



Original Article

Living with Epilepsy: Psychosocial and Clinical Determinants of Quality of Life in Patients with Epilepsy

Syed Messum Ali Kazmi¹, Ali Haider Chattha², Hasnain Afzal³, Rabia Karim^{4*} and Huma Akhtar⁵

¹Higher Education Department, Government of the Punjab, Pakistan

²Department of Clinical Psychology, Government College University Lahore, Pakistan

³Department of Psychiatry and Behavioral Sciences, Faisalabad Medical University, Faisalabad, Pakistan

⁴Department of Psychology, Government Jinnah Associate College for Women, Lahore, Pakistan

⁵Department of Clinical Psychology, Lahore School of Professional Studies, University of Lahore, Pakistan

ARTICLE INFO

Key Words:

Social Support, Psychological Distress, Quality of Life, Resilience, Epilepsy

How to Cite:

Kazmi, S. M. A., Chattha, A. H. ., Afzal, H. ., Karim, R. ., & Akhtar, H. (2023). Living with Epilepsy: Psychosocial and Clinical Determinants of Quality of Life in Patients with Epilepsy: Psychosocial and Clinical Determinants of Quality of Life in Patients with Epilepsy. *Pakistan Journal of Health Sciences*, 4(01). <https://doi.org/10.54393/pjhs.v4i01.337>

***Corresponding Author:**

Rabia Karim
 Department of Psychology, Government Jinnah Associate College for Women, Lahore, Pakistan
rabiakarim50@gmail.com

Received Date: 10th November, 2022

Acceptance Date: 23rd January, 2023

Published Date: 31st January, 2023

ABSTRACT

The present study assessed the role psychosocial (social support, resilience and psychological distress) and clinical determinants (duration of disease and number of seizures per month) in predicting quality of life in epileptic patients. Past research findings have established the role of social support and resilience in impacting psychological distress in quality of life in epileptic patients. **Objectives:** To evaluate the psychosocial and clinical determinants of quality of life in epileptic patients and to contribute to the gap in the literature. **Methods:** A quantitative research design was used for the study in which out of 230 progressive patients, 200 were recruited for the study out of which 117 suffered from generalized and 73 suffered from focal epilepsy. In terms of gender differentiation, 110 were male and 90 were females. Kessler Psychological Distress Scale, Brief Resilience Scale and Social Provisions Scale were used. Clinical determinants were assessed through measuring disease duration and number of seizures per month. Data analysis was done using Pearson Product Moment Correlation, MANOVA and Mediation Analysis. **Results:** Results had shown that there is a significant negative predictive association of psychological distress with quality of life, social support and resilience. However, a significant positive predictive association was identified among psychological distress, duration of disease and number of seizures per month. **Conclusion:** Significant differences were identified in epileptic patients with regard to psychological distress (high/low) in terms of social support, resilience and quality of life. Social support and resilience significantly mediated the association between psychological distress and quality of life.

INTRODUCTION

Epilepsy is marked by recurring unprovoked seizures that disrupt an individuals psychophysical functioning [1]. Although in a number of individuals, seizures emerge and are triggered through a number of endogenous as well as exogenous factors including traumatic psychological measures and experiences [2]. Researchers have also reported that exogenous triggers including global emergencies, natural calamities and events can also trigger seizures in such patients. There is also evidence to show that serious psychological distress among epileptic patients who do not have access to social support and are low on resilience [3]. Moreover, experts have reported that

while resilience might play a protective role against psychological distress in epileptic patients, lack of social support can have an adverse impact on the quality of life [4]. Moreover, the role of resilience in contributing towards a better understanding about quality of life cannot be undermined has also been confirmed across studies [5]. Social adjustment, a core component of quality of life, is also impacted on the basis of resilience and social support [6]. Research has shown epilepsy affects a significant number of people around the world. The prevalence of this condition in Pakistan has been assessed as being 9.99 per 1000 individuals [7]. Global incidence of the disease shows

that about 50 million individuals are impacted by this condition globally with almost 90 % individuals with this condition are residing in developing regions [8]. With such high rates of incidence, it is marked for being one of the leading and most common forms of neurological diseases. Severity and frequency of seizures has also been identified as a major risk factor for epileptic patients [9]. Previous studies have highlighted that quality of life is significant associated with seizure frequency and severity [10]. Nonetheless, psychological distress often remains unrecognized in a majority of such patients due to which the adverse psychosocial and clinical effects of this condition might not be documented in individuals where there are limited psychosocial support services [11]. Individuals with epilepsy are prone to experiencing different psychological issues and conditions including psychological distress, stress, anxiety, poor quality of life, reduced resilience and depression [12]. Moreover, to our knowledge, few studies have assessed the role played by different domains of psychological distress along with the protective role of resilience and the correlations of these factors with demographic as well as clinical indicators of epilepsy. In view of the above findings, the purpose of the present study was focused on assessing psychosocial and clinical determinants of quality of life in patients with epilepsy. The study also assesses patients with poor access to social support and low scores on resilience along with analysis of clinical features of high-risk epileptic patients. Moreover, the pattern of increased frequency and severity of seizures and its association with psychological distress, resilience, social support and quality of life will provide an improved understanding about the interplay between neurological and psychosocial factors.

METHODS

The participants for the study were recruited through different outpatient health facilities in Lahore including Mayo Hospital, Bahawal Victoria hospital, Nishter hospital Multan, Punjab Institute of Mental Health Lahore, Ehab Hospital Lahore, Sir Ganga Ram Hospital and General Hospital. Out of 230 progressive patients, 200 were recruited for the study out of which 117 suffered from generalized and 73 suffered from focal epilepsy. G power analysis with a confidential interval of 95 % showed that this sample size was justified. In terms of gender differentiation, 110 were male and 90 were females. The inclusion criteria for the study included a) adherence to medication i.e. antiepileptic drugs and b) satisfactory scores on global cognitive status. This measure was used to avoid any form of biases with regard to administration of the undermentioned psychological instruments. There were around 30 patients who refused participation in the study. The clinical details including adherence to

treatment, usage of any drugs and alcohol, any other chronic condition and current occupational status was assessed through phone interviews. The questionnaires were then sent via a google forms link that was shared with patients via email and via WhatsApp. Two experienced clinical psychologists explained the details of the research project to the participants. The ethical approval for the topic was attained through the Institutional Ethics Review Board of the University of Lahore. To assess psychosocial determinants including psychological distress, social support, quality of and resilience scale were used, different standardized and validated instruments were used. Kessler Psychological Distress Scale (K10) was used to assess psychological distress [13]. The scores on the test range from a level of 0.42 to about -0.74. To measure another psychosocial determinant i.e. social support, Social Provisions Scale was used to assess the social support [14]. Translated version of social provisional scale was used which has Cronbach's alpha reliability of .78 ($\alpha = .78$). To assess resilience, Brief Resilience was used for examining interpersonal and intrapersonal measures and protectives which are beneficial for individuals in responding and adaption to psychosocial adversities [15]. The scale was developed through guidance by a theoretical categorization of resilience and has an alpha reliability of the scale is .90 [16]. The cross cultural alpha reliability in German and Brazilian samples of the scale ranges from .85 to .90. World health organization QoL Scale developed the WHOQOL-100 assessments was used for assessing quality of life. The alpha reliability of the scale is .83 [17]. For measurement of clinical determinants of epilepsy, duration of disease and number of seizures per month were identified. Research evidence has shown that duration of epilepsy diagnosis along with number of seizures were month are central clinical determinants of the disease [18]. The SPSS 21.0 was used for data analysis. Firstly, descriptive analysis were used to assess frequencies and percentages in association with demographic variables. In the second stage, reliability analysis was performed. In the third stage, correlation, multiple regression and mediation analysis were used. P-values of less than 0.05 were identified as being significant.

RESULTS

The demographic characteristics of the sample used in the study has been presented in Table 1. A majority of the participants were male. Moreover, a majority of the participants were in the age range of 30 to 50 years.

Variables	n (%)
Gender	
Male	110 (55%)
Female	90 (45%)

Age	
18-30	75 (50.8%)
30-50	125 (49.2%)
Clinical Features	
Generalized	117 (58.5%)
Focal	73 (41.5%)
Number of Seizures	
1 Seizure per month	53 (26.5%)
1-3 Seizures per month	45 (22.5%)
5-10 Seizures per Month	52 (26.0%)
10 or More per Month	50 (25.0%)
Diagnosis	
Generalized	117 (58.5%)
Focal	73 (41.5%)
Disease Duration (Years)	
5 to 10 Years	62 (31%)
10 to 15 years	49 (24.5%)
15 to 20 years	65 (32.5%)
20 years or more	24 (12.0%)

Table 1: Demographic Variables of the Sample

Table 2 depicts significant associations among the study variables including quality of life, psychological distress, resilience, social support and disease duration.

Variable	1	2	3	4	5	6
1. Quality of Life	-	-.84**	.44**	.35**	-.45**	-.54**
2. Psychological Distress		-	-.42**	-.35**	.53**	.65**
3. Resilience			-	.44**	-.53**	-.41**
4. Social Support				-	-.44**	-.33**
5. Disease Duration					-	.42**
6. Number of Seizures per month						-

Table 2: Inter-Correlation among Quality of Life, Psychological Distress, Resilience and Social Support
Note. **p<.01

Table 3 depicts multiple regression analysis showing significant predictive effects of resilience, social support, psychological distress, disease duration and number of seizures per month.

Variable	B	SE	B	95 % CI
Constant	-48.04	10.20		[-68.25, -27.83]
Resilience	.24*	.07	.22	[.09, .39]
Social-Support	.21*	.07	.13	[.06, .29]
Psychological Distress	-1.70*	.18	.58	[1.32, 2.02]
Disease Duration	-.55*	.05	-.51*	[-.09, -.59]
No. of Seizures/Month	-.33*	.12	-.29*	[-.07, -.39]
R2			.59	
F			66.25	
R			.73	

Table 3: Resilience, Social-Support, Psychological Distress, Disease Duration and Number of Seizures per Month as predictors of Quality of Life

*p<.05, CI=Confidence Interval

In terms of the current investigation, Preacher and Hayes bootstrapping method was used. The results showed that social support and resilience significantly mediated the

relationship between psychological distress and quality of life as shown in Table 4.

Step 1 (Path c)			
Outcome: QOL			
PD	-1.11**	.04	.000
Step 2 (Path a)			
PD(Path a)	-.47**	.09	.000
Outcome: SS (M2)			
PD	-.23**	.10	.021
Step 3 (Path b)			
Outcome: QOL			
Resilience	.35**	.03	.000
Social Support	.21**	.03	.002
(Path c')			
Mediators: Social Support and Resilience			
Predictor: PD	-.001	.006	ns.

Table 4: Two Way Mediating Effect of Social Support and Resilience on the Association between Psychological Distress and Quality of Life Note.

PD=Psychological Distress, QOL=Quality of Life, B=standardized coefficient. *p<.05, **p<.01

DISCUSSION

The study assesses patients with poor access to social support and low scores on resilience along with analysis of clinical features of high-risk epileptic patients. Moreover, the pattern of increased frequency and severity of seizures and its association with psychological distress, resilience, social support and quality of life will provide an improved understanding about the interplay between neurological and psychosocial factors. The findings of the present study offered a confirmation of this hypothesis which is consistent with the relevant literature. Research has shown that seizure frequency, seizure duration and psychological distress are significantly and negatively associated with resilience, social support and quality of life in epileptic patients [19]. Secondly, the results had shown that resilience, social support, disease duration, number of seizures per month and quality were significantly associated with one another. Moreover, it has also been identified a predictive association of social support, resilience and psychological distress with quality of life in epileptic patients [20]. In addition, lack of social support and psychological distress can cause a significant burden of disease in patients with epilepsy [21]. Moreover, the findings established a strong negative predictive association of social support and psychological distress with quality of life. There is also evidence that has categorized psychological distress and duration of disease as having an adverse impact on quality of life in epileptic patients with social support and resilience having a protective effect [22]. Thirdly, it was hypothesized that Social support and resilience would mediate the relationship between psychological distress and quality of

life in epileptic patients. The literature reported social support and resilience as having a significant mediating influence in quality of life in patients with severe illness including epilepsy [23]. Furthermore, there is evidence to show that social support has a moderating and mediating influence between the association of resilience and quality of life in epileptic patients [24]. Relevant research findings have also shown promoting social support networks and resilience in epileptic patients can improve their quality of life [25].

CONCLUSIONS

It can be concluded that psychological distress, duration of disease and number of seizures per month had an adverse effect on quality of life in epileptic patients. However, the provision of social support and resilience had a protective effect against psychological distress. It has also been established that social support and resilience have a mediating influence on the association between psychological distress and quality of life. This further shows how important it is to ensure social support and promote resilience in epileptic patients in order to enhance their quality of life.

Conflicts of Interest

The authors declare no conflict of interest

Source of Funding

The author(s) received no financial support for the research, authorship and/or publication of this article

REFERENCES

- [1] Xu Y, Hackett ML, Glozier N, Nikpour A, Bleasel A, Somerville E, et al. Frequency and predictors of psychological distress after a diagnosis of epilepsy: A community-based study. *Epilepsy & Behavior*. 2017 Oct; 75: 190-5. doi: 10.1016/j.yebeh.2017.07.044
- [2] Hao X, Zhou D, Li Z, Zeng G, Hao N, Li E, et al. Severe psychological distress among patients with epilepsy during the COVID-19 outbreak in southwest China. *Epilepsia*. 2020 Jun; 61(6): 1166-73. doi: 10.1111/epi.16544
- [3] Bushnik T, Lukow HR, Godwin EE, Marwitz JH, Mills A, Hsu NH, et al. Relationship between resilience, adjustment, and psychological functioning after traumatic brain injury: a preliminary report. *Journal of Head Trauma Rehabilitation*. 2015 Jul; 30(4): 241-8. doi: 10.1097/HTR.000000000000137
- [4] de Holanda Coelho GL, Hanel PH, Medeiros Cavalcanti T, Teixeira Rezende A, Veloso Gouveia V. Brief Resilience Scale: Testing its factorial structure and invariance in Brazil. *Universitas Psychologica*. 2016 Jun; 15(2): 397-408. doi: 10.11144/Javeriana.upsy15-2.brst
- [5] Gargiulo AJ, Sarudiansky M, Videla A, Lombardi N, Korman GP, Oddo S. Perceived stress, resilience, and stress coping in patients with drug resistant epilepsy and functional dissociative seizures. *Seizure*. 2022 Oct; 101: 141-8. doi: 10.1016/j.seizure.2022.08.002
- [6] Geng Y, Gu J, Zhu X, Yang M, Shi D, Shang J, et al. Negative emotions and quality of life among adolescents: A moderated mediation model. *International Journal of Clinical and Health Psychology*. 2020 May; 20(2): 118-25. doi: 10.1016/j.ijchp.2020.02.001
- [7] Tanveer M, Ahmed A, Iqbal M, Aslam F, Saqlain M, Rehman IU, et al. Excessive Daytime Sleepiness and Sleep Quality and their Impact on Health-Related Quality of Life in People with Epilepsy: A study from Pakistan. *Epilepsy & Behavior*. 2022 Mar; 128. doi: 10.1016/j.yebeh.2022.108565
- [8] Johnson EK, Jones JE, Seidenberg M, Hermann BP. The relative impact of anxiety, depression, and clinical seizure features on health-related quality of life in epilepsy. *Epilepsia*. 2004 May; 45(5): 544-50. doi: 10.1111/j.0013-9580.2004.47003.x
- [9] Kyriazos T, Stalikas A. Psychometric Evidence of the 10-Item Connor-Davidson Resilience Scale (CD-RISC10, Greek Version) and the Predictive Power of Resilience on Well-Being and Distress. *Open Journal of Social Sciences*. 2021 Nov; 9(11): 280-308. doi: 10.4236/jss.2021.911022
- [10] Lai ST, Tan WY, Wo MC, Lim KS, Ahmad SB, Tan CT. Burden in caregivers of adults with epilepsy in Asian families. *Seizure*. 2019 Oct; 71: 132-9. doi: 10.1016/j.seizure.2019.07.008
- [11] Oguz A, Kurul S, Dirik E, Eylül D. Relationship of epilepsy-related factors to anxiety and depression scores in epileptic children. *Journal of Child Neurology*. 2002 Jan; 17(1): 37-40. doi: 10.1177/088307380201700109
- [12] Rawlings GH, Brown I, Reuber M. Predictors of health-related quality of life in patients with epilepsy and psychogenic nonepileptic seizures. *Epilepsy & Behavior*. 2017 Mar; 68: 153-8. doi: 10.1016/j.yebeh.2016.10.035
- [13] Andrews G and Slade T. Interpreting scores on the Kessler psychological distress scale (K10). *Australian and New Zealand journal of public health*. 2001 Dec; 25(6): 494-7. doi: 10.1111/j.1467-842X.2001.tb00310.x
- [14] Russell DW and Cutrona CE. *Social provisions scale*. Iowa State University, 1984.
- [15] Ring A, Jacoby A, Baker GA, Marson A, Whitehead MM. Does the concept of resilience contribute to understanding good quality of life in the context of

- epilepsy?. *Epilepsy & Behavior*. 2016 Mar; 56: 153-64. doi: 10.1016/j.yebeh.2016.01.002
- [16] Smith BW, Dalen J, Wiggins K, Tooley E, Christopher P, Bernard J. The brief resilience scale: assessing the ability to bounce back. *International journal of behavioral medicine*. 2008 Sep; 15(3): 194-200. doi: 10.1080/10705500802222972
- [17] Vahedi S. World Health Organization Quality-of-Life Scale (WHOQOL-BREF): analyses of their item response theory properties based on the graded responses model. *Iranian journal of psychiatry*. 2010; 5(4): 140-153.
- [18] Seid S, Demilew D, Yimer S, Mihretu A. Prevalence and associated factors of mental distress among caregivers of patients with epilepsy in ethiopia: a cross-sectional study design. *Psychiatry journal*. 2018 Sep; 2018. doi: 10.1155/2018/2819643
- [19] Semple BD, Zamani A, Rayner G, Shultz SR, Jones NC. Affective, neurocognitive and psychosocial disorders associated with traumatic brain injury and post-traumatic epilepsy. *Neurobiology of disease*. 2019 Mar; 123: 27-41. doi: 10.1016/j.nbd.2018.07.018
- [20] Tedrus GM, Souza DC, Crepaldi CR, Petrarca YM. Suicide risk in epilepsy: Clinical variables, psychiatric disorders, and social support. *Revue neurologique*. 2022 Sep. doi: 10.1016/j.neurol.2022.05.009
- [21] Wang H, Yue H, Ren M, Feng D. Dyadic effects of family-functioning and resilience on quality of life in advanced lung cancer patients and caregivers: an actor-partner interdependence mediation model. *European Journal of Oncology Nursing*. 2021 Jun; 52. doi: 10.1016/j.ejon.2021.101963
- [22] Wei W, Yang R, Zhang J, Chen H, Ye J, Su Q, et al. The Mediating Roles of Family Resilience and Social Support in the Relationship Between Illness Severity and Depressive Symptoms Among Primary Caregivers of Children With Epilepsy in China. *Frontiers in Neurology*. 2022 Feb: 277-285. doi: 10.3389/fneur.2022.831899
- [23] Ring A, Jacoby A, Baker GA, Marson A, Whitehead MM. Does the concept of resilience contribute to understanding good quality of life in the context of epilepsy?. *Epilepsy & Behavior*. 2016 Mar; 56: 153-64. doi: 10.1016/j.yebeh.2016.01.002
- [24] Jakobsen AV and Elklit A. Self-control and coping responses are mediating factors between child behavior difficulties and parental stress and family impact in caregivers of children with severe epilepsy. *Epilepsy & Behavior*. 2021 Sep; 122.. doi: 10.1016/j.yebeh.2021.108224
- [25] Evett D, Hutchinson K, Bierbaum M, Perikic N, Proctor C, Rapport F, et al. Peer support and social network groups among people living with epilepsy: A scoping review. *Epilepsy & Behavior*. 2021 Nov 1; 124: 108381. doi: 10.1016/j.yebeh.2021.108381