

PSYCHOLOGICAL CHALLENGES OF PATIENTS WITH EPILEPSY

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Abstract

Epilepsy, a chronic neurological disorder characterized by recurrent seizures, clearly impacts physical health but also the psychological and social well-being of individuals. The focus of clinical management has traditionally been on seizure control which, if effective, improves quality of life. But due to a largely unknown etiology of epilepsy, it is important to focus on what can be improved in the patient's life, such as their psychological challenges. Thankfully, there is a growing recognition of the psychological challenges faced by patients. These challenges range from daily emotional distress and stigma to broader impacts on social interactions and family dynamics. This paper explores the psychological effects of epilepsy on patients, focusing on emotional distress, stigma, social isolation, and its profound influence on quality of life, supported by a range of recent studies.

KEYWORDS: distress, epilepsy, mental health, quality of life, social isolation, social stigma

INTRODUCTION – THE STORY OF PHINEAS GAGE

Epilepsy affects approximately 50 million people globally, with challenges beyond the seizures themselves. Patients with epilepsy often struggle with psychological difficulties, societal stigma, and functional limitations, which significantly impair their quality of life (QOL).^{1,2} It is essential to recognize that stigma associated with epilepsy manifests in two primary forms: felt stigma and enacted stigma. Felt stigma refers to the internalized fear of discrimination and judgment, leading individuals to experience shame, diminished self-worth, and negative self-perception. This psychological burden often results in social withdrawal and avoidance behaviors, further exacerbating isolation.³ Enacted stigma, the more overt form, encompasses tangible acts of discrimination in domains such as education, employment, and personal relationships, thereby limiting opportunities for social integration.⁴ The combination of negative self-perception and enacted stigma among individuals with epilepsy profoundly affects their psychological well-being, exacerbating anxiety, depression, and other mental health challenges.^{1,3} Addressing these challenges through a holistic lens (a method that looks at the entirety of a system, each facet of an individual to determine the best approach) seeks to identify pathways for improving outcomes and promoting resilience among patients. This paper aims to identify the major psychological and societal factors affecting QOL of individuals with epilepsy.

EMOTIONAL AND PSYCHIATRIC COMORBIDITIES

Patients with epilepsy frequently experience high rates of emotional distress, including anxiety, depression, and social

phobia. Depression is notably prevalent, with studies indicating its significant role in reducing QOL, often independent of seizure control.⁵ Anxiety disorders, including generalized anxiety and social phobia, also occur at elevated rates, contributing to difficulties in social integration and exacerbating feelings of isolation.^{1,6} This psychological burden often leads to a reduced capacity to engage in routine activities, contributing to the formation of a cycle of helplessness and frustration among patients.

A review by Salpekar and Mula shows the bidirectional relationship between epilepsy and mood disorders, implying that these conditions may share common neurobiological underpinnings such as neurotransmitter imbalances, chronic neuroinflammation, and dysfunction of the limbic system, which is crucial for emotional regulation.¹ Findings from this study emphasize the need for healthcare professionals to adopt integrated treatment approaches addressing both seizure management and mental health. Cognitive behavioral therapy (CBT) has shown promising results in decreasing mood disorders such as anxiety and depression, thus increasing QOL.⁷

In addition to anxiety and depression, epilepsy has been linked to heightened levels of stress, which can trigger more frequent or severe seizures.⁶ A study by Jhaveri DJ, McGonigal A, Becker C, et al. found that stress significantly contributes to both the onset and worsening of epilepsy, with major life stressors increasing the risk of developing epilepsy and triggering seizures in individuals with pre-existing conditions.⁸ Neurobiological mechanisms linking stress and epilepsy include HPA axis dysfunction, impaired hippocampal neurogenesis, and reduced brain-derived

neurotrophic factor (BDNF) levels. This often creates an overwhelming emotional cycle for patients. Social support, mindfulness training, and CBT have shown potential in alleviating stress,⁸ promoting resilience and emotional stability amongst individuals with epilepsy.

COGNITIVE AND SOCIAL FUNCTIONING

Cognitive impairments, particularly in memory and attention, are common in epilepsy and contribute to difficulties in social awareness. These challenges often manifest as impaired emotion recognition and reduced capability in maintaining interpersonal relationships.^{9,10} Cognitive impairment is a significant concern for epilepsy patients, with around 30–40% experiencing deficits in memory, language, executive function, and attention. A study involving 257 patients found that lower educational levels, higher seizure frequency, multiple antiseizure medication (ASM) use, and depression were strong predictors of cognitive decline.¹¹ Temporal lobe epilepsy in particular, has been associated with deficits in theory of mind, which hinders patients' ability to understand others' emotions and intentions.⁹ These cognitive impairments contribute to social difficulties by making it harder to follow conversations, recall past interactions, or respond appropriately in social situations.⁹ These challenges can lead to frustration on both sides, ultimately discouraging engagement in social activities, further isolating patients from their communities and reinforcing their feelings of helplessness.

Social functioning is further reduced by the unpredictability of seizures, which leads to a fear of public embarrassment and a reluctance to participate in social activities. This withdrawal exacerbates feelings of loneliness and depression, creating a vicious cycle that diminishes patients' quality of life.^{10,12} The emotional burden of anticipating seizures often prevents individuals from fully engaging in daily life, limiting their potential for personal and professional growth.

Emerging therapeutic strategies, such as cognitive training and virtual reality-based social skill programs, aim to enhance cognitive and social functioning in epilepsy patients. By addressing specific deficits, these interventions can help rebuild confidence, which can in hand help restore meaningful social connections. Cognitive training programs focus on improving attention, memory, and executive functions, which are crucial for effective social interactions.¹⁰ Virtual reality (VR) programs provide immersive environments where patients can practice real-world social scenarios, improving their ability to recognize emotions and respond appropriately.¹³

Despite their promise, these interventions face notable limitations. The high cost of VR-based programs and the need for specialized equipment restrict accessibility for many patients.¹⁰ Moreover, traditional social skills training has been criticized for poor generalization of learned behaviors outside controlled settings, necessitating continuous support to ensure long-term effectiveness.¹⁰ Additionally, many programs are still in the early stages of development and require further research to validate their impact on social functioning and quality of life.¹³

STIGMA AND SOCIAL ISOLATION

Stigma remains one of the most pervasive psychological challenges for individuals with epilepsy. Negative societal attitudes often lead to implicit discrimination in employment, education, and social relationships, significantly reducing opportunities for meaningful engagement.¹² The stigma associated with epilepsy has been linked to heightened levels of social phobia, further isolating patients from support networks.⁶ This isolation exacerbates the psychological toll, as patients often withdraw from social interactions to avoid potential embarrassment or misunderstanding.

The connection between stigma and mental health outcomes has been well-documented. According to Yildirim et al., stigma plays a central role in exacerbating depressive symptoms among patients with epilepsy. In their study, 46.9% of patients rated themselves as experiencing at least mild depressive symptoms, with highly stigmatized patients significantly more likely to report severe depression.³ Stigmatization correlates with factors such as low educational attainment, frequent seizures, and unemployment. The study also highlighted that stigma accounts for 26.2% of the variance in depression scores, showing its profound impact on mental health and in hand QOL.

Additionally, stigma can perpetuate feelings of inadequacy, isolation, and discrimination, forming a self-fulfilling prophecy.¹⁴ Social isolation not only exacerbates psychological distress but also hinders patients' access to supportive resources and interventions. Addressing stigma requires a multifaceted approach, including public education campaigns to challenge misconceptions about epilepsy and targeted interventions to help build resilience and self-esteem among patients. After an awareness campaign conducted in Saudi Arabia in 2013, the number of people who wrongly believed epilepsy was untreatable dropped from 826 to just 47, while those recognizing it as a brain disease rose from 1,224 to 1,874.¹⁵ Peer support networks and counseling can also play vital roles in mitigating the negative effects of stigma,¹⁶ providing patients with a sense of community and empowerment, which is necessary for patient improvement.

Moreover, research has highlighted the importance of community-based programs and peer support networks in lessening the impact of stigma.¹⁷ Such programs provide patients with opportunities to share experiences, build resilience, and reclaim their sense of agency. These interventions also educate communities, promoting empathy and understanding, which are critical to break down the barriers of discrimination. Fighting stigma is a necessary step to enhance overall QOL for patients with epilepsy.³

IMPACT ON RELATIONSHIPS

Epilepsy not only affects individuals but also places significant psychological strain on family members. Parents of children with epilepsy often face immense familial strain, spanning emotional, financial, and social domains. The unpredictability of seizures, coupled with the long-term medical management required, places a heavy burden on caregivers. Parents

experience significantly higher levels of stress compared to parents of healthy children, particularly in relation to role restriction and the emotional toll of caregiving.¹⁸ In a cohort study conducted by Braams et al., total parenting stress in parents of children with epilepsy was significantly higher before surgery (mean (M) = 91.4, standard deviation (SD) = 17.5) compared to controls (M = 82.3, SD = 15.9), and although stress decreased after surgery, it remained higher than in control groups.¹⁸ However, even after a successful epilepsy surgery, parenting stress often does not fully normalize, emphasizing the need for ongoing support.¹⁸ This ongoing stress is further seen in parents of children with frontal lobe epilepsy that report increased stress when seizures persist over time, with behavioral problems in children exacerbating the perceived burden.¹⁹ Additionally, financial concerns arise due to the cost of ongoing medical care, missed work opportunities, and adjustments to daily routines.

Marriages can also experience profound strains when one partner has epilepsy. Studies have consistently shown that people with epilepsy (PWEs) have lower marriage rates, increased divorce rates, and greater marital dissatisfaction compared to the general population.^{20,21} In a study of 278 adult PWEs, 46% of men and 38% of women were unmarried, and among those who had been married, 10% of men and 12% of women had experienced divorce, with epilepsy being the primary cause in 24% of those cases.²⁰ Notably, only 30% of men and 22% of women had their seizures under control at the time of marriage, indicating that active epilepsy did not entirely prevent marriage but often contributed to later difficulties.²⁰ Stigma plays a crucial role in shaping marital experiences, particularly in cultures where arranged marriages are common, as epilepsy is often concealed during marital negotiation, leading to conflict post-marriage.²² The study also found that in arranged marriages, only 26% of PWEs disclosed their epilepsy before marriage, compared to 86% in love marriages.²⁰ Unresolved tensions, secrecy, and the burden of caregiving can lead to fractured relationships, underscoring the need for tailored psycho-social interventions.²³ The financial dependency of a spouse with epilepsy can further strain the relationship, with employment status strongly correlating with marital stability; among unemployed men with epilepsy, only 11% were married, compared to 51% of employed men.²⁰ However, it is important to note that the correlation between employment and marital status has a plethora of factors not included in the data acquisition. While some studies indicate that being married provides social support and improves quality of life for PWEs,²³ others highlight that marital stress is exacerbated by factors such as medication side effects, seizure frequency, and societal stigma.²² Importantly, families with extreme emotional closeness tend to have better outcomes, fostering psychological well-being for PWEs; for example, individuals from “Extremely Close” families reported significantly higher quality of life scores (M = 78.3, SD = 11.5) compared to those from “Fractured” families (M = 59.4, SD = 13.7, $p = 0.013$).²⁴ These findings further stress the importance of implementing resources such as family therapy to improve interrelationships between family members in order to take a step towards improved quality of life.

To address these challenges, family therapy and support

groups have emerged as effective tools in fostering communication and resilience within families. Family quality of life is significantly impacted, with interventions such as structured family management strategies by Liu et al.,²⁵ improving parental well-being. In an intervention study, families who received structured management strategies showed a significant increase in family quality of life scores with a decrease in variance (baseline: M = 60.5, SD = 12.1; after 12 months: M = 75.2, SD = 10.4), whereas control families showed little to no improvement.²⁵ Providing education on epilepsy management and coping strategies empowers family members, enabling them to better support their loved ones while maintaining their own mental health. Innovative interventions, such as online counseling platforms and mobile health applications, have also expanded access to resources for families, ensuring timely and comprehensive support for the entire family unit.

INTERVENTIONS AND RECOMMENDATIONS

While the exact mechanisms underlying epilepsy remain incompletely understood, there is well-documented association between epilepsy and mental health. Given this correlation, it is essential to consider and address mental well-being as an integral part of epilepsy management. ZMILE, a structured self-management intervention for adults with epilepsy, integrates education, goal-setting, and self-monitoring to enhance patient autonomy and treatment adherence.²⁶ Guided by nurse practitioners, it spans five weekly sessions and a booster meeting, encouraging participants to set personalized goals and utilize e-health tools or written diaries for self-monitoring.²⁶ By fostering proactive coping strategies, ZMILE aims to improve seizure control, medication adherence, and overall quality of life. Adopting a non-judgmental perspective and treatment may contribute to reshaping negative feelings linked to the demoralizing impact of an epilepsy diagnosis, which should lead to improvements of felt stigma.

Similarly, mindfulness-based interventions (MBIs) offer a patient-centered focus on the psychological dimension to epilepsy care, significantly reducing depression and improving mindfulness and epilepsy-related quality of life. Participants were guided to acknowledge and adopt an attitude of acceptance toward negative emotions related to seizures, such as fear of breakthrough episodes and physical discomfort, cultivating a mindset of awareness and control.²⁷ A randomized controlled trial with 28 participants (14 intervention, 14 control) by Lai et al. found that after six weeks of MBI, 42.9% of participants showed clinically significant improvements in quality of life compared to only 7.1% in the control group.²⁷ Additionally, 35.7% of MBI participants demonstrated improved mindfulness, compared to 21.4% in controls. Notably, 45.5% of the intervention group exhibited reliable improvements in depression scores at a six-week follow-up, while none of the control participants showed similar progress.²⁷ The MBI program led to sustained psychological benefits, which is recognized as a factor in improved quality of life. Given the complex needs of epilepsy patients, a multidisciplinary team (MDT) approach—incorporating neurologists, metabolic specialists, psychologists, dietitians,

and social workers—ensures holistic care that extends beyond seizure management to address psychosocial, vocational, and long-term treatment challenges.²⁸ The integration of structured self-management, psychological interventions, and comprehensive multidisciplinary care represents a critical step toward optimizing outcomes for people with epilepsy.

Despite their benefits, ZMILE, mindfulness-based interventions (MBIs), and multidisciplinary team (MDT) approaches face notable limitations. ZMILE's primary outcome measure, disease-specific self-efficacy, did not show a statistically significant improvement, and the intervention's long-term sustainability is challenged by patient engagement barriers

and the evolving availability of e-health.²⁶ MBIs, while effective in improving depression and quality of life, had limited effects on anxiety and life satisfaction, with only 15% of eligible patients enrolling, indicating recruitment challenges and difficulties in maintaining engagement beyond structured sessions.²⁷ MDT care improves coordination but remains hindered by lack of intercommunication within the healthcare systems, lack of provider awareness, and inadequate transition planning between pediatric and adult care.²⁸ These limitations highlight the need for constant reform within these programs and ones that will follow in order to provide the most efficient and beneficial care for PWEs.

CONCLUSION

The psychological effects of epilepsy are multifaceted, including emotional distress, social stigma, cognitive challenges, and personal relationships. Recognizing all the facets of these challenges is essential for developing comprehensive care strategies that address the spectrum of patients' needs. By

prioritizing psychological health alongside seizure control, healthcare providers can significantly improve the QOL for individuals living with epilepsy. Through targeted treatments, community engagement, and continued research, society and individuals themselves can create a more supportive environment for those affected by epilepsy, empowering them to lead fulfilling lives.

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PSIHOLOŠKI IZAZOVI PACIJENATA S EPILEPSIJOM

Sažetak

Epilepsija je kronični neurološki poremećaj koji se očituje ponavljanim napadajima te, osim na tjelesno zdravlje, snažno utječe i na psihološku i socijalnu dobrobit oboljelih. Kliničko se liječenje tradicionalno usmjerava na kontrolu napadaja, što, ako je uspješno, može značajno poboljšati kvalitetu života. Međutim, s obzirom na to da je etiologija epilepsije u velikoj mjeri još uvijek nepoznata, važno je usmjeriti pozornost i na one aspekte života pacijenata koje je moguće unaprijediti, poput psiholoških teškoća s kojima se suočavaju. Sve veći broj istraživanja ističe važnost razumijevanja tih izazova, koji obuhvaćaju svakodnevni emocionalni stres, stigmatizaciju, otežane socijalne odnose te promjene unutar obiteljskog okruženja. Ovaj rad istražuje psihološke učinke epilepsije na oboljele, s naglaskom na emocionalne poteškoće, stigmu, socijalnu izolaciju i njihov utjecaj na ukupnu kvalitetu života, uz potporu recentnih znanstvenih studija.

KLJUČNE RIJEČI: epilepsija, kvaliteta života, mentalno zdravlje, socijalna izolacija, socijalna stigma, tjeskoba