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# INTERNALIZED STIGMA AND QUALITY OF LIFE IN PATIENTS WITH EPILEPSY AND FUNCTIONAL NEUROLOGICAL DISORDER

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## ABSTRACT

*The aims of this research are two-folded: First to examine the differences on internalized stigma and quality of life in patients diagnosed with epilepsy and functional neurological disorder. Second, to examine the gender differences on internalized stigma and quality of life in patients diagnosed with epilepsy and functional neurological disorder. A purposive sample of 60 patients with epilepsy and 60 with functional neurological disorder was recruited. Internalized Stigma of Mental Illness Scale, Internalized Stigma of Epilepsy Scale and World Health Organization Quality of Life Scale were used. Results indicate that patients with functional neurological disorder had a significantly higher mean internalized stigma score than those with epilepsy whereas patients with epilepsy had a significantly higher mean quality of life score. Additionally, male patients had a considerably higher mean quality of life score than female patients, while female patients had a significantly higher mean internalized stigma score. The present research has implications for clinical practice as well as future research.*

***Keywords:*** *Epilepsy, Qualility of Life, Functional Neurosis, Stigma*

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## INTRODUCTION

The issue of stigma has been highlighted through the literature through many studies (Clement et al., 2015; Henderson et al., 2017; Schnyder et al., 2017) indicating the way such negative connotation with mental health or health damages an individual's interpersonal interaction and the sense of well-being. The stigma of being a sufferer of a mental health issue, induces a sense of shame, which is carried by a person, and in some cases, internalized to such an extent that it becomes a part of their identity (Cruwys & Gunaseelan, 2016). It has been evidenced that stigma associated with the presence of mental health issues creates challenges for an individual, such as declining quality of social interaction and encountering the unjustified prejudice (Stangl et al., 2019).

Similar to other mental health issues, people with epilepsy have to deal with discriminatory attitude from the people in their social circle (Benson et al., 2016), with negative influence on the quality of life in this context (Boling et al., 2018). Another variable which is a focus of the study is functional neurological disorder which also creates disruption in the social interaction of a person and subsequently deteriorates their quality of life due to the social stigma (Robson et al., 2018). Researchers (Foley et al., 2022; MacDuffie et al., 2020; McLoughlin et al., 2024; Rawlings et al., 2017) concluded that the individuals suffering from conversion disorder are more likely to face higher degree of stigma, owing to the psychological undertones of their diagnosis. Nevertheless, epilepsy has also been stigmatized for many decades, making the patients feel ashamed of their diagnosis (Kuramochi et al., 2022). Moreover, earlier studies have suggested that gender of a person as shaping the degree of stigma experienced by an individual due to epilepsy and mental health issues (Kuramochi et al., 2022; Fernandes, 2007). Generally it is assumed that female are more sensitive than men. With reference to Pakistani literature, men and women both experience discrimination on the basis of their psychiatric disorder yet female scores were high as compare to male when stigma comes under discussion (Khan et al., 2015).

Summing up, there are ample amount of studies examining the difference in patients with functional neuroslogical disorder and epilepsy as both disorders have more or less same symptoms presentations. Sometimes it becomes difficult to differentiate between the two. However, these studies have been conducted in different countries, with relatively lower emphasis on exploring these variables in Pakistan (Akhter, 2016). It is observed that in rural areas of Pakistan and uneducated families did not understand psychological issues are important and they need to be addressed until unless there are some physical ailments like fever or cough. Stigma poses substantial barriers to patients seeking help and adhering to therapy by promoting fear of judgment, shame, and discrimination. This can lead to delayed diagnosis, increasing symptoms, social isolation, and overall poorer health outcomes (Clement et al., 2015; McLoughlin et al., 2024). The delays in healthcare can significantly lower a person's overall quality of life by affecting a number of vital areas of life, such as the capacity to keep a job, cultivate relationships, and carry out necessary self-care activities (Corrigan, 2016). Envisaging the repercussions of the internalized stigma for the patients life as well as the gap in existing literature from Pakistani culture, the objectives of the present study are: first, to examine the differences on internalized stigma and quality of life of patients with epilepsy and functional neurological disorder; and to examine the gender differences on internalized stigma and quality of life of patients with epilepsy and functional functional neurological disorder.

## METHOD

### *Participants*

The sample of the present study comprised of 120 participants older than 18 years and with mean age of 32.31years including 60 Patients with Epilepsy (PWE) and 60 Patients with Functional Neurological Disorder (PWFND). The sample was taken from various hopsitals of Faisalabad, Punjab Pakistan including Allied Hospital, Social Security Hospital and DHQ Hospital. The following inclusion and exclusion criteria to recruit particpants was employed:

- Patients diagnosed with Functional neurological disorder according to Diagnostic and Statistical Manual of Disorders, Fifth Edition, text revision (American Psychiatric Association, 2022) were included.

- Patients with Epilepsy diagnosed by a Neurologist were inlcused

- Patients with any physical disability and other co-morbid psychiatric conditions were excluded.

## *Measures*

### Demographic Sheet

Demographic sheet was utilized to obtain information related to participant’s gender, age, birth order, family structure, place of residence, socioeconomic position, and marital status, as well as information about occupations if appropriat

### Internalized Stigma Measure

The Internalized Stigma of Mental Illness (ISMI) Scale developed by Ritsher et al. (2003) was used to assess internalized stigma in patients with functional neurosis. Internalized Stigma of Epilepsy (ISEP) was adapated from ISMI scale by Ghanean et al. (2013) by substituting "epilepsy" for "mental illness" in the questionnaire. The ISEP was used to assess internalized stigma in patients with epilepsy. Both scales ISMI and ISEP comprise of 29 items rated on a 4-point Likert scale, ranging from *Strongly Agree* to *Strongly Disagree*. Both, ISMI scale and ISEP scale, comprises five domains: 6 items for Alienation, 7 for Stereotype Endorsement, 5 for Discrimination Experience, 6 for social Withdrawal and 5 for Stigma resistance. The score can range from 29 to 116. The ISMI scale (Ritsher et al., 2003) has demonstrated a high degree of internal consistency (α=.94). Similarly, ISEP Ghanean et al. (2013) is shown to have excellent inernal consistency (α=.91). The Cronbach's alpha obtained in present stud is .96 suggesting excellent internal consistency.

### World Health Organization Quality of Life Scale-BREF

The World Health Organization Quality of Life Scale-BREF is a 5-point Likert scale with 26 items. The WHOQOL Group (1997) developed this scale, and Khan et al. (2003) translated it into Urdu. These 26 items were divide into four domains: seven items physical health, 6 items psychological domain, 3 items social relationship and 8 items for environmental domain. 2 items for general health concerns. Test Re-Test reliability for each domain is .74, .83, .81 and .90 respectively. Internal consistency for the current sample is .86.

### *Procedure*

Initially approval was acquired from the Board of Studies of Riphah International University Faisalabad Campus. Afterwards approval was also acquired from the Board of Advance Studies and Research. Additionally, researcher took permission from the author of the scale to avoid copy right issues as well as authorities of the organization from where data has been collected. Participants were briefed about the present study, informed consent was taken before going to administer quality of life and stigma scale. They were also ensured regarding the anonymity and right to withdraw participation from research. Their volunteer participation was acknowledged at the end

### *Statistical Analysis*

To measure sample characteristics, descriptive statistics was used whereas to evaluate the differences on internalized stigma and quality of life, independent sample t-test was used.

# RESULTS

Table 1

*Descriptive Statistics for Demographic Characteristics of the Participants*

| Variables | *f* | % |
|---|---|---|
| Gender | | |
| Male | 67 | 57.5 |
| Female | 51 | 42.5 |
| Caregiver | | |
| Father | 91 | 75.8 |
| Husband | 29 | 24.2 |
| Socioeconomic Status | 43 | 43 |
| Low | 64 | 53,3 |
| Middle | 47 | 39.2 |
| Upper | 09 | 7.5 |
| Marital Status | | |
| Married | 42 | 42 |
| Unmarried | 52 | 52 |

Table 2

*Comparison between Patients with Epilepsy and Patients with Functional Neurological Disorder on Internalized Stigma and Quality of Life (N=120)*

| Variables | PWE (*n* =60) | PWFND (*n*=60) | *t* | *p* | *95%CI* | |
|---|---|---|---|---|---|---|
| | *M* | *M* | | | *LL* | *UL* |
| Internalized Stigma | 60.12 | 81.48 | -5.58 | .00 | -28.96 | -13.78 |
| Alienation | 12.35 | 16.43 | -4.68 | .00 | -5.81 | -2.36 |
| Stereotype Endorsement | 14.47 | 20.12 | -5.71 | .00 | -7.61 | -3.69 |
| Discrimination Experience | 10.50 | 14.47 | -5.54 | .00 | -5.38 | -2.55 |
| Social Withdrawal | 12.22 | 16.48 | -4.95 | .00 | -5.97 | -2.56 |
| Stigma Resistance | 10.58 | 14.27 | -4.90 | .00 | -5.17 | -2.19 |
| Quality of life (QOL) | 80.18 | 71.52 | 4.39 | .00 | 4.76 | 12.57 |
| Physical QOL | 22.92 | 21.10 | 3.15 | .00 | .67 | 2.96 |
| Psychological QOL | 19.88 | 17.87 | 3.73 | .00 | .95 | 3.09 |
| Social QOL | 10.83 | 9.30 | 3.41 | .00 | .64 | 2.43 |
| Environment QOL | 26.55 | 23.25 | 3.75 | .00 | 1.56 | 5.05 |

Note: *PWE* = Patients with Epilepsy; PWFND =Patients with Functional Neurological Disorder

$^*p$<.05

Table 3

*Gender Differences on Internaled Stigma and Quality of Life (N=120)*

| Variables | Male (*n* =69) | Female (*n*=51) | *t* | *p* | 95%CI | |
|---|---|---|---|---|---|---|
| | *M* | *M* | | | *LL* | *UL* |
| Internalized Stigma | 62.86 | 81.55 | -4.67 | .00 | -26.62 | -10.77 |
| Alienation | 12.63 | 16.76 | -4.68 | .00 | -5.87 | -2.38 |
| Stereotype Endorsement | 15.42 | 19.82 | -4.17 | .00 | -6.49 | -2.31 |
| Discrimination Experience | 11.16 | 14.27 | -4.10 | .00 | -4.62 | -1.60 |
| Social Withdrawal | 12.80 | 16.45 | -4.07 | .00 | -5.43 | -1.88 |
| Stigma Resistance | 11.03 | 14.31 | -4.22 | .00 | -4.82 | -1.74 |
| Quality of life (QOL) | 79.91 | 70.35 | 4.87 | .00 | 5.67 | 13.44 |
| Physical QOL | 22.99 | 20.69 | 4.04 | .00 | 1.17 | 3.42 |
| Psychological QOL | 19.62 | 17.86 | 3.17 | .00 | .66 | 2.85 |
| Social QOL | 10.70 | 9.22 | 3.24 | .00 | .57 | 2.38 |
| Environment QOL | 26.61 | 22.59 | 4.64 | .00 | 2.30 | 5.73 |

*Note.* **p*<.05

## DISCUSSION

The objective of the study was two folded: to examine the differences on internalized stigma and quality of life in patients diagnosed with epilepsy and functional neurological disorder; and to examine the gender differences on internalized stigma and quality of life in patients diagnosed with epilepsy and functional neurological disorder. The results reveal some unique patterns. Patients with functional neurological disorder had a significantly higher mean internalized stigma score than those with epilepsy whereas patients with epilepsy had a considerably higher mean quality of life score than those with functional neurological disorder (Table 2). Additionally, female patients had a significantly higher mean internalized stigma score than male patients whereas male patients had a notably higher mean quality of life score than female patients (Table 3).

Previous researchers have demonstrated the presence of stigma and the way it influences the quality of social interaction of the patients of epilepsy and conversion (Ritsher et al., 2003; Cottencin, 2014), demographic variables such as gender also effecting response to stigmatization (Rawlings et al., 2017). The embarrassment of dealing with a mental health issue is a real challenge for the patients as well as healthcare providers. The main problem that negatively effects the social functioning of a patient is the stigma of suffering from mental health problems. Individuals have to cope with the negative comments from the people in their surrounding (Akhtar & Akhtar, 2016).

Epilepsy and the associated stigma has caused different issues for the patients as they are at times isolated and alienated due to their disease. The stereotypes that are prevalent in the society make it more difficult for a person with epilepsy to be included as a part of the normal functioning social group as people refrain from interacting with such individuals (Brigo et al., 2015). In addition, the people with epilepsy find it difficult to find work opportunities and have to often deal with prejudice due to their mental health condition (Szaflarski, 2015).

Some researchers have found that other mental health issues such as functional neurological disorder are stigmatized, to a greater extent as the society regards the people with such ailment as being inferior as compared to the seemingly normal functioning individuals (DeBoer, 2008). As found in the present study, the experience of stigma was greater for people who had conversion and other mental health issues than the individuals who were dealing with epilepsy.

In conclusion, the results from the present study suggest that Patients with functional neurological disorders are more prone to internalized stigma and higher risk of reduced quality of life than the patients with epilepsy, with gender being an important variable in differential experience of stigma and quality of life. All in all, stigmatization makes it difficult for people with epilepsy and functional neurological disorder to feel a part of their social circle. The present study has some limitations which can be addressed in future studies. The present study has limited sample, future studies can include larger sample size and with diverse demographic variables. The patients with different types of epilepsy can also be included to have more clear picture with respect to the variables under inverstigation.

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