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The Effect of Perceived Stigma on the Quality of Life Among a Sample of Epileptic Seizure Patients

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Abstract

Objective: The current research examined the relationship between perceived stigma Quality of life in people with epilepsy. It also investigated the role of moderation On the relationship of perceived stigma with quality of life. Methods: Using a survey design, a Convenience sample N = 100 (40% men, 60% women) patients diagnosed with epilepsy who attended Follow-up clinic in the Neurology Unit, outpatient clinics at Menoufia University for those aged 18 to 50 years Data for this study were collected using the Stigma Scale for Epilepsy (SSE) and a measure of The Quality of Life in Epilepsy Inventory (QOLIE-31). Data was They were analyzed using Pearson's multiple correction IBM/SPSS Version 25.0 Results: Recognizing results as having significant interaction Between perceived stigma there is life and the results revealed a direct and telling relationship between them Perceived stigma and frequency of epileptic seizures. It was also shown that the conclusion: the perception of stigma and Quality of life can lead to important deliberations among perceivers Stigma exists among people with epilepsy.

Keywords: *perceived stigma and Quality of Life, Epilepsy*

Introduction

Epilepsy encompasses a heterogeneous array of illnesses with distinct etiologies, symptoms, patterns, and prognoses. A significant proportion of patients, approximately 40%, experience ongoing seizures despite their efforts to control them. These individuals face the negative effects of both the seizure episodes and the treatments they undergo. Researchers aim to reduce the negative effects of seizure disorders on everyday activities (Begley, Famulari & Annegers, 2000). Nevertheless, the psychological consequences of the disease diminish the patient's ability to cope with stress by serving as catalysts for further epileptic seizures, thus intensifying psychological and social problems. This leads to a higher occurrence of seizures. The effectiveness of behavioral intervention for epilepsy patients has been emphasized in multiple studies, which has sparked the researcher's interest in the current study.

Epilepsy is classified as a chronic condition that has a substantial impact on the physical health and general welfare of individuals. It results in deficits in social functioning, activities, and employment, resulting in psychological anguish and cognitive deficiencies. Additional research has demonstrated that epilepsy is linked to a perception of social stigma, reduced self-worth, and impaired social connections with both friends and family. Extensive research has been conducted to examine the quality of life of individuals with epilepsy and their families. These

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studies have highlighted the importance of psychological analysis in improving the well-being of both patients and their families (Ogata & Amano, 2000). Moreover, persons with epilepsy may have feelings of humiliation as a result of seizures, especially when they occur in public, which can lead to apprehension about how others will react (Fisher et al., 2000; Mittan, 2005).

Epilepsy is a broad term used to describe a specific type of biological condition that is defined by the occurrence of irregular symptoms. These illnesses present as seizures or convulsions, which seem to arise from disturbances in the electrical and physiological functioning of certain brain cells. (Imam; Al-Ramadi, 2001: 40) These studies have indicated a correlation between epilepsy and several socio-psychological characteristics, such as diminished self-worth, unease, melancholy, cognitive impairment, a lack of self-regulation, and societal discrimination. Additionally, individuals afflicted with epilepsy may encounter challenges in their professional or educational pursuits, as well as in their personal and marital connections, possibly stemming from their perceived lack of control over epileptic convulsions. Souza and Salgado (2006)

Epilepsy is considered a unique chronic neurological disorder with a significant impact on the quality of life. Onset often occurs at a young age, hindering social and cognitive development, in addition to restrictions on employment, driving, and accompanying psychological disturbances (Hermann, Seidenberg, Bell, Woodard, Rutecki, & Sheth, 2000b; Kanner and Palac, 2000; Gilliam, Hecimovic & Sheline, 2003).

Hills and Baker (1992) suggest a relationship between social stigma, reduced self-esteem, social support, and impaired social communication in epilepsy patients based on a study conducted on 28 adults. They noted that educating patients about their condition is more effective in increasing self-esteem among those with epilepsy. Approximately 31% of epilepsy patients experience social stigma (Lee, Yoo & 2005).

Raty, Larsson, & Soderfeldt (2003) claim that there is a direct association between the feeling of social stigma and a decline in the overall well-being of individuals with epilepsy. Put simply, as individuals experience more stigma, their perception of their quality of life diminishes. On the other hand, Ettinger, Weisbrot, and Nolan (1998a) underline that emotions of exhaustion and despair have a substantial impact on the poor quality of life of epilepsy patients. Barker and Jacoby (2002) also emphasize a direct correlation between the quality of life and the level of social support for people diagnosed with epilepsy. According to the 2003 study by Valquez and Devinsky, anxiety disorders are associated with a lower level of quality of life. Anxiety emerges as a consequence of psychological responses, leading to a decline in self-worth, feelings of disgrace, and rejection by society. This condition results in a heightened occurrence of epileptic seizures.

Several studies, such as Hermann et al. (2000), and Haut et al. (2003), have found that the relationship between epilepsy and psychological stress is a functional one. These studies highlight that increased emotional and behavioral stress is associated with a decrease in the quality of life for epilepsy patients. Researchers emphasize the need to dedicate efforts and attention to studying the latent impact of psychological stress accompanying epilepsy. Broadly speaking, it can be said that stress and environmental factors often trigger seizures in patients with epilepsy, underscoring the importance of behavioral theories in reducing stress and improving control.

Nancy and Davis (1984) conducted a study on the impact of stressful daily life events on epilepsy patients and found a positive correlation between stress and the frequency of seizures. The study revealed that seizure frequency increases as patients become more aware of daily life

stresses. Additionally, Neugebauer et al. (1994) mentioned that unpleasant life events and various stressors, such as attacks, physical abuse, and conflicts with family members, increase the occurrence of seizures in epilepsy patients. These seizures often occur within twenty-four hours of the stressful events.

It is evident from the above that the correlation between epilepsy and psychological variables is confirmed through the results of these studies. Moreover, the impact extends beyond psychological outcomes to affect organic aspects. Loring, Meador, and Lee (2004) clarified that symptoms of seizure-related anxiety and depression are crucial factors contributing to the recurrence of seizures in patients with refractory seizures that do not respond to medical treatment. Seizure-related anxiety contributes by 16%, and depression contributes by up to 45%.

The literature on epilepsy has offered a substantial amount of valuable information, highlighting the concept of stigma as a crucial aspect for understanding the psychological and social consequences experienced by sufferers. 320 epilepsy patients between the ages of 19 and 75 underwent examination in a study by Dilorio et al. (2003). The findings showed that individuals who faced significant social stigma had low self-efficacy and struggled with managing their seizures effectively. This study emphasizes the significance of comprehending the aspects linked to social stigma in order to improve care and safeguard patients. The study by Watten and Watten in 1999 emphasized that people with epilepsy experience social isolation, anxiety, self-imposed isolation, and a decline in self-assurance, all of which have a negative impact on their capacity to develop social skills. According to Morrel (2002), social stigma has a negative impact on personal relationships, health, employment prospects, and overall well-being. The study conducted by Baker et al. in 1997b revealed that around 51% of European people diagnosed with epilepsy encounter social stigma. Additional researchers carried out studies to clarify the factors that contribute to the social stigma that adults with epilepsy experience, highlighting in particular the difficulties some people have embracing their medical condition.

Various scholars have employed theoretical models to depict the correlation between epilepsy, diminished quality of life, self-esteem, and coping mechanisms. Researchers such as Jacoby (1992), Hermann et al. (2000), and Au et al. (2002) emphasize the growing significance of psychosocial factors compared to biological factors when predicting the quality of life for individuals with epilepsy. Furthermore, the research indicates that a decrease in the overall well-being is linked to a higher occurrence of seizures, heightened levels of anxiety and despair, and a lack of adequate social support. In recent years, there has been an increasing focus on identifying the elements that influence the quality of life for those with epilepsy. Researchers, like Bishop, Berven, Hermann, and Chan (2002), emphasized the significance of psychological and social elements, signifying a shift in emphasis from solely medical and biological aspects in forecasting the quality of life for individuals with epilepsy. In their study, Lacho et al. (2008) assessed the quality of life in older adults with epilepsy and found a noteworthy decline in all categories when compared to the non-epileptic group. Baker (2001) stressed the significance of comprehending the effects of epilepsy on several aspects of life, such as social, psychological, neurological, and medical intervention, in order to properly examine the quality of life.

Birbeck, Hays, and Cui (2002) observed an increasing fascination with epilepsy and its treatment, not only for the purpose of describing the impact of the disease but also to examine the influence of antiepileptic drugs and the severity of seizures. In a study by Zhu et al. (1998), a comparison was made between 117 epilepsy patients and 84 controls. The results showed a

notable decline in the quality of life among epilepsy patients who experienced recurring seizures. Barry (2003) examined the effects of mood disorders on quality of life. The study emphasized the significance of cognitive-behavioral intervention in enhancing quality of life and addressing mood disorders. Multiple studies (e.g., Roth et al., 1994; Arida et al., 2003) have shown that people with epilepsy encounter challenges when participating in physical exercise because it might potentially provoke seizures and provide a risk of harm. In addition, Suurmeijer et al. (2005) and Mula et al. (2006) conducted research on the psychological and social aspects of epilepsy patients, uncovering indications of anxiety, isolation, social stigma, and a diminished quality of life. Research (e.g., Sabaz et al., 2001; Szaflarski et al., 2006) has shown a strong association between decreased quality of life and clinical factors associated with the condition, such as the length of time the disease has been present, the frequency of seizures, and the age at which the disease began. Rodriguez Altshuler et al. (1999) emphasized that epilepsy can lead to heightened social isolation, dependency, compromised psychosocial functioning, and the development of personality disorders. The sole factor linked to these diseases was the occurrence of an epileptic aura, and individuals experiencing auras were more susceptible to depression. In their study, Harden et al. (2007) examined how the severity of seizures affected the quality of life in a group of 118 adult women. The findings demonstrated a statistically significant correlation between the intensity of seizures and cognitive and social abilities, anxiety connected to seizures, and the overall adverse effect on quality of life.

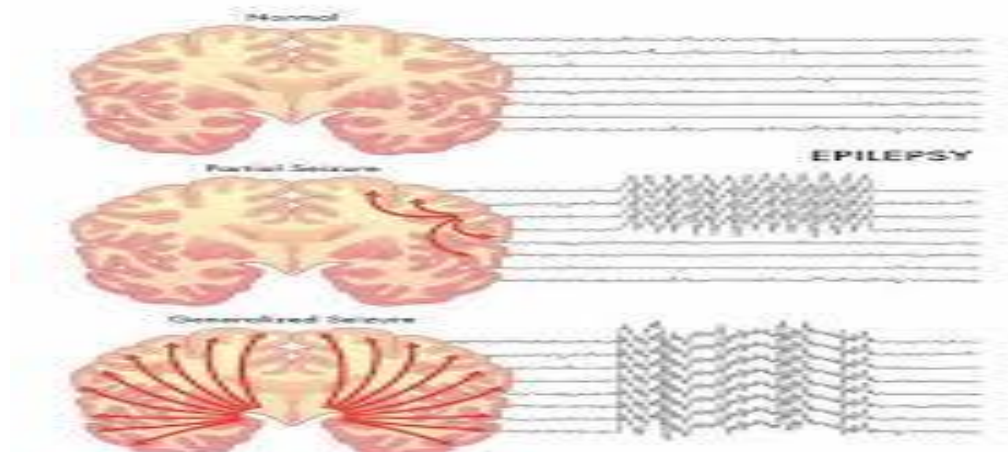


Figure1 Electroencephalogram for Epilepsy.

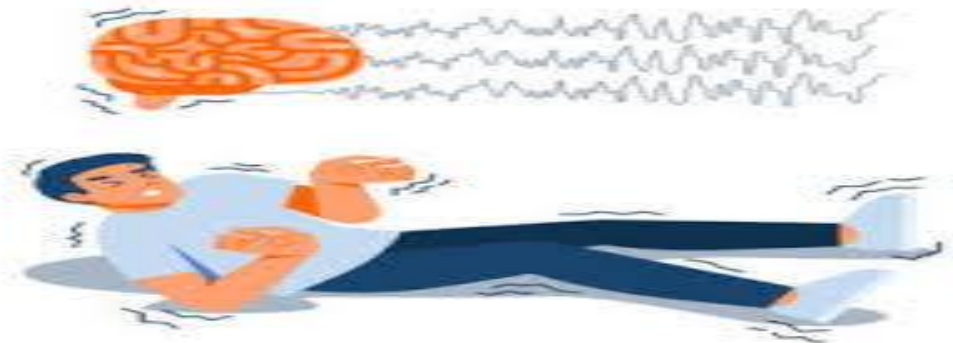


Figure2 The form of an Epileptic Seizure.

Methods

Design

The current research used the survey method. BasicData were obtained through psychological measures. A convenience sampling method was used to determine Population study. A convenient sample was selected, which consisted of: N = 100 people diagnosed with epilepsy Clinic visits to the Neurology Department at Menoufia University and to psychiatric and neurological clinics in Menoufia Governorate

The inclusion criteria

Inclusion criteria were for participants

- With confirmed epilepsy
- Whoever gave his consent to participate in Study
- Without any other health condition
- They must be between 18 and 50 years old
- Attend regular clinical follow-up

Exclusion criteria

Exclusion criteria were for participants

- with a significant medical condition (such as hypertension, diabetes)
- who did not give consent to to participate
- with history of inpatient admission three prior
- with duration of epilepsy less than one year

Measures

The Stigma Scale of Epilepsy (SSE) The 24-item scale employs 5 items to assess self-perceived stigma. The rating is measured using a four-point Likert scale, where 1 represents "not at all," 2 represents "a little," 3 represents "a lot," and 4 represents "totally." There is no reverse coding involved in this scale. The purpose of this tool is to assess the level of social stigma experienced by individuals both with and without epilepsy. The total scores span a range of 0 to 100, where higher numbers signify a greater degree of stigma towards epilepsy, while lower levels indicate a lack of stigma towards epilepsy. The internal consistency and content validity coefficients (Cronbach's α) for those with epilepsy and those without epilepsy were 0.88 and 0.81, respectively.

Cramer, Perrine, Devinsky, Bryant-Comstock, Meador, and Hermann developed the Quality of Life in Epilepsy Inventory (QOLIE-31) in 2003. The initial iteration of the scale comprises 31 items that assess seven domains: seizure fear, mood, cognitive functioning, social functions, pharmaceutical effects, energy/fatigue, and overall quality of life. The brevity, simplicity, and low patient load of this exam make it a widely used global assessment for epilepsy patients. It only requires replies to 31 questions, in contrast to the 89-item Quality of Life in Epilepsy Inventory. The scale creator utilized many methodologies to assess the trustworthiness of the scale, which encompassed

- Alpha coefficient, which reaches up to 0.70.
- Used to calculate validity: internal consistency validity, concurrent validity, all of which indicate that the test enjoys high validity coefficients.

Data Analysis

Data analyses was done using Pearson multiple correction as well as model 1 of moderation Process

macro. The analyses were executed with PROCESS Marco for IBM/SPSS version 25.0 editio

Results

A total of 100 participants were included in the current session Study: 40 men and 60 women 18-60 years from Results: 20 were single,30 married and 10 were separated. A further 15

were divorced or widowed. Most were unemployed 10 , 15 were student, 5 were retired, 10 were civil servants and 5 were artisans. In terms of epileptic seizures, 20 reported not having any, 53 said these happen most of the time, 10 said some of the time and17described having seizures all of the time.

Table 1. Sociodemographic Characteristics for N=100.

Percentages(%)	Frequency	Groups	Variables
40%	40	Male	Gender
60%	60	Female	
20%	20	Single	Marital Status
30%	30	Married	
15%	15	Divorced/ Widowed	
10%	10	Separated	
5%	5	Artisan	Occupation
15%	15	Student	
10%	10	Civil Servant	
5%	5	Retired	
10%	10	Unemployed	
20%	20	seizures Not at all	Experiencing
10%	10	Not most of the time	
53%	53	Most of the time	
17%	17	Always	

Table 2 (below) presented descriptive analysis of the study variables. The results showed that quality of life had mean and standard deviation ($\bar{X} = 25.3$, $SD = 11.0$) and variance of 121.7 while perceived stigma had mean and standard deviation ($\bar{X} = 40.3$, $SD = 27.9$) and variance of 779.9

Table 2. Descriptive Statistics of Variables (N=100).

Variance	SD	Mean	N	Measure
445.5	18.6	34.1	100	Perceived stigma
234.8	15.3	33.2	100	quality of life

Table 3. Summary of Multiple Pearson Correlation Between Variables (N=100)

quality of life	STIGMA	Mean (SD(Variables
.,360**	1	43.08(27.9)	Perceived stigma
1	.,390**	25.37(12.03)	quality of life

Note: ** Correlation is Significant at the 0.05 Level (2-Tailed).

Discussion

The present study investigated the correlation between the perception of stigma and the overall quality of life in individuals diagnosed with epilepsy. An investigation was conducted to examine the moderating influence of perceived stigma and its associated factors. Regarding the well-being of individuals with epilepsy The main objective of this study was to examine the correlation between perceived stigma and quality of life in individuals diagnosed with epilepsy. The findings were disclosed. The association between perceived stigma and quality of life is significant. Kumari et al.'s study (2009) revealed a significant association between social stigma and diminished quality of life in individuals with epilepsy, representing the first investigation of its nature in India.

The study conducted by Szaflarski and Szaflarski (2004) demonstrated that mood disorders, particularly depression, and social stigma had a detrimental effect on the overall well-being of individuals with epilepsy. A separate study emphasized the influence of epilepsy on overall well-being, specifically for individuals experiencing regular seizures and utilizing antiepileptic medications.

Fisher and colleagues (Fisher, Vickrey & Gibson, 2000) highlighted that 50% of individuals with epilepsy encounter insufficient seizure management, apprehension of mortality during seizures, social isolation, and the negative perception associated with epilepsy as the most unfavorable consequence for a patient. Women, specifically, voice apprehensions regarding their safety during seizures, as well as uncertainties about their capacity to effectively conceive and nurture children.

In addition, Bishop and Allen (2003) conducted an analytical study to assess the influence of epilepsy on the quality of life of 46 people with refractory seizures. The study demonstrated a distinct influence of epilepsy on the lives of patients, namely in the secondary effects on cognitive processes linked to epileptic seizures. Common factors contributing to lower quality of life include dyspnea, social stigma, anxiety due to seizures, and cognitive decline.

Baker et al. (2005) conducted a study on the quality of life of individuals with epilepsy in Iran, the Gulf, and the Middle East, highlighting the impact of epilepsy on health status. They pointed out that more than two-thirds of the study sample suffer from seizure recurrence and medication side effects, and the disease affects their aspirations, future, and self-perception

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Conflicts of Interest

The authors declare that no conflicts of interest related to that work

Consent for Publication

All authors accept the final version submitted to the journal.

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