidentification of focal-onset symptoms during generalized seizures, leading to a higher prevalence.[21-23] Our study is consistent with these findings, indicating that the majority of patients received monotherapy (63%), experienced generalized tonic-clonic seizures (96.3%), and had a mean seizure duration of 94.2±101.5 months.[21,24] In our study, we initially aimed to include patients with both focal and generalized epilepsy. However, due to recruitment challenges, the final sample consisted exclusively of patients with generalized epilepsy.

Table 1. Subject characteristics

Characteristics	n (81)	%
Sex		
- Male	40	49.4
- Female	41	50.6
Age, years	Mean=34.7±14.5; Median=31.0 (18.0-73.0)	
Level of education		
- Primary	2	2.5
- Middle school	4	4.9
- High school	33	40.7
- University	42	51.9
Occupation		
- College students	26	32.1
- Civil servant	21	25.9
- Entrepreneur	13	16.0
Unemployed	11	13.6
- Housewife	7	8.6
- Retired	3	3.7
Type		
- Generalized tonic-clonic	78	96.3
- Absence	3	3.7
Duration of epilepsy	Mean=94.2±101.5; Median=60.0 (1.0-480.0)	
Antiepileptic drug		
- Monotherapy	51	63.0
- Polytherapy	30	37.0

Table 2. ISEP score

Characteristics	n (81)	%
Level of internalized stigma		
- Low (<50.75)	17	21.0
- Moderate (50.75-94.25)	64	79.0
- Severe (>94.25)	0	0
Mean ISEP scores		
- Alienation	Mean=13.7±3.1; Median=13.0 (9.0-20.0)	
- Stereotype	Mean=13.3±2.7; Median=14.0 (8.0-20.0)	
- Discrimination	Mean=9.4±2.8; Median=10.0 (5.0-15.0)	
- Social withdrawal	Mean=12.1±3.1; Median=13.0 (6.0-19.0)	
- Stigma resistance	Mean=9.4±2.7; Median=10.0 (5.0-18.0)	
- Total score	Mean=57.9±9.9; Median=60.0 (36.0-79.0)	

ISEP: Internalized Stigma of Epilepsy

Epilepsy is often stigmatized, with a study in Sudan reporting depression (28%), anxiety (18%), and social problems (37%) among patients with epilepsy. In the present study, 79% of patients experienced moderate self-stigma. While most subjects disagreed with items related to alienation, stereotype endorsement, discrimination experience, and social withdrawal, certain items, particularly those related to embarrassment, feelings of inferiority, and negative stereotypes, revealed persistent negative stigmas toward epilepsy.[21,24]

In general, in our study, the patient's answers to the alienation, stereotype endorsement, discrimination experience, and social withdrawal subscales, the majority of subjects answered disagree, which describes a positive thing where the stigma experienced by the subjects in this component was relatively minimal. However, several items included questions number 4 (I feel embarrassed because I suffer from epilepsy) and number 6 (I feel inferior to other people who do not suffer from epilepsy), which are part of the alienation subscale, as well as question number 7 (because I suffer from epilepsy, the stereotype of "wrong assumptions" about epilepsy applies to me) part of stereotype endorsement subscale. Most of the subjects answered in the affirmative, which illustrates that there is still a negative stigma toward PWE. Likewise, in question number 25 (I feel comfortable appearing in public with someone who is known to suffer from epilepsy), the majority of subjects still answered "disagree," which also illustrates the negative stigma toward patients with epilepsy.[4,12]

Stigma in patients with epilepsy may be linked to low health score coping. The low score of coping is found in one in five patients with epilepsy. Having seizures more than three times per month lowers the score of patients with epilepsy.[21,24] In our study, higher stigma scores (indicating more negative perceptions) were found in male patients, those with at least an elementary school education, unemployed individuals, those with absence seizures, and those using monotherapy. Sex and type of epilepsy had a statistically significant influence on stigma formation. However, there were no significant differences in stigma scores based on education level, occupation, and AED use, contrary to some previous studies. The results in this study are certainly not in line with several studies that state that epilepsy patients with an education level less than high school or who do not work are reported to be significantly more susceptible to experiencing stigma.[25]

Mao et al.[26] found a significant negative correlation between self-confidence and stigma among patients with epilepsy and a significant positive correlation between self-confidence and knowledge. This indicates that proper knowledge about epilepsy can increase the self-confidence of patients with epilepsy and can decrease the stigma associated with epilepsy. Low education level, long seizure duration, and young age at first onset have an impact on the formation of stigma. However, no relationship was found

Table 3. Prevalence of internalized stigma in percentages

Item	Strongly disagree [n (%)]	Disagree [n (%)]	Agree [n (%)]	Strongly agree [n (%)]
Alienation				
I feel out of place in the world because I have epilepsy.	15 (18.5)	41 (50.6)	20 (24.7)	5 (6.2)
Having epilepsy has spoiled my life.	11 (13.6)	51 (63.0)	15 (18.5)	4 (4.9)
People without epilepsy could not understand me.	9 (11.1)	47 (58.0)	21 (25.9)	4 (4.9)
I am embarrassed or ashamed that I have epilepsy.	11 (13.6)	34 (42.0)	32 (39.5)	4 (4.9)
I am disappointed in myself for having epilepsy.	12 (14.8)	43 (53.1)	21 (25.9)	5 (6.2)
I feel inferior to others without epilepsy.	10 (12.3)	29 (35.8)	30 (37.0)	12 (14.8)
Stereotype endorsement				
Stereotypes about epilepsy apply to me.	21 (25.9)	31 (38.3)	29 (25.8)	0 (0.0)
People can tell that I have epilepsy by the way I look.	18 (22.2)	54 (66.7)	9 (11.1)	0 (0.0)
Individuals with epilepsy tend to be violent.	27 (33.3)	54 (66.7)	0 (0.0)	0 (0.0)
Because I have epilepsy, I need others to make decisions for me.	9 (11.1)	36 (44.4)	23 (28.4)	13 (16.0)
People with epilepsy cannot enjoy a fulfilling life.	31 (38.3)	39 (48.1)	10 (12.3)	1 (1.2)
Persons with epilepsy should not marry.	38 (46.9)	35 (43.2)	7 (8.6)	1 (1.2)
I cannot contribute anything to society because I have epilepsy.	26 (32.1)	51 (63.0)	3 (3.7)	1 (1.2)
Discrimination experience				
People discriminate against me because I have epilepsy.	23 (28.4)	50 (61.7)	6 (7.4)	2 (2.5)
Others think that I can't achieve much in life because I have epilepsy.	24 (29.6)	48 (59.3)	5 (6.2)	4 (4.9)
People ignore or take me less seriously because I have epilepsy.	29 (35.8)	33 (40.7)	16 (19.80)	3 (3.7)
People often patronize me or treat me like a child just because I have epilepsy.	26 (32.7)	31 (38.3)	24 (29.6)	0 (0.0)
Nobody would be interested in getting close to me because I have epilepsy.	26 (32.1)	44 (54.3)	9 (11.1)	2 (2.5)
Social withdrawal				
I do not talk about myself because I do not want to burden others with my epilepsy.	14 (17.3)	39 (48.1)	25 (30.9)	3 (3.7)
I do not socialize as much as I used to because my epilepsy might make me look or behave "weird".	14 (17.3)	51 (63.0)	16 (19.8)	0 (0.0)
Negative stereotypes about epilepsy keep me isolated from the "normal" world.	14 (17.3)	49 (60.5)	17 (21.0)	1 (1.2)
I stay away from social situations to protect my family or friends from embarrassment.	21 (25.9)	39 (48.1)	20 (24.7)	1 (1.2)
Being around people who do not have epilepsy makes me feel out of place or inadequate.	23 (28.4)	50 (61.7)	6 (7.4)	2 (2.5)
To avoid rejection, I avoid getting close to people who do not have epilepsy.	16 (19.8)	54 (66.7)	11 (13.6)	0 (0.0)
Stigma resistance				
I feel comfortable being seen in public with a person known to have epilepsy.	3 (3.7)	29 (35.8)	28 (34.6)	21 (25.9)
In general. I can live my life the way I want to.	0 (0.0)	7 (8.6)	43 (53.1)	31 (38.3)
I can have a good. fulfilling life despite my epilepsy.	2 (2.5)	4 (4.9)	45 (55.6)	30 (37.0)
Individuals with epilepsy make important contributions to society.	2 (2.5)	3 (3.7)	62 (76.5)	14 (17.3)
Living with epilepsy has made me a tough survivor.	2 (2.5)	11 (13.6)	46 (56.8)	22 (27.2)

between stigma and age, gender, wealth, and type/frequency of seizures.[26] A study found that many PWE experiencing internalized stigma tend to have lower education levels and limited access to quality healthcare services. These patients often received misleading information about epilepsy from unreliable sources. Most PWE acknowledge epilepsy as a neurological disorder, and those who understand its cause tend to have less fear, more positive attitudes, and greater confidence in managing or treating their condition than those who lack this understanding.[27] Stigma in patients with epilepsy was also positively correlated with the severity of seizures ($p=0.034$), number of epilepsy medications ($p=0.035$), depression score ($p<0.0001$), and quality of life ($p<0.0001$). However, stigma was negatively correlated with health literacy ($p=0.0001$), self-efficacy ($p<0.0001$), social support ($p<0.0001$), and functional status ($p<0.0001$ for mental component, $p=0.0005$ for functional component).[28]

One study found that patients with a disease duration of 2-5 years are four times more likely to experience self-stigma than those with less than 1 year of illness. This heightened perception may arise from the chronic nature of the disease, inadequate coping strategies, and difficulty in resisting stigma, which can worsen cultural and social challenges. Likewise, individuals with 6-10 years and 11 or more years of illness also exhibit a fourfold increase in stigma perceptions compared to those with shorter durations. Differences from previous studies may be attributed to variations in health systems, research methods, and stigma measurement scales.[25]

Table 4. ISEP score based on subject characteristics

Characteristics	Stigma score [median (min-max)]	p
Sex		0.039
- Male	62.5 (36.0-71.0)	
- Female	59.0 (36.0-79.0)	
Level of education		0.267
- Primary	66.5 (63.0-70.0)	
- Middle school	61.5 (55.0-70.0)	
- High school	61.0 (36.0-79.0)	
- University	59.0 (36.0-70.0)	
Occupation		0.904
- College students	59.5 (36.0-71.0)	
- Unemployment	62.0 (50.0-70.0)	
- Housewife	59.0 (36.0-71.0)	
- Enterpreneur	59.0 (36.0-79.0)	
- Civil servant	61.0 (36.0-70.0)	
- Retired	59.0 (59.0-63.0)	
Type		0.012
- Generalized tonic-clonic seizure	59.5 (36.0-71.0)	
- Absence	71.0 (65.0-79.0)	
Antiepileptic drug		0.875
- Monotherapy	61.0 (36.0-79.0)	
- Polytherapy	59.5 (36.0-70.0)	

*Mann-Whitney and Kruskal-Wallis test.
min-max: Minimum-maximum, ISEP: Internalized Stigma of Epilepsy

Study Limitations

The current study has several limitations, including a small sample size consisting of only patients with generalized epilepsy and a lack of exploration into the relationship between seizure duration and self-stigma. The knowledge levels of epilepsy and seizure causes were not extensively examined.

CONCLUSION

Our study identified various factors influencing internalized stigma in epilepsy, highlighting the role of gender. However, it is important to note that we initially aimed to include patients with both focal and generalized epilepsy. Due to recruitment challenges, the final sample consisted of patients with generalized epilepsy. This limitation may have affected the generalizability of our conclusions, but we believe our findings still provide valuable insights into this specific group. In conclusion, our study underscores the need for raising awareness and enhancing knowledge to reduce epilepsy-related stigma.

Ethics

Ethics Committee Approval: This study was approved by the Research Ethics Committee of the Faculty of Medicine, Universitas Sumatera Utara (number: 2/KEPK/USU/2023, date: 20.03.2023).

Informed Consent: A written informed consent form was obtained from each patient.

Presented in: The study has been presented as a virtual poster presentation at the International League Against Epilepsy Congress 2023.

Footnotes

Authorship Contributions

Surgical and Medical Practices: F.I.F., A.N.Z.N., Concept: F.I.F, A.F., A.K., Design: F.I.F., A.F., A.N.Z.N., Data Collection or Processing: A.N.Z.N., O.A.D., Analysis or Interpretation: F.I.F., O.A.D., Literature Search: F.I.F., A.F., A.N.Z.N., O.A.D., Writing: F.I.F., A.K., O.A.D.

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