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Perceived Stigma and Social Misconceptions in People with Epilepsy

Kebire Eylül Arslan, İrem Fatma Uludağ

University of Health Sciences Türkiye, İzmir Tepecik Education and Research Hospital, Clinic of Neurology, İzmir, Türkiye

Kebire Eylül Arslan MD,

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Corresponding Author: İrem Fatma Uludağ, MD. Prof., University of Health Sciences Türkiye, İzmir Tepecik Education and Research Hospital, Clinic of Neurology, İzmir, Türkiye, **E-mail:** fatmairem@yahoo.com

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Abstract

Objective: Although advances in diagnosis and treatment have improved seizure control in epilepsy, the psychosocial burden of the condition remains substantial. Stigma, social misconceptions, and perceived barriers in education, employment, and interpersonal relationships continue to shape the lived experience of people with epilepsy. Understanding these challenges in contemporary clinical populations is essential for informing patient-centered care and public awareness strategies. To investigate the social, educational, occupational, and relational experiences of adults with epilepsy, with particular emphasis on perceived stigma and societal attitudes.

Methods: In this cross-sectional study conducted at a tertiary epilepsy clinic, 90 adult patients (mean age 36.8±12.0 years) completed a structured questionnaire consisting of Likert-type items and open-ended questions exploring experiences related to education, employment, social relationships, and stigma. Clinical data, including epilepsy type, seizure frequency, and treatment characteristics, were obtained from medical records. Responses were analyzed descriptively, and open-ended questions were thematically categorized.

Results: Participants reported a range of psychosocial challenges, including perceived negative reactions from others, concerns regarding relationships and family life, and difficulties in educational and occupational settings. A notable proportion of patients reported difficulties related to societal attitudes (38.8%). Open-ended responses indicated that difficulty in socializing (26.7%), fear of seizures (20%), and challenges in finding employment (15.6%) were among the most frequently reported concerns. Misconceptions in the community included beliefs that people with epilepsy may be dangerous to others (37.7%) or may be less productive at work (11.1%).

Conclusion: Despite advances in clinical management, epilepsy remains associated with substantial psychosocial burden and perceived stigma. These findings highlight the need for ongoing efforts to address public misconceptions, support patients in social and professional domains, and integrate psychosocial considerations into routine epilepsy care.

Keywords: Epilepsy, misconceptions, quality of life, social perceptions, stigma

INTRODUCTION

Epilepsy is one of the most common chronic neurological disorders worldwide, characterized not only by recurrent seizures but also by a broad spectrum of psychosocial consequences. Although advances in diagnostic techniques, pharmacological treatments, and surgical interventions have improved seizure control for many individuals, living with epilepsy continues to be associated with challenges that extend beyond the clinical manifestations of the disease.[1]

Stigma has long been recognized as a central aspect of the experience of epilepsy. It encompasses both enacted stigma, referring to experiences of discrimination, and felt stigma, which reflects internalized perceptions of shame, social distance, or fear of negative judgment. Theoretical models suggest that stigma arises through complex interactions among cultural beliefs, social power dynamics, and misconceptions regarding the nature of the condition.[2] Even in settings where medical understanding of epilepsy has advanced considerably, stigma persists as a significant contributor to reduced quality of life and social participation.[3,4]

Research has demonstrated that stigma and negative societal attitudes toward epilepsy can affect multiple domains of life, including education, employment, interpersonal relationships, and family formation. Misconceptions—such as beliefs that epilepsy is contagious, associated with mental illness, or indicative of reduced competence—continue to influence how individuals with epilepsy are perceived and treated within their communities.[3] Moreover, psychosocial factors such as depression, social support, and socioeconomic conditions have been shown to interact with perceived stigma, further shaping individual experiences.[5]

While previous studies have examined stigma and psychosocial outcomes in diverse populations, there remains a need for contemporary clinical data reflecting the real-world experiences of patients receiving routine care. Understanding how individuals with epilepsy perceive their condition within their social environments may help identify ongoing barriers and inform interventions aimed at reducing stigma and improving overall well-being.[2]

The present study aimed to explore the educational, occupational, relational, and social experiences of adults with epilepsy in a tertiary care setting, with particular attention to perceived stigma and common societal misconceptions. By combining structured questionnaire data with patients' own perspectives, we sought to provide a comprehensive view of the psychosocial dimensions of living with epilepsy in the modern era.

METHODS

This study was conducted in January 2026 at the Neurology Clinic of the University of Health Sciences Türkiye, İzmir Tepecik Education and Research Hospital. The study protocol was approved by the University of Health Sciences Türkiye, İzmir Tepecik Education and Research Hospital Non-Interventional Research Ethics Committee (approval no: 2026/01-14, date: 02.02.2026) and was conducted in accordance with the principles of the Declaration of Helsinki.[6] Informed consent was obtained from all subjects.

A total of 90 adult patients with epilepsy who were followed up at the epilepsy outpatient clinic and who voluntarily agreed to participate were included in the study; 57 were female and 33 were male. The mean age of the participants was 36.8±12.0 years (range: 19-63 years).

During their routine outpatient visits, participants were asked to complete a questionnaire administered by the investigators. The questionnaire was developed by the investigators specifically for this study and consisted of 15 Likert-type items and additional open-ended questions. Patients who had psychiatric or neurological conditions that could interfere with their ability to respond to the questionnaire, such as aphasia or cognitive impairment, were excluded.

The first 90 consecutive patients who met the inclusion criteria—being between 18 and 65 years of age, having regular follow-up and available medical records, having no condition that would prevent them from answering the questionnaire, and providing voluntary consent—were enrolled in the study. No additional selection criteria were applied with respect to epilepsy type, seizure type, or treatment regimen.

MAIN POINTS

- Epilepsy continues to impose a substantial psychosocial burden beyond seizure control.
- Perceived stigma affects education, employment, relationships, and social integration.
- Patients report persistent societal misconceptions and fears of negative reactions.
- Psychosocial concerns remain prominent even in patients under regular clinical follow-up.
- Targeted stigma-reduction strategies are needed alongside medical treatment.

Internal consistency was assessed exclusively for the 15 Likert-type items using Cronbach's alpha. Responses to open-ended questions in which participants expressed their views (e.g., "In your opinion, what is the greatest challenge of living with epilepsy?") were categorized into thematic groups and analyzed descriptively using frequencies and percentages.

Statistical Analysis

In addition to the information obtained from the questionnaire on the day of assessment, data regarding epilepsy type, seizure frequency, and use of antiseizure medications were verified by review of patients' medical records. Frequency analyses and descriptive statistics were performed using SPSS software version 27 (IBM Corp., Armonk, NY, USA).

RESULTS

The demographic and clinical characteristics of the patients are presented in Table 1. Eighty patients (88.9%) reported attending regular medical follow-up visits even in the absence of symptoms, whereas 10 patients (11.1%) stated that they consulted a physician only in emergency situations. Nine patients (10.0%) reported difficulties in accessing healthcare services. Among the 21 patients (23.3%) who had applied for disability-related benefits, 8 had their applications approved.

Regarding educational status, 3 patients (3.3%) had never attended school, 35 (38.9%) had completed primary education, 36 (40.0%) had completed high school, and 16 (17.8%) had completed university education.

Sixteen patients (17.8%) reported difficulties in their education due to epilepsy, while 43 patients (47.8%) stated that epilepsy did not affect their education. Thirty-one patients (34.4%) did not respond to this question (Figure 1).

Table 1. Demographic and clinical features

Patients (n)	**90**
Age	36.8±12.0 (19-63) years ± SD
Female/male	57/33
Disease duration	16.9±11 (1-48) years ± SD
Focal/generalized/combined/unknown epilepsy	21/63/4/2
The most common pre-ictal symptoms	Restlessness (7 patients) Fear (7 patients each)
The most common seizure trigger	Fatigue (12 patients) Stress (16 patients)
Seizure frequency (mean seizure/year)	
0	8
1-12	70
≥12	12
Number of anti-seizure medications currently used	
0	8
1	47
2	22
≥3	13

SD: Standard deviation

In terms of employment status, 33 patients (36.7%) were employed full-time, 7 (7.8%) were employed part-time, 36 (40.0%) were unemployed, 10 (11.1%) were retired, and 4 (4.4%) were students. The difficulties experienced throughout the patients' educational and occupational trajectories are shown in Figure 2.

Among the patients, 42 (46.7%) were single and 48 (53.3%) were married. Patients' views on romantic relationships, marriage, and having children are presented in Figure 3.

Thirty-five patients (38.8%) reported experiencing various difficulties related to societal attitudes toward epilepsy (Figure 4).

The most frequently reported responses to the questions "What is the greatest challenge of living with epilepsy?" and "What is the most common misconception about epilepsy in society?" are presented in Table 2.

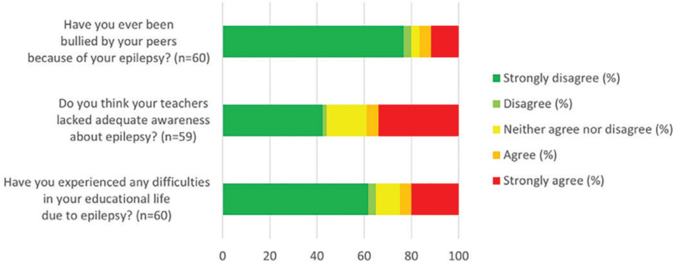

Figure 1. Educational impact

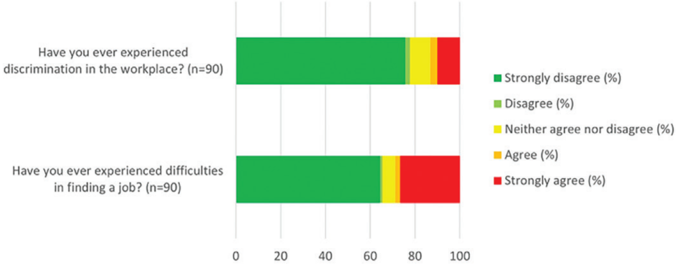

Figure 2. Workplace impact

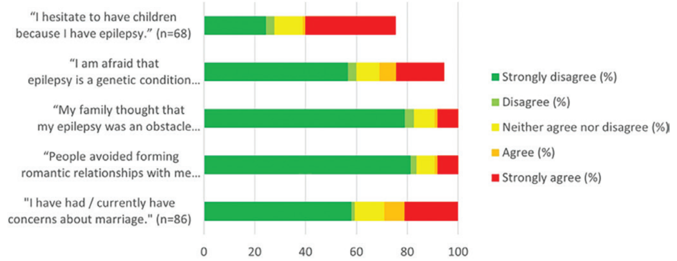

Figure 3. Relationship concerns

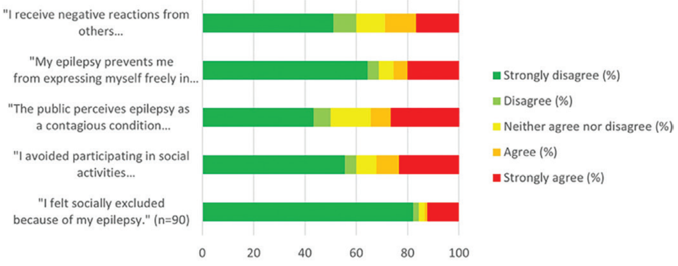

Figure 4. Perceived stigma

DISCUSSION

Our study aimed to re-examine the social, familial, and professional challenges experienced by people with epilepsy in the context of contemporary advances in awareness and treatment. Despite improvements in seizure control, reductions in medication side effects, and increased public education efforts, our findings indicate that people with epilepsy continue to face substantial psychosocial difficulties.

During their education, 20% of our patients reported that their education was more difficult in some respects due to epilepsy, and 40% stated that their teachers' awareness of epilepsy was insufficient (Figure 1). Previous studies have shown that awareness of epilepsy among teachers, and especially among high school students, is quite high, and that attitudes toward people with epilepsy are generally positive.[7,8] Although general attitudes and tendencies are positive, beliefs such as the idea that children with epilepsy should be kept separate from other children have also been reported among teachers at non-negligible rates.[9,10] Educational difficulties may have long-term implications, potentially influencing future employment opportunities and social participation.

Employment-related findings in our cohort are consistent with the literature documenting challenges in workplace integration for people with epilepsy.[11,12] A total of 26.7% of patients had difficulty finding a job, and 10% reported experiencing discrimination in the workplace due to epilepsy (Figure 2). A study conducted in Poland reported that three-quarters of respondents did not consider working with an individual with epilepsy problematic. According to this study, only 55% of employed people with epilepsy had informed their coworkers about their condition, and the majority attempted to conceal their condition for fear of job loss or mistreatment.[13] A study conducted in Australia reported workplace discrimination at a rate of 47%.[14]

Our observation that many patients avoid romantic relationships or express concerns about having children is in line with previous research showing that misconceptions about epilepsy may affect attitudes toward marriage and parenthood (Figure 3). A study conducted among healthcare professionals in Riyadh showed that even 13.4% of healthcare workers believed that patients with epilepsy should not have children.[15] In another study conducted among healthcare workers in Nigeria, the proportion of respondents who did not object to marrying a person with epilepsy was found to be only 12%.[16] These results underscore the persistence of deeply rooted beliefs that may shape interpersonal experiences.

Social withdrawal was also common in our sample, with a notable proportion of patients avoiding social activities due to epilepsy (Figure 4). Such avoidance may reflect fear of seizures occurring in public, anticipated stigma, or prior negative experiences.[17]

Patients frequently reported that epilepsy made socializing, finding employment, and forming a family more difficult, emphasizing the broad impact of the condition on daily life (Table 2).

Importantly, our findings indicate that a considerable proportion (1/3) of patients believes that society perceives them as potentially

Table 2. Most common challenges of living with epilepsy and societal misconceptions

		n (%)
The greatest challenge of living with epilepsy	Fear of having seizures	18 (20%)
	Difficulty in socializing	24 (26.7%)
	Difficulty in finding employment	14 (15.6%)
	Concerns regarding marriage and having children	12 (13.3%)
	Inability to obtain a driver's license	6 (6.6%)
The most common misconception about epilepsy in the community	People with epilepsy may be dangerous to others	34 (37.7%)
	Epilepsy manifests only as generalized tonic–clonic seizures	23 (25.5%)
	Epilepsy is a mental illness or is related to religious beliefs	11 (12.2%)
	Individuals with epilepsy are less productive at work than those without epilepsy	10 (11.1%)

dangerous (Table 2). This perception highlights the ongoing need to address public attitudes toward epilepsy and improve understanding of epilepsy, as such beliefs may contribute to self-limiting behaviors and reduced social participation.[18]

Taken together, our results reinforce the notion that epilepsy should be understood not only as a neurological disorder but also as a condition with significant social implications.

Recent qualitative syntheses have further deepened understanding of stigma in epilepsy by demonstrating that stigma can affect quality of life to a degree comparable to the physical burden of seizures. A meta-synthesis of qualitative studies identified recurring themes, including societal misconceptions, internalized shame, concealment behaviors, and the need for supportive relationships, and highlighted that stigma was experienced across cultural contexts despite differences in healthcare systems and levels of public awareness.[2] These observations resonate with our findings, in which participants reported concerns related to social participation, relationships, and perceived public attitudes, suggesting that stigma remains a multidimensional construct that affects everyday functioning.

The literature also emphasizes that individuals with epilepsy frequently adopt coping strategies such as selective disclosure or avoidance of social situations to mitigate anticipated negative reactions. Such adaptive behaviors may inadvertently reinforce social isolation and reduce opportunities for engagement, contributing to a cycle in which stigma and withdrawal perpetuate each other.[5] The patterns observed in our cohort, including reports of social exclusion and concerns regarding interpersonal relationships, are consistent with this conceptual framework.

Furthermore, previous studies have highlighted the importance of sociocultural context in shaping stigma experiences. Cultural narratives, religious interpretations, and community beliefs can influence whether epilepsy is perceived primarily as a medical condition or as a source of social difference. The persistence of misconceptions—including fears related to contagion or diminished competence—underscores the need for culturally sensitive educational initiatives.[1] Our findings, particularly those related to perceived public attitudes, support the notion that improving community awareness remains a critical component of comprehensive epilepsy care. Continued efforts aimed at improving public awareness, supporting patients in educational and occupational settings, and addressing misconceptions among both the general population and professionals may help reduce the burden experienced by people with epilepsy.

Another aspect underscored in prior research is that stigma can affect major life decisions, including employment, marriage, and family planning. Concerns about disclosure in the workplace or fears of being perceived as unreliable have been reported as barriers to career advancement, while anxieties related to relationships may influence decisions about partnership and parenthood.[19] The relational concerns identified in our study align with these observations and reinforce the broader impact of epilepsy beyond clinical symptoms.

These findings support the view that epilepsy continues to carry a psychosocial burden beyond its clinical manifestations. Stigma appears to remain a central factor in understanding these challenges. Importantly, stigma has been conceptualized as operating at multiple levels—anticipated, enacted, and internalized—each contributing differently to patient experience. Many of the difficulties reported by our patients—including perceived social distance, concerns about being viewed as dangerous, and avoidance behaviors—may reflect both internalized fears and lived experiences within their social environments. Recognizing these dimensions may help clinicians better identify individuals at risk of psychosocial distress and guide interventions that address both individual coping and societal attitudes.[2,20]

This study has several strengths. It provides contemporary data from a real-world tertiary epilepsy clinic, capturing patient experiences within routine clinical care. The use of both structured questionnaire items and open-ended responses allowed for a more nuanced understanding of psychosocial challenges. Additionally, examining multiple domains—including education, employment, relationships, and perceived stigma—enabled a comprehensive assessment of the lived experience of epilepsy.

Study Limitations

Several limitations should be acknowledged. The cross-sectional design limits the ability to draw causal inferences regarding the relationship between clinical variables and psychosocial outcomes. Data were collected from a single tertiary center, which may limit the generalizability of the findings to broader populations or to different healthcare settings. Self-reported measures are subject to recall bias and may be influenced by individual perceptions. Furthermore, psychiatric comorbidities, such as depression and anxiety, were not systematically assessed, although these factors are known to interact with stigma and quality of life.

CONCLUSION

In conclusion, the findings of this study indicate that despite significant advances in the medical management of epilepsy, the condition continues to be associated with substantial psychosocial challenges. Patients still report difficulties related to education, employment, interpersonal relationships, and social participation, many of which appear to be closely linked to persistent societal misconceptions and perceived stigma. These observations highlight that improving seizure control alone may not be sufficient to address the broader impact of epilepsy on daily life. Efforts aimed at increasing public awareness, promoting accurate knowledge about epilepsy, and supporting patients in educational, occupational, and social environments remain essential components of comprehensive epilepsy care. Addressing stigma through targeted educational initiatives and patient-centered interventions may contribute to improvements in social integration and overall well-being among people living with epilepsy.

Ethics

Ethics Committee Approval: The study protocol was approved by the University of Health Sciences Türkiye, İzmir Tepecik Education and Research Hospital Non-Interventional Research Ethics Committee (approval no: 2026/01-14, date: 02.02.2026) and was conducted in accordance with the principles of the Declaration of Helsinki.

Informed Consent: Informed consent was obtained from all subjects.

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For transparency, the authors note that an artificial intelligence-assisted language model (ChatGPT, OpenAI) was utilized to support language correction. This assistance was limited to linguistic refinement; all scientific content, critical analysis, and final editorial decisions were made exclusively by the authors.

Footnotes

Author Contributions

Surgical and Medical Practices: K.E.A., Design: İ.F.U., Data Collection or Processing: K.E.A., Analysis or Interpretation: İ.F.U., K.E.A., Literature Search: K.E.A., Writing: İ.F.U., K.E.A.

Conflict of Interest: No conflict of interest was declared by the authors.

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