Trauma Monthly 2026; 31(4): 1935-1943

10.30491/tm.2026.596426.1982

Trauma Monthly

Research Article

The Psychosocial Trauma of Epilepsy: Stigma, Social Isolation, and Patient Outcomes

Ali. F. Hassan[1], Ahmed Mohammed Jasim Shlash[2*], Mohammad Basim Nadheer[3], Ali Alaa Alhashmi[4], Mohammad K. Abdul-Jaleel[5], Abbas. F. Mousa[6]

[1] Community Health Nursing Department, College of Nursing, University of Al-Ameed, Iraq
[2] Adults Health Nursing Department/ College of Nursing, University of Babylon, Iraq
[3] Adults Health Nursing Department, College of Nursing, University of Al-Ameed, Iraq

***Corresponding Author**: Ahmed Mohammed Jasim Shlash, Adults Health Nursing Department / College of Nursing, University of Babylon, Iraq. dr.ahmed.shlash@uobabylon.edu.iq, ORCID: 0000-0003-2828-1003.

Received 2025-12-05 ; **Accepted** 2026-05-25; **Online Published** 2026-08-29

Abstract

Introduction: Epilepsy is a chronic neurological disorder that has an impact on a person's social and psychological health. Social stigma and isolation are major psychosocial traumas affecting mental health, quality of life, and social participation. These factors critically influence mental health, quality of life, and social participation, yet they remain underrecognized in routine clinical care. This study aimed to (1) assess the effects of psychosocial factors—specifically stigma and social isolation—on patients with epilepsy, and (2) examine the association between patients' demographic and clinical characteristics and their psychosocial outcomes

Method: A descriptive cross-sectional study was conducted from 16/5/2024 to 20/10/2024, using purposive non-probability sampling to select 100 patients with epilepsy from the Middle Euphrates Neurological Center in Najaf Governorate, Iraq.

Result: Most participants were male, aged 20 to 30 years, married, and illiterate; disease onset was at age 21 or older; most were non-smokers; and the pathology was idiopathic. Lastly, overall psychosocial aspects of the patients with stigma were at a moderate level and a severe level according to social isolation, so the overall effect of psychological aspects was at a moderate level psychosocially.

Conclusion : Patients with epilepsy experience considerable psychosocial trauma, with moderate levels of stigma and severe social isolation. These findings emphasize the urgent need to combine routine psychosocial assessment and trauma-informed supportive interventions into epilepsy care to improve patients' overall well-being and clinical outcomes.

Keywords: Stigma, social isolation, psychosocial aspects.

Introduction

Epilepsy is a neurological disorder affecting individuals worldwide. It is characterized by recurrent, brief seizures accompanied by abnormal movements that can affect the entire body or a specific area. Epilepsy can be partial or generalized. Generalized epilepsy affects the entire body and may cause seizures anywhere within it. Loss of consciousness accompanied by urinary incontinence or bedwetting is a symptom of generalized epilepsy [1].

Because the cause of epilepsy remains unknown, many physicians are unprepared to treat patients experiencing seizures. Approximately 2.5 million people in the United States have epilepsy in some form. Different types of seizures characterize this disease. People with epilepsy cannot predict when seizures will occur. The severity and causes of epilepsy vary. People with epilepsy are also more prone to seizures. In practice, the disease affects the lives of those affected by making them more dependent on others, making driving difficult, and creating obstacles at school, work, and social gatherings [2].

Many prenatal and postnatal conditions, including congenital disabilities, head problems and tumors, blood clots, vascular disorders, metabolic processes, brain

infections (bacterial or viral), and metabolic imbalances (hypoglycemia, hypocalcemia, etc.), can lead to seizures. Other, less well-known factors contribute to cerebellar inflammation. Antiepileptic drugs are most effective in children whose epilepsy symptoms are not yet apparent [3].

Families' perceptions of epilepsy and how they cope with it play a crucial role in its management. Educating people about epilepsy takes time to alleviate their anxiety, but when they or their loved ones experience social exclusion, they need even more psychological support [4].

Social isolation and impaired social integration are consequences of the perceived social stigma associated with the illness or excessive dependence on others. Fear of seizures is a common symptom among people with epilepsy. Seizures can be embarrassing, which in turn can lead to social isolation, low self-esteem, and poor academic performance [5]. According to Boyer, social stigma is evident when adults are unable to marry, when people with epilepsy are unable to work, and when they face difficulty finding stable employment due to their condition [6]. However, there is a lack of studies examining the psychosocial experiences of epilepsy patients in Iraq, and the specific contribution of stigma and social isolation to patient outcomes remains unexplored.

Given the significant psychosocial trauma imposed by epilepsy and the particular vulnerability of patients in stigmatizing cultural contexts, this study was designed to assess the impact of psychosocial factors—specifically stigma and social isolation—on patients with epilepsy in Najaf Governorate, Iraq. The study also examined the association between patients' demographic and clinical characteristics and their psychosocial outcomes.

Methods

Study Design

A cross-sectional study design was conducted from 16/5/2024 to 20/10/2024 to assess the psychosocial impact of epilepsy—specifically stigma and social isolation—among patients attending the Middle Euphrates Neurological Center in Najaf Governorate, Iraq.

Study Setting

Data were collected at the Middle Euphrates Neuroscience Center in Iraq between 5/7/2024 and 5/8/2024. The Institutional Review Board (IRB)/Ethics Committee formally approved the study (Approval No. 146), dated 24/6/2024.

Study Sample and Sampling Strategy

The study included 100 patients with epilepsy who were selected from the Middle Euphrates Neurological Center in Najaf Governorate, Iraq, using purposive non-probability sampling.

Inclusion and Exclusion Criteria

Inclusion Criteria:

Diagnosis of tonic-clonic (generalized) epilepsy, confirmed by a neurologist

Age more than 20 years

Duration of epilepsy diagnosis of at least one year

History of recurrent visits to the center (established patient)

Willingness to provide an informed consent form

Exclusion Criteria:

Age less than 20 years

Duration of epilepsy diagnosis less than one year

First visit to the center (no established patient history)

Diagnosis of focal (partial) epilepsy or other seizure types without tonic-clonic components

Cognitive impairment or psychiatric conditions that would interfere with the ability to complete the questionnaire

The focus on tonic-clonic epilepsy was intentional, as this seizure type is most visibly associated with stigma due to its dramatic presentation and higher likelihood of public occurrence (Scambler & Hopkins, 1986).

Data collection:

Data were collected using a revised and updated questionnaire administered through structured face-to-face interviews with each participant. The Arabic version of the questionnaire was distributed individually to all participants at the Middle Euphrates Neuroscience Center. To ensure consistency, all interviews were conducted at the same location using the same questionnaire and standardized interview procedures. Each interview lasted approximately 15–20 minutes, allowing ample time for participants to complete all questionnaire items.

Measurement Instruments: To confirm the instrument's suitability for this study, the questionnaire was revised and evaluated by a panel of 10 experts who are specialists in (adult/psychiatric/community) health nursing with a scientific degree in philosophy of nursing and above; minor modifications were made based on the experts' recommendations. The CVI values for items ranged from 0.80 to 0.90, and the average was 0.84. The CVR values ranged from 0.65 to 1.00, indicating acceptable value, resulting in a final questionnaire consisting of three sections:

Section one: Socio- demographical Data:

The first section focused on the demographic and personal characteristics of the participants. It included 12 variables: age, sex, and age at onset of the disease, occupation before and after onset of the disease, marital status, number of children, educational level, monthly income, place of residence, smoking status, and family history of epilepsy.

Section two: Clinical Pathological Data:

The second section focused on clinical characteristics and included 11 items covering the causes of epilepsy, the frequency of seizures before and after treatment, the method of treatment, the duration and cost of medication, adherence to medication, family and social support, participation in social activities, ability to drive, and ability to travel.

Section three: Psychosocial domain:

Section three consisted of 15 items divided into two domains: social isolation (10 items) and stigma (5 items). Participants' responses were measured using a three-point Likert scale, with scores assigned as follows: 3 = Agree, 2 = Unsure, and 1 = Disagree.

Data Analysis: The data were analyzed using SPSS 22. Descriptive statistics, including frequencies, percentages, mean scores, and SD, were used to summarize the data. Statistical tests, including the independent samples t-test, ANOVA, and chi-squared test, were applied to examine differences and correlations. A P-value of 0.05 was considered significant.

Informed Consent: Informed consent was obtained from all included patients. Participation was entirely voluntary, and completing the questionnaire served as confirmation of consent to participate.

Ethical Considerations: Formal ethical approval was obtained from the Institutional Review Board (IRB)/Ethics Committee of Al-Ameed University, College of Nursing (Approval Number: 146, dated 24/6/2024).

Results

Sociodemographic Characteristics

A total of 100 patients with epilepsy were included. Most participants were male (64%, n = 64) and aged 20-30 years (44%, n = 44). Most participants were married (60%, n = 60), and 45% (n = 45) had no children.

Regarding educational attainment, 32% were illiterate, and only 10% (n = 10) held a bachelor's degree or higher. Employment status changed substantially following epilepsy diagnosis: before illness, the highest proportion was housewives (31%), and this proportion increased to 37%, while the proportion of students decreased from 22% to 1%.

Financial dissatisfaction was prevalent, with 60% reporting that their monthly income was insufficient. The majority resided in urban areas (73%), were non-smokers (83%), and reported no family history of epilepsy (73%) (Table 1).

Clinical Characteristics

Table 2 presents the patients' clinical characteristics. The majority of patients had idiopathic epilepsy (81%, n = 81), with no identifiable cause. Before treatment, 63% (n = 63) experienced 1–3 seizures, while 32% (n = 32) experienced 4–6 seizures. Following treatment, 71% (n = 71) reported being seizure-free, showing a good treatment response.

Regarding treatment, 57% (n = 57) were on monotherapy, while 43% (n = 43) required multiple antiepileptic drugs. Medication duration varied: 41% (n = 41) had been taking medication for years, 39% (n = 39) for days, and 20% (n = 20) for months. Medication adherence was high, with 78% (n = 78) reporting regular use.

61% (n = 61) of patients reported receiving social and family support, while 39% (n = 39) reported no such support. However, 63% (n = 63) did not participate in community activities, and the vast majority reported being unable to drive (90%, n = 90) or travel independently (77%, n = 77)—significant contributors to social isolation.

Psychosocial Outcomes: Stigma and Social Isolation

Social isolation appeared as the most severe psychosocial burden, with 68% (n = 68) of patients categorized as experiencing severe social isolation (mean score = 2.43, SD = 0.51). In contrast, stigma was assessed as moderate overall, with 52% (n = 52) categorized as experiencing severe stigma (mean score = 2.25, SD = 0.55) (Table 3).

Scoring Interpretation: Mean scores are based on a 3-point Likert scale (1 = Disagree, 2 = Unsure, 3 = Agree)

Cutoff points: Severe > 2.34; Moderate 1.67–2.33; Mild < 1.67.

Overall Psychosocial Burden

The overall psychosocial burden—combining stigma and social isolation scores—was assessed as moderate, with a mean score of 2.28 (SD = 0.46). 50% (n = 50) of participants experienced severe overall burden, while 41% (n = 41) experienced moderate burden, and 9% (n = 9) experienced mild burden (Table 4).

Item-Level Analysis: Stigma Domain

Table 5 presents the stigma domain. Eight out of ten items (80%) were rated as severe. These findings demonstrate that internalized stigma—shame, self-blame, and negative self-perception—is pervasive among participants, despite the overall moderate assessment. The severe rating on items related to medication side effects and memory problems further emphasizes the condition's multifaceted burden.

Item-Level Analysis: Social Isolation Domain

As shown in Table 6, three out of five items (60%) in the social isolation domain were rated as severe, with the remaining two items rated as moderate. The most severe items included:

"I always have to prove myself because of the seizure condition" (mean = 2.44, SD = 0.87)

"I feel comfortable being seen in public with a person who is known to have epilepsy" (mean = 2.40, SD = 0.91).

These findings highlight the profound social alienation experienced by patients, consistent with the conceptualization of stigma and isolation as psychosocial trauma. Association between Psychosocial Burden and Sociodemographic Factors We examined the relationship between overall psychosocial burden and sociodemographic characteristics using the chi-square test (Table 7). Only one variable showed a statistically significant association: occupation before illness onset ($\chi^2 = 23.87$, df = 10, p = 0.008). This suggests that patients' occupational status before diagnosis may influence their psychosocial adjustment.

No other sociodemographic factors—including age, sex, age at diagnosis, marital status, educational level, income, residency, smoking status, or family history—were significantly associated with psychosocial burden (all $p > 0.05$).

Association between Psychosocial Burden and Clinical Factors

Table 8 presents the association between psychosocial burden and clinical characteristics. Two variables showed statistically significant associations: medication cost and social/family support. Medication Cost ($\chi^2 = 6.00$, df = 2, p = 0.05): Patients who did not receive free medication reported higher psychosocial burden. Social and Family Support ($\chi^2 = 7.59$, df = 2, p = 0.02): Patients without social and family support experienced significantly greater psychosocial burden. No other clinical factors—including disease type, seizure frequency (before or after treatment), treatment type, medication duration, medication adherence, community activity participation, or ability to drive/travel—were significantly associated with psychosocial burden (all $p > 0.05$).

Table 1: Sociodemographic Characteristics of Study Participants (N = 100)

Characteristic	Category	Frequency (n)	Percentage (%)
Age (years)	20–30	44	44
	31–41	31	31
	≥ 42	25	25
Sex	Male	64	64
	Female	36	36
Age at disease onset (years)	1–5	10	10
	6–10	11	11
	11–15	23	23
	16–20	16	16
	≥ 21	40	40
Occupation before illness	Employed	18	18
	Student	22	22
	Not working	7	7
	Self-employed	21	21
	Housewife	31	31
	Retired	1	1
Occupation after illness	Employed	15	15
	Student	1	1
	Not working	13	13
	Self-employed	28	28
	Housewife	37	37
	Retired	6	6
Marital status	Single	27	27
	Married	60	60
	Divorced	7	7
	Separated	1	1
	Second marriage	3	3
	Widowed	2	2
Number of children	None	45	45
	1–4	36	36
	≥ 5	19	19
Educational level	Illiterate	32	32
	Read and write only	19	19
	Primary school	19	19
	Secondary school	20	20
	Bachelor's or higher	10	10
Income satisfaction	Satisfied	13	13
	Unsatisfied	60	60
	Somewhat satisfied	27	27
Residency	Rural	27	27
	Urban	73	73
Smoking status	Smoker	17	17
	Non-smoker	83	83
Family history of epilepsy	Present	27	27
	Absent	73	73

Table 2: Clinical Characteristics of Study Participants (N = 100)

Clinical Variable	Category	Frequency (n)	Percentage (%)
Disease type	Symptomatic	19	19
	Idiopathic	81	81
Seizure frequency before treatment	1–3	63	63
	4–6	32	32
	≥ 7	5	5
Seizure frequency after treatment	None	71	71
	1–3	23	23
	4–6	4	4
	≥ 7	2	2
Treatment type	Monotherapy	57	57
	Polytherapy	43	43
Medication duration	Days	39	39
	Months	20	20
	Years	41	41
Medication cost	Free	31	31
	Not free	69	69
Medication adherence	Regular	78	78
	Irregular	16	16
	Discontinued	6	6
Social/family support	Present	61	61
	Absent	39	39
Community activity participation	Yes	37	37
	No	63	63
Ability to drive	Able	10	10
	Unable	90	90
Ability to travel	Able	23	23
	Unable	77	77

Table 3: Levels of Stigma and Social Isolation Among Study Participants (N = 100)

Domain	Level	Frequency (n)	Percentage (%)	Mean Score	Assessment
Social Isolation	Severe	68	68	2.43	Severe
	Moderate	19	19		
	Mild	13	13		
Stigma	Severe	52	52	2.25	Moderate
	Moderate	26	26		

Table 4: Overall Psychosocial Burden (N = 100)

Domain	Level	Frequency (n)	Percentage (%)	Mean Score	Assessment
Overall Psychosocial Burden	Severe	50	50	2.28	Moderate
	Moderate	41	41		
	Mild	9	9		
	Total	100	100		

Table 5: Item-Level Analysis of Stigma Domain (N = 100)

Item	Mean	SD	RS%	Assessment
1. I feel out of place in the world because I have epilepsy.	2.42	0.83	80.67	Severe
2. Having epilepsy has spoiled my life.	2.50	0.82	83.33	Severe
3. People without epilepsy could not possibly understand me.	2.32	0.86	77.33	Moderate
4. I am embarrassed or ashamed that I have epilepsy.	2.43	0.86	81.00	Severe
5. I am disappointed in myself for having epilepsy.	2.52	0.81	84.00	Severe
6. I feel inferior to others who don't have epilepsy.	2.42	0.83	80.67	Severe
7. Because of my seizure condition, I have problems developing intimate relationships.	2.19	0.94	73.00	Moderate
8. Anti-epileptic drugs bother me; they affect my mental condition.	2.61	0.78	87.00	Severe
9. I worry that I might hurt myself during a seizure.	2.48	0.81	82.67	Severe
10. I have problems with my memory.	2.46	0.82	82.00	Severe

Table 6: Item-Level Analysis of Social Isolation Domain (N = 100)

Item	Mean	SD	RS%	Assessment
1. I feel comfortable being seen in public with a person who is known to have epilepsy.	2.40	0.91	80.00	Severe
2. In general, I am able to live my life the way I want to.	2.22	0.92	74.00	Moderate
3. Epileptic patients can make important contributions to the community.	2.15	0.95	71.67	Moderate
4. Living with epilepsy has made me a tougher survivor.	2.05	0.95	68.33	Moderate
5. I always have to prove myself because of the seizure condition.	2.44	0.87	81.33	Severe

Table 7: Association between Psychosocial Burden and Socio-demographic Factors

Variable	χ^2	df	p-value	Significance
Age	2.78	4	0.59	NS
Sex	1.35	2	0.50	NS
Age at disease onset	8.25	8	0.40	NS
Occupation before-illness	23.87	10	0.008	S
Occupation after-illness	10.70	10	0.38	NS
Marital status	3.46	10	0.96	NS
Number of children	5.37	4	0.25	NS
Educational level	9.27	8	0.32	NS
Income satisfaction	2.71	4	0.60	NS
Residency	1.38	2	0.50	NS
Smoking status	2.89	2	0.23	NS
Family history of epilepsy	4.09	2	0.12	NS
NS = Non-significant; S = Significant ($p < 0.05$).				

Table 8: Association between Psychosocial Burden and Clinical Factors

Variable	χ^2	df	p-value	Significance
Disease type (idiopathic/symptomatic)	0.58	2	0.74	NS
Seizure frequency before treatment	8.57	12	0.73	NS
Seizure frequency after treatment	11.34	14	0.65	NS
Treatment type (mono/polytherapy)	5.81	2	0.05	NS
Medication duration	4.70	4	0.31	NS
Medication cost	6.00	2	0.05	S
Medication adherence	0.92	4	0.92	NS
Social and family support	7.59	2	0.02	S
Community activity participation	0.37	2	0.82	NS
Ability to drive	0.45	2	0.79	NS
Ability to travel	0.59	2	0.74	NS
NS = Non-significant; S = Significant ($p < 0.05$).				

Discussion

The findings indicate that most people with epilepsy are married and male, and aged between 20 and 30 years. Several studies have shown that young, single males constitute the majority of epilepsy patients in Baghdad. Males, particularly those in their 20s, also formed the majority of the sample in other studies [7]. Most samples were homemakers experiencing dissatisfaction with their monthly income and suffering from the disease for a long period. Other studies supported these findings, revealing similar levels of education among the samples; 51% were unemployed, were unsatisfied with their monthly income, and had been ill for five years or less [8]. A study showed that the majority of the sample lived in urban areas. Given the significant impact of smoking on epileptic health, understanding one's history is crucial.

Several studies have linked cigarette smoking to unexpected patient deaths, although none of the patients in this study were smokers [9]. Most participants reported having no children, which supports the findings of a researcher who investigated the effects of epilepsy and antiepileptic drugs on the reproductive system and increased infertility [10]. Since no family members exhibited symptoms, other studies suggested a hereditary component to the disease. A previous case-control study had already demonstrated an association between consanguineous marriage and family history [11]. Based on clinical data, idiopathic epilepsy associated with a localized focus was found to be more common

than symptomatic epilepsy, as confirmed by Table 2. A high number of seizures were observed, which is a cause for concern for the patients in this study. 71% of epileptic patients without seizures after antiepileptic drug administration and pre-treatment had 1-3 seizures occur daily; the results are consistent with those of a study [12], which found that nearly 70% of epilepsy patients ceased experiencing seizures after starting antiepileptic drugs. According to the study [13], which demonstrated that antiepileptic monotherapy is the most effective, the majority of epilepsy patients require only one course of treatment. Assuming the patient continues taking the medication as prescribed, a significant improvement in their ability to control seizures and prevent relapse is expected [14].

Regarding coverage for antiepileptic medication, the majority of epilepsy patients do not receive free medication [15]. The findings show that most of these patients lacked social and family support, were unable to travel or drive, and were also unable to participate in social activities. A study by Wang et al. (2015) found that most patients received assistance from their families or friends. Social status and family support are crucial factors in improving social well-being and predicting health among people with chronic illnesses. Patients' social lives improve significantly when they can participate in activities and drive themselves; however, some studies prohibit them from driving [22]. Furthermore, data suggest that the inability of most epilepsy patients to travel between regions may be a side effect of their treatment. An increase in seizures among epilepsy patients has been linked to air travel, according to one study [16].

Also, the findings reveal a moderate level of impact of psychosocial aspects, which include stigma and social isolation. In fact, seizures can have a psychological impact on them, causing them to isolate themselves from others because of fear of rejection or embarrassment. Among the numerous studies supporting this, the study [17] stands out, demonstrating how people with epilepsy face a variety of psychosocial challenges, including myths, stereotypes, and stigma. Of these challenges, patients ranked social isolation, loneliness, perception of stigma, coping mechanisms, and psychological distress as having the greatest impact on their quality of life. Regarding psychosocial aspects, findings reveal a moderate level of social withdrawal but a severe level of stigma; these findings are supported by [18], who found that patients' friends and family may feel ashamed upon learning of their epilepsy diagnosis. A non-statistically significant relationship was observed between the patient's overall psychosocial aspects and their demographic data. Only before-illness occupation was significant. Clinical and demographic data associated with psychological distress include unemployment, disabilities (with treatment), and illness severity. Several studies have reported psychological distress. It was also found that all women participating in the study were unemployed, with a significant number being single [19].

Finally, the findings reveal a non-statistically significant relationship between clinical data and psychosocial aspects overall across all items ($p > 0.05$), except for medication cost, family, and social support. The economic and social outcomes of epilepsy include direct and indirect costs, which is consistent with a study [20] that examined a national sample by age, gender, and social follow-up. Another study [21] analyzed the cost-effectiveness of antiepileptic drugs in newly diagnosed epilepsy cases in 12 European countries and found that cost-effectiveness affects the quality of life of epilepsy patients.

Conclusion

Patients with epilepsy had severe psychosocial trauma, including social isolation and stigma. These psychosocial aspects were at moderate levels, and there was a significant relationship between medication cost, occupation before illness, family and social support, and psychosocial aspects. This emphasizes the importance of holistic care that addresses both the psychological and clinical aspects of their condition. It is essential to increase the self-confidence of epilepsy patients and provide them with the necessary social support through psychological programs.

Acknowledgment

None.

Conflict of Interest Disclosures

The authors declare that they have no competing interests.

Funding Sources

None.

Authors' Contributions

All authors read and approved the final manuscript. All authors take responsibility for the integrity of the data and the accuracy of the data analysis.

Ethical Statement

The data were collected at the Middle Euphrates Neuroscience Center in Iraq between 5/7/2024 to 5/8/2024. This study was formally approved by the Institutional Review Board (IRB) / Ethics Committee has considered the application for research ethics (Approval No. 146), date 24/6/2024.

Declaration of Generative AI and AI-assisted technologies

None.

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