

Factors associated with the internalized stigma in people with epilepsy: A hospital-based study in Medan, Indonesia

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Abstract

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Background: Stigma towards 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 large majority of PWE live.

Aim: This study aimed to assess and identify factors associated with internalized stigma in people with epilepsy (PWE).

Method: A cross-sectional study was conducted among epilepsy patients 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 over 18, literate in Bahasa Indonesia, and without psychiatric comorbidities, were included. We used Internalized Stigma of Epilepsy (ISEP), validated in Bahasa Indonesia, measured stigma across five subscales.

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Results: The mean age was 34.7±14.5 years with approximately equal gender distribution. Most participants (79%) demonstrated a moderate level of internalized stigma, with a mean Internalized Stigma of Epilepsy score of 57.96±9.90. Males exhibited higher ISEP scores compared to 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 epilepsy 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 each type of epilepsy (p=0.012; p<0.05).

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

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Keyword: epilepsy, stigma, Indonesia

Introduction

Epilepsy is a neurological disorder that can affect individuals of diverse ages, races, social backgrounds, and geographical locations.¹ It exerts a significant impact on global disease burden, with approximately 50 million people worldwide experiencing epilepsy. Annually, around 5 million new cases are diagnosed, and an estimated four to ten 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 cities in Indonesia in 2013 identified 2,288 cases of epilepsy, including 487 new cases.^{3,4}

Epilepsy is defined as 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 commonly encounter challenges in education, at home, and in the workplace.⁶

Stigma encompasses societal perceptions marked by labeling, stereotyping, and discrimination arising 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 also emerges as a risk factor for somatic disorders and mental health issues in epilepsy patients, influencing therapy outcomes, prognosis, and quality of life. Several studies have identified factors contributing to stigma in epilepsy patients, 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 (ILAE) 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 epilepsy patients. Adapted by Ghanean from the Internalized Stigma of Mental Illness (ISMI)¹², ISEP has undergone various studies and validations in multiple

countries, including Indonesia. It is recognized as a valid and reliable instrument for assessing stigma perceptions, making it applicable for use in the context of epilepsy in Indonesia.⁴

Method

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Study design and participants

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

Procedures

We collected demographic data included age, sex, occupation and level of education. The internalized stigma of epilepsy was assessed using the Internalized Stigma of Epilepsy (ISEP) that has been validated in Bahasa Indonesia. The ISEP consists of 29 items about 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 that respondents agree with common stereotypes regarding people with epilepsy. The "Discrimination Experience" subscale is composed of five items intended to capture the respondent's perception of the way that he or she currently is 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 towards 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 is stated as low (<50.75), medium (50.75-94.25), and high (>94.25).^{4,12}

Data Analysis

Data was coded and entered into SPSS windows version 25 program for analysis. Descriptive statistics were used for the socio-demographic and clinical variables. Data are presented as mean value \pm standard deviation (SD) for normally distributed continuous variables, median

(minimum – maximum) for continuous variables with a non-normal distribution, or frequency (%) for categorical variables. We used Mann-Whitney and Kruskal Wallis test for comparison of the mean of stigma score to the demographic variables. A significant level was set at $p < 0.05$.

Ethics

This study was approved by the research ethics committee of Faculty of Medicine Universitas Sumatera Utara number 312/KEPK/USU/2023

Results

The study involved 81 epilepsy patients, with a mean age of 34.7 ± 14.5 years and an almost equal gender distribution. Regarding the patients' education levels, 2.5% (n=2) had completed primary school, 4.9% (n=4) were medium high school graduates, 40.7% (n=33) had completed senior school, and 51.9% (n=42) were university graduates. Among the participants, 32.1% (n=26) were college students, 25.9% (n=21) were civil servants, 16.0% (n=13) were entrepreneurs, 13.6% (n=11) were unemployed, 8.6% (n=7) were housewives, and 3.7% (n=3) were retirees. The majority of subjects experienced generalized epilepsy (96.3%), while 3.7% experienced absence seizures. The mean duration of seizures in this study was 94.2 ± 101.5 . Regarding treatment, most subjects used antiepileptic drug (AED) monotherapy (63%), while 37% of research subjects used polytherapy. The subject characteristics are presented in table 1.

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)	
Education		
- Elementary School	2	2,5
- Middle School	4	4,9
- High School	33	40,7
- College/University	42	51,9
Occupation		
- College Student	26	32,1
- Unemployment	11	13,6

- Housewife	7	8,6
- Entrepreneur	13	16,0
- Civil Servant	21	25,9
- Retired	3	3,7
Type		
- Generalized	78	96,3
- Absence	3	3,7
Durasi of epilepsy, months	Mean = 94.2 ± 101,5; Median = 60.0 (1.0-480.0)	
Antiepileptic Drug		
- Monotherapy	51	63.0
- Polytherapy	30	37.0

The majority of subjects exhibited a moderate level of internalized stigma (79%), while 21% displayed a low level of internalized stigma. The mean Internalized Stigma of Epilepsy (ISEP) score was 57.96±9.90. 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. Detailed responses to various items in the questionnaire are presented in Table 3.

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 of 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)	

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Table 3. Prevalence of internalized stigma in percentages.

Item	Strongly Disagree (n (%))	Disagree (n (%))	Agree (n (%))	Strongly Agree (n (%))
Item 1	15 (18,5)	41 (50,6)	20 (24,7)	5 (6,2)
Item 2	11 (13,6)	51 (63,0)	15 (18,5)	4 (4,9)
Item 3	9 (11,1)	47 (58,0)	21 (25,9)	4 (4,9)
Item 4	11 (13,6)	34 (42,0)	32 (39,5)	4 (4,9)
Item 5	12 (14,8)	43 (53,1)	21 (25,9)	5 (6,2)
Item 6	10 (12,3)	29 (35,8)	30 (37,0)	12 (14,8)
Item 7	21 (25,9)	31 (38,3)	29 (25,8)	0 (0,0)
Item 8	18 (22,2)	54 (66,7)	9 (11,1)	0 (0,0)
Item 9	27 (33,3)	54 (66,7)	0 (0,0)	0 (0,0)
Item 10	9 (11,1)	36 (44,4)	23 (28,4)	13 (16,0)
Item 11	31 (38,3)	39 (48,1)	10 (12,3)	1 (1,2)
Item 12	38 (46,9)	35 (43,2)	7 (8,6)	1 (1,2)
Item 13	26 (32,1)	51 (63,0)	3 (3,7)	1 (1,2)
Item 14	23 (28,4)	50 (61,7)	6 (7,4)	2 (2,5)
Item 15	24 (29,6)	48 (59,3)	5 (6,2)	4 (4,9)
Item 16	29 (35,8)	33 (40,7)	16 (19,8)	3 (3,7)
Item 17	26 (32,7)	31 (38,3)	24 (29,6)	0 (0,0)
Item 18	26 (32,1)	44 (54,3)	9 (11,1)	2 (2,5)
Item 19	14 (17,3)	39 (48,1)	25 (30,9)	3 (3,7)
Item 20	14 (17,3)	51 (63,0)	16 (19,8)	0 (0,0)
Item 21	14 (17,3)	49 (60,5)	17 (21,0)	1 (1,2)
Item 22	21 (25,9)	39 (48,1)	20 (24,7)	1 (1,2)
Item 23	23 (28,4)	50 (61,7)	6 (7,4)	2 (2,5)
Item 24	16 (19,8)	54 (66,7)	11 (13,6)	0 (0,0)
Item 25	3 (3,7)	29 (35,8)	28 (34,6)	21 (25,9)
Item 26	0 (0,0)	7 (8,6)	43 (53,1)	31 (38,3)
Item 27	2 (2,5)	4 (4,9)	45 (55,6)	30 (37,0)

Item 28	2 (2,5)	3 (3,7)	62 (76,5)	14 (17,3)
Item 29	2 (2,5)	11 (13,6)	46 (56,8)	22 (27,2)

In this study, we observed that males exhibited higher Internalized Stigma of Epilepsy (ISEP) scores compared to 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 epilepsy 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 each type of epilepsy ($p=0.012$; $p<0.05$). However, there were no significant differences in stigma scores based on education level, occupation, and the use of antiepileptic drugs (AEDs).

Table 4. ISEP Score Based on Subject Characteristics.

Characteristics	Stigma Score (Median (Min-Max))	p
Sex		
- Male	62,5 (36,0-71,0)	0,039
- Female	59,0 (36,0-79,0)	
Education		
- Elementary School	66,5 (63,0-70,0)	0,267
- Middle School	61,5 (55,0-70,0)	
- High School	61,0 (36,0-79,0)	
- College/University	59,0 (36,0-70,0)	
Occupation		
- College Student	59,5 (36,0-71,0)	0,904
- Unemployment	62,0 (50,0-70,0)	
- Housewife	59,0 (36,0-71,0)	
- Entrepreneur	59,0 (36,0-79,0)	
- Civil Servant	61,0 (36,0-70,0)	
- Retiree	59,0 (59,0-63,0)	
Type		
- Generalized	59,5 (36,0-71,0)	0,012
- 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

Discussion

This study aimed to assess stigma and identify factors associated with internalized stigma in people with epilepsy. The study involved 81 subjects from neurology outpatient clinics at two university teaching hospitals in Medan, North Sumatra, Indonesia. The mean age of the patients was 34.7 ± 14.5 , with an approximately equal gender distribution. Age is considered related to epilepsy prevalence and incidence, with lower prevalence in children, increasing in adolescents and young adults, and decreasing after 30 years.^{13,14} Older age at epilepsy diagnosis correlates with a poorer quality of life, potentially due to better emotional control when diagnosed at a younger age.¹⁵ Studies report 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 women, attributed to differences in brain development and social effects.^{17,18}

Among the 408 patients studied, 71.8% had seizure frequencies ranging from 1-11 times per year. Most participants (76%) received monotherapy, and 67.2% had a history of antiepileptic drug (AED) nonadherence.¹⁹ Generalized tonic-clonic seizures were the most common type in Sudan (68%), followed by focal seizures (11%).²⁰

A study with 431 epilepsy patients 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 higher prevalence.²¹⁻²³ Our study aligns with these findings, indicating that the majority of patients received monotherapy (63%), experienced generalized seizures (96.3%), with a mean seizure duration of 94.2 ± 101.5 months.^{21,24}

Epilepsy is often stigmatized, with a study in Sudan reporting depression (28%), anxiety (18%), and social problems (37%) among epilepsy patients. In our study, 79% of patients experienced a moderate degree of 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 include 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 subjects answered in the affirmative which illustrates that there is still a negative stigma towards people with epilepsy. 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 towards patients with epilepsy.^{4,12}

Stigma in epilepsy patients 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 coping 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. Gender and type of epilepsy showed 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 which 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

A significant negative correlation of moderate strength was found between self-confidence and stigma of patients with epilepsy ($P < .001$, $\rho = -.423$). A weak significant positive correlation was found between self-confidence and knowledge ($P = .005$, $\rho = .177$). This states that proper knowledge about epilepsy can increase the self-confidence of patients with epilepsy and then it can decrease stigma related to epilepsy. Low education level, long duration of seizures, and young age at first onset have an impact on the formation of stigma. However, no relationship was found between stigma and age, gender, wealth, and type/frequency of seizures.²⁶ In a study it was reported that, most of PWE with internalized stigma have low levels of education and are unable to access good health services. Patients often acquire inaccurate knowledge about epilepsy from disorganized pathways. Most PWE recognize epilepsy as a neurological disorder. Causes of epilepsy in patients include head injury, perinatal

trauma, encephalitis or meningitis, hypertension, stroke, malnutrition, febrile seizures, and so on. A number of patients admitted that they did not know the cause. Patients who know the cause have less fear, have more positive attitudes, and higher confidence in curing or controlling their condition than those who do not know the cause.²⁷ Stigma in patients with epilepsy was also considered to be positively correlated with the severity of seizures ($p=0.034$), the number of epilepsy medications ($p= 0.035$), depression score ($p<0.0001$), and quality of life ($p<0.0001$). However, stigma was assessed as 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

In addition to the factors mentioned earlier, patients with a disease duration of 2-5 years are found to be four times more likely to experience self-stigma compared to those with an illness duration of less than one year. This could be attributed to the chronic nature of the disease, a lack of coping strategies against the impact of seizures, or the patient may not have developed the ability to resist stigma. This lack of resistance may hinder the patient's ability to overcome differences in cultural beliefs, social stigma, and the overall impact of the disease, contributing to their perception of stigma. These findings suggest that individuals with a longer disease duration are more prone to perceiving stigma than those with a shorter duration. Specifically, patients with an illness duration of 2-5 years are four times more likely to develop stigma perceptions compared to those with less than a year of illness. Similarly, patients with a disease duration of 6-10 years and those with an illness duration of more than or equal to eleven years are also four times more likely to form perceptions of stigma compared to those with less than a year of illness. The different results in this study from previous studies occurred due to differences in health systems and research methods used. This could also be due to differences in the stigma scale used.²⁵

The study has limitations, including a small sample size and a lack of exploration into the relationship between seizure duration and self-stigma. Knowledge levels about epilepsy and seizure causes were not extensively examined. In conclusion, our study identified various factors influencing internalized stigma in epilepsy patients, emphasizing the importance of raising awareness and improving knowledge to reduce epilepsy-related stigma.

Conclusion

Our study found that internalized stigma in patients with epilepsy was influenced by several factors, such as gender and type of epilepsy. However, factors such as education, seizure duration, and AED use cannot be excluded. This study highlights the need to improve knowledge and raise awareness of epilepsy to reduce the stigma associated with epilepsy.

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