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Original Article

Relationship between Stigma, Psychological Flexibility, Positive and Negative Affect in Patients with Epilepsy

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ABSTRACT

Background: Epilepsy is a neurological disorder that significantly impacts the daily lives of individuals, leading to psychological, social, and cognitive challenges. Despite advancements in its management, stigma remains a substantial issue for epilepsy patients.

Objective: This study aimed to investigate the relationship between stigma, psychological flexibility, and positive and negative affect in patients with epilepsy.

Methods: This cross-sectional study included 200 participants, with 100 epilepsy patients and 100 healthy individuals, aged 18 to 45 years, from four major cities in Punjab, Pakistan. Data were collected using convenience sampling. The instruments used were the Internalized Stigma of Mental Illness (ISMI) inventory (epilepsy version), the Cognitive Fusion Questionnaire (CFQ), the Acceptance and Action Questionnaire (AAQ-II), and the Positive and Negative Affect Schedule (PANAS). Data analysis was conducted using SPSS version 25. Descriptive statistics summarized the demographic and clinical characteristics, and independent samples t-tests were used to compare the groups.

Results: Epilepsy patients had significantly higher levels of internalized stigma (ISMI total score: 84.05 ± 11.77) compared to healthy individuals (52.79 ± 13.67), $t(198) = 17.33$, $p < 0.01$. They also exhibited lower psychological flexibility (AAQ-II score: 39.23 ± 8.92 vs. 26.04 ± 10.07), $t(198) = 9.81$, $p < 0.01$, and higher cognitive fusion (CFQ score: 39.62 ± 9.19 vs. 27.56 ± 10.44), $t(198) = 8.67$, $p < 0.01$. Positive affect was lower in epilepsy patients (12.58 ± 4.13) compared to healthy individuals (15.30 ± 4.08), $t(198) = 4.68$, $p < 0.01$, while negative affect was higher (19.97 ± 4.51 vs. 14.89 ± 4.69), $t(198) = -7.81$, $p < 0.01$.

Conclusion: The study demonstrated significant relationships between stigma, psychological flexibility, and affect in epilepsy patients. Addressing these factors is crucial for improving the psychological well-being and quality of life for individuals with epilepsy.

Keywords: Epilepsy, Stigma, Psychological Flexibility, Positive Affect, Cognitive Fusion.

INTRODUCTION

Epilepsy is a neurological disorder characterized by recurrent, unprovoked seizures, reflecting underlying brain dysfunction (1). This condition poses significant challenges to individuals, impacting their daily lives through psychological, social, and cognitive consequences (2). Despite advancements in understanding and managing epilepsy, stigma remains a persistent issue (3). It contributes to negative outcomes for those affected, including heightened psychological distress and reduced access to treatment and protective factors.

The global prevalence of epilepsy ranges from 4 to 10 per 1,000 people, with approximately 80% of those affected residing in developing countries (4). In Pakistan, it is estimated that around 2.2 million individuals live with epilepsy, though only a fraction seek treatment (5). Epileptic seizures can be provoked by various factors, with sleep and stress being notable triggers (6). The etiological classification of epilepsy includes structural, metabolic, genetic, and unknown origins, with childhood epilepsies often being polygenic or genetic, and acquired epilepsies resulting from brain injuries, infections, and cerebrovascular diseases (7, 8). In adults aged 30 to 50 years, brain tumors are a common cause of epilepsy, while cerebrovascular diseases are predominant in those over 50. In developing countries, conditions like malaria and parasitic diseases are significant contributors (9).

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Seizures result from disruptions in the brain's electrical activity, temporarily affecting communication between brain cells. These can be categorized into focal onset, generalized onset, and unknown onset (10). Clinical diagnosis of epilepsy is based on a combination of symptomatology and assessments, requiring at least two unprovoked seizures more than 24 hours apart, or one unprovoked seizure with a high likelihood of recurrence (11). Management involves setting treatment goals, developing a treatment plan, and regular evaluation.

Stigma associated with epilepsy exacerbates health problems by increasing risks and limiting access to therapies. Psychological flexibility, the ability to act in accordance with one's values despite adverse thoughts and feelings, is crucial in managing the impact of stigma. This concept is integral to Acceptance and Commitment Therapy (ACT), which aims to enhance psychological flexibility through acceptance and mindfulness strategies (12). Positive Affect (PA) and Negative Affect (NA) are key emotional states, with PA encompassing feelings of joy and satisfaction, and NA including emotions like anger, fear, and sadness (13, 14). Low self-esteem and negative self-concept are closely linked to the negative perspectives associated with epilepsy in adults (15).

Theoretical frameworks such as Relational Frame Theory (RFT) and ACT provide insights into the processes of stigmatization and psychological flexibility in epilepsy. RFT focuses on how individuals respond to events based on their relationships rather than their inherent properties, while ACT seeks to reduce experiential avoidance and promote psychological flexibility in challenging situations (16,17). Effective epilepsy management includes appropriate medication, surgical interventions, and psycho-behavioral therapies aimed at reducing seizure triggers and enhancing coping mechanisms (18). Cognitive Behavioral Therapy (CBT), including motivational interviewing, has shown potential in improving treatment adherence and mental health outcomes in epilepsy (19,20).

In summary, epilepsy significantly impacts individuals' lives, with stigma and psychological inflexibility contributing to negative outcomes. Understanding the relationships between stigma, psychological flexibility, and emotional states is essential for improving the quality of life for those with epilepsy. This study aims to explore these relationships, providing insights into the experiences of epilepsy patients and informing interventions to support their well-being.

MATERIAL AND METHODS

This study employed a cross-sectional design to investigate the relationship between stigma, psychological flexibility, and positive and negative affect in patients with epilepsy. Data were collected from four major cities in Punjab: Lahore, Multan, Bahawalpur, and Rahim Yar Khan. The sample consisted of 200 participants, including 100 epilepsy patients and 100 healthy individuals. Participants were aged between 18 and 45 years, with epilepsy patients recruited from hospitals and healthy individuals from the general population. Convenience sampling was used for data collection.

Ethical approval for the study was obtained from the Board of Studies, and the research was conducted in accordance with the ethical standards laid out in the Declaration of Helsinki. Participants were fully informed about the purpose of the study, their voluntary participation, and their right to withdraw at any time. Written informed consent was obtained from all participants prior to data collection.

Four validated instruments were used to assess the study variables. The Internalized Stigma of Mental Illness (ISMI) inventory (epilepsy version) measured stigma. This 29-item scale includes five sub-scales: Alienation, Stereotype Endorsement, Discrimination Experience, Social Withdrawal, and Stigma Resistance. Higher scores indicated higher levels of internalized stigma (1). The Acceptance and Action Questionnaire (AAQ-II) was used to measure psychological flexibility. This 7-item scale is scored on a Likert scale from 1 to 7, with higher scores indicating greater psychological flexibility (20, 21). The Cognitive Fusion Questionnaire (CFQ) assessed cognitive fusion and psychological inflexibility. This 7-item scale also uses a 7-point Likert scale, with higher scores reflecting greater cognitive fusion (2). Positive and Negative Affect were measured using the Positive and Negative Affect Schedule (PANAS), which includes ten positive and ten negative words, with participants rating their feelings on a Likert scale (4).

To establish the psychometric properties of the Urdu version of the CFQ, a pilot study was conducted. The translation followed a back-translation method, and the reliability and validity of the scales were confirmed. Data collection occurred in two phases: initially from epilepsy patients in hospitals and subsequently from healthy individuals in the community. Hospital data collection followed institutional guidelines and was approved by the medical superintendent. Participants completed the ISMI, AAQ-II, PANAS, and CFQ questionnaires, along with a demographic information sheet.

Data analysis was performed using SPSS version 25. Descriptive statistics summarized demographic and clinical characteristics of the sample. Independent samples t-tests compared the mean scores of patients and healthy individuals on the ISMI and its sub-scales, AAQ-II, CFQ, and PANAS. The significance level was set at $p<0.01$ for all statistical tests. The study findings were interpreted within the context of the hypotheses, and the results provided insights into the relationships between stigma, psychological flexibility, and emotional affect in epilepsy patients.

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RESULTS

The study included 200 participants, with 100 epilepsy patients and 100 healthy individuals. The demographic and clinical characteristics of both groups are presented in Table 1. The patient group consisted of 45 males and 55 females, while the healthy group included 39 males and 61 females. The majority of participants in both groups were from middle-class backgrounds and resided in urban areas.

Table 1: Demographic and Clinical Characteristics of Healthy and Epilepsy Patients (n=200)

Variables	Healthy (n=100)	Patients (n=100)
Gender		
Males	39	45
Females	61	55
Educational Status		
Educated	75	65
Un-Educated	25	35
Age Groups		
From 18 to 25 Years	45	27
From 26 to 35 Years	48	57
From 36 to 45 Years	7	16
Socio-Economic Status		
Lower class	9	12
Middle class	85	73
Upper class	6	15
Residential Area		
Urban Area	77	60
Rural Area	23	40
Family Status		
Joint Family	55	59
Nuclear Family	45	41

Table 2 presents the comparison of stigma levels between healthy individuals and epilepsy patients using the Internalized Stigma of Mental Illness (ISMI) and its sub-scales. The results showed that epilepsy patients had significantly higher levels of stigma across all sub-scales compared to healthy individuals.

Table 2: Comparison of ISMI and Sub-scales between Healthy and Epilepsy Patients (n=200)

Variable	Healthy Group (n=100)	Patients Group (n=100)	t-value	p-value
Alienation	10.77 (3.11)	17.48 (2.93)	15.70**	0.000
Stereotype Endorsement	12.44 (3.31)	19.75 (3.31)	15.60**	0.000
Discrimination Experience	8.92 (2.57)	14.55 (2.57)	15.50**	0.000
Social Withdrawal	11.06 (3.17)	17.67 (2.71)	15.84**	0.000
Stigma Resistance	9.60 (2.67)	14.60 (2.01)	14.99**	0.000
ISMI Total Score	52.79 (13.67)	84.05 (11.77)	17.33**	0.000
p<0.01				

Table 3 shows the comparison of psychological flexibility and cognitive fusion between healthy individuals and epilepsy patients. Patients with epilepsy had significantly lower psychological flexibility and higher cognitive fusion compared to healthy individuals.

Table 3: Comparison of Psychological Flexibility and Cognitive Fusion between Healthy and Epilepsy Patients (n=200)

Variable	Healthy Group (n=100)	Patients Group (n=100)	t-value	p-value
Acceptance and Action Questionnaire (AAQ-II)	26.04 (10.07)	39.23 (8.92)	9.81**	0.000
Cognitive Fusion Questionnaire (CFQ)	27.56 (10.44)	39.62 (9.19)	8.67**	0.000
p<0.01				

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Table 4 presents the comparison of positive and negative affect between the two groups. Healthy individuals exhibited significantly higher positive affect and lower negative affect compared to epilepsy patients.

Table 4: Comparison of Positive and Negative Affect between Healthy and Epilepsy Patients (n=200)

Variable	Healthy Group (n=100)	Patients Group (n=100)	t-value	p-value
Positive Affect	15.30 (4.08)	12.58 (4.13)	4.68**	0.000
Negative Affect	14.89 (4.69)	19.97 (4.51)	-7.81**	0.000
p<0.01				

The results indicated that epilepsy patients experienced higher levels of internalized stigma, lower psychological flexibility, higher cognitive fusion, and more negative affect compared to healthy individuals. Conversely, healthy individuals demonstrated higher positive affect. These findings support the hypotheses that stigma, psychological flexibility, and affect are significantly related in patients with epilepsy.

DISCUSSION

The present study investigated the relationship between stigma, psychological flexibility, and positive and negative affect in patients with epilepsy, comparing these factors with those in healthy individuals. The findings revealed significant differences between the two groups, highlighting the profound impact of epilepsy on psychological and emotional well-being.

The first hypothesis, which suggested that epileptic patients would exhibit higher levels of stigma compared to healthy individuals, was supported by the data. Epilepsy patients reported significantly higher scores on the Internalized Stigma of Mental Illness (ISMI) inventory and its sub-scales, indicating that stigma remains a pervasive issue despite advances in epilepsy management and public awareness (22). This aligns with previous research, which has consistently shown that stigma contributes to negative psychological outcomes and hinders access to treatment and support (1).

The second hypothesis proposed that patients with epilepsy would have lower psychological flexibility than healthy individuals. The results confirmed this, with epilepsy patients scoring lower on the Acceptance and Action Questionnaire (AAQ-II). This finding is consistent with the theoretical underpinnings of Acceptance and Commitment Therapy (ACT), which posits that psychological inflexibility exacerbates mental health issues (23). The higher levels of cognitive fusion observed in epilepsy patients further support this, indicating a tendency to become entangled in distressing thoughts and feelings, which impairs their ability to pursue valued life goals (2).

The third hypothesis, suggesting that negative affect would be higher in epilepsy patients compared to healthy individuals, was also supported. Patients with epilepsy reported significantly higher levels of negative affect, which encompasses a range of distressing emotions such as fear, guilt, and sadness (14). This is in line with previous studies that have documented elevated negative emotions in individuals with epilepsy, contributing to a diminished quality of life and increased psychological distress (23). Conversely, the fourth hypothesis, which predicted lower positive affect in epilepsy patients, was confirmed. Healthy individuals exhibited higher levels of positive affect, indicating that they experienced more frequent positive emotions such as joy and satisfaction (13).

The study's strengths include the use of validated instruments to measure stigma, psychological flexibility, and affect, as well as a reasonably large sample size that enhances the generalizability of the findings. However, there were several limitations. The cross-sectional design precludes any causal inferences, and the use of convenience sampling may introduce selection bias. Additionally, the reliance on self-report measures could result in response biases, particularly among uneducated participants who may have had difficulty comprehending the items despite assistance from the researchers.

Future research should address these limitations by employing longitudinal designs to explore causal relationships and utilizing random sampling methods to enhance representativeness. Incorporating qualitative methods could provide deeper insights into the lived experiences of epilepsy patients and the nuanced ways in which stigma and psychological flexibility interact to affect their emotional well-being. Furthermore, interventions aimed at reducing stigma and enhancing psychological flexibility should be developed and tested, as these could potentially mitigate the negative impact of epilepsy on mental health.

CONCLUSION

In conclusion, the study demonstrated significant relationships between stigma, psychological flexibility, and affect in epilepsy patients, underscoring the need for comprehensive psychological support alongside medical treatment. Addressing stigma and fostering psychological flexibility could improve the overall quality of life for individuals with epilepsy, highlighting the importance of integrated care approaches that encompass both physical and mental health aspects.

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