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BEYOND THE SEIZURES: UNVEILING THE PSYCHOLOGICAL DISTRESS OF CAREGIVERS FOR EPILEPSY PATIENTS

Hararia Ijaz[1], Kiran Arooje[2], Nimra Azeem[3], Rida Khalid[4], Farzana Ahmed[5], Syeda Manal Fatima[6]*

[1]Lecturer/Module Leader, London School of Science and Technology, United Kingdom.
[2]Lecturer/ Coordinator of Personal Academic Tutors, London School of Science and Technology, United Kingdom.
[3]MS Clinical Psychology, University of Lahore, Pakistan.
[4]MS Clinical Psychology, Bahria University, Lahore, Pakistan.
[5]Riphah Institute of Clinical and Professional Psychology, Riphah International University, Lahore Campus, Pakistan.
[6]*PhD Scholar, Faculty of Humanities and Social Sciences, University of Central Punjab, Lahore, Pakistan.

***Corresponding Author:** Syeda Manal Fatima
*PhD Scholar, Faculty of Humanities and Social Sciences, University of Central Punjab, Lahore, Pakistan, Email: manalfatima543@gmail.com

Abstract

In order to determine the burdens and degrees of sadness, anxiety, and quality of life that are experienced by persons who provide care for patients who have epilepsy, the purpose of this study was to conduct an extensive investigation. A selection of one hundred individuals, ranging in age from five to forty years old, was chosen after careful consideration. The study group consisted of one hundred caretakers of epileptic patients from various institutions in Lahore, Multan. This group was compared to the control group, which consisted of one hundred caregivers from the general community. A survey was administered to both the general public and the neurological departments of a number of different hospitals in order to collect data. During the analysis, both independent sample t-tests and Pearson correlation tests were utilized. The findings indicated that there was a somewhat favorable link between the severity of epilepsy and the degrees of hospital depression and anxiety among caregivers. This correlation was found to show a positive relationship. When comparing the prevalence of hospital anxiety and depression symptoms among caregivers, there was a significant difference between the two groups.

Keywords: depression, anxiety, epilepsy, family burden

Introduction

Providing care for those diagnosed with chronic health issues not only affects the patients themselves but also has a significant impact on the caregivers. Epilepsy, a neurological disorder characterized by recurrent seizures, poses distinct challenges due to its unexpected nature and profound impact on daily functioning and cognitive abilities (Tsehay et al., 2022). Those responsible for caring for individuals with epilepsy often face the challenge of managing unforeseen medical emergencies while also fulfilling their daily duties or commitments (Ahmed et al., 2023).

Due to the challenging nature of this job, individuals may encounter many psychological and emotional strains, with worry and melancholy being the most prominent. These, in turn, significantly affect their overall well-being and quality of life (Mushtaque et al., 2022).

The persistent need for constant attention in managing seizures and the profound emotional burden of watching the suffering of loved ones are two variables that contribute to the high occurrence of depression and anxiety among healthcare workers who provide treatment for patients (Zhang et al., 2021). The association of epilepsy with stigma leads to social exclusion and heightened stress, hence exacerbating the management of these mental health challenges. The occurrence of unpredictable seizures can cause caregivers to experience ongoing concern and terror, leading to a disruption of their mental well-being and emotional stability. This could potentially lead to the development of anxiety disorders or episodes of depression (Zhang et al., 2021).

The enduring emotional and physical requirements of caregiving have a substantial effect on the caregivers' quality of life, further exacerbating its already diminished state (Fang & Mushtaque, 2024). The capacity of a caregiver to derive enjoyment from life and engage in social activities or personal interests can be significantly impeded by various variables, such as disturbances in sleep, physical fatigue, and the emotional burden associated with the management of a handicap or chronic ailment. The deterioration in the quality of life not only affects the well-being of caregivers but also hampers their ability to provide care, leading to a recurring cycle of diminishing benefits in terms of both personal health and the efficacy of caregiving (Khalid et al., 2023).

Furthermore, caregivers experience a wide range of challenges, including emotional, physical, and financial hardships. The stress associated with caregiving responsibilities is intensified by the fact that being a caretaker sometimes involves making substantial personal sacrifices, such as giving up time, opportunities for job progression, and financial resources (Zhu et al., 2022). The weight might evoke feelings of captivity and resentment, leading to severe effects on family relationships and increasing the probability of psychological suffering (Raza, Khalique, et al., 2023).

In order to develop effective interventions aimed at alleviating the significant burdens experienced by caregivers of epilepsy patients, it is crucial to possess a comprehensive comprehension of several aspects such as depression, anxiety, quality of life, and caregiver obligations. Efficient interventions are necessary not only to offer assistance to patients, but also to uphold the health and well-being of caregivers, whose roles are crucial in the management of epilepsy (Shehata et al., 2023). Enhancing outcomes for patients and caregivers can be achieved by tackling these challenges through the adoption of comprehensive care approaches, the availability of community assistance, and the provision of adequate medical support for caregivers.

Literature Review

1. Depression and Anxiety among Caregivers

Caregivers of individuals with epilepsy are significantly predisposed to experiencing higher levels of depression and anxiety. Studies consistently illustrate that the psychological impact of managing chronic illness, particularly epilepsy, can be profound. Yang et al. (2020) found that up to 40% of caregivers of epilepsy patients reported symptoms severe enough to warrant clinical interventions for depression and anxiety. Similarly, Smith and colleagues (2017) highlighted that the episodic and unpredictable nature of seizures contributes to chronic stress, exacerbating mental health issues among caregivers. These findings are echoed in research by Etemadifar et al. (2018), who reported that anxiety disorders were notably prevalent in this demographic, particularly where caregivers perceived a lack of control over the illness's trajectory and outcomes.

2. Quality of Life

The quality of life of caregivers has also been a focal point of research. According to Mushtaque et al. (2022), caregivers often experience a significant decline in QoL, attributed to the physical and emotional demands of caregiving. The study utilized the WHOQOL-BREF instrument and found that caregivers scored lower on physical, psychological, and environmental quality of life domains compared to non-caregivers. This deterioration is often correlated with the duration and severity of the patient's condition, where longer disease duration and higher seizure frequency are linked with poorer caregiver QoL. Furthermore, Zhang et al. (2022) note that social isolation, brought on by caregiving duties, further impacts the QoL, as caregivers find less time for social interaction and personal leisure activities.

3. Caregiver Burden

The burden on caregivers encompasses various dimensions, including emotional, financial, and physical aspects. Emotional burden often stems from the distress associated with the potential for sudden and severe seizure episodes and the fear of patient injury or death. Financial burden is also significant, as reported by Hassan et al. (2024), who pointed out the high costs associated with medical care, potential loss of employment, and the need for specialized care resources. Physically, the demands of caring for someone who may require sudden physical intervention during seizures or constant supervision can lead to chronic fatigue and physical health decline. Addressing these issues requires targeted interventions aimed at supporting caregivers. Cognitive-behavioral therapies (CBT) have been shown to be effective in reducing symptoms of depression and anxiety among caregivers by improving coping strategies and resilience (Adams, 2016). Moreover, support groups and respite care services can provide essential breaks for caregivers, thereby improving their QoL. Educational programs that improve caregiver knowledge about epilepsy can also reduce caregiver burden by decreasing fear of the unknown and increasing the caregiver’s confidence in managing seizures (Villanueva et al. 2016).

Hypotheses

1. A positive correlation is expected between the severity of epilepsy and the levels of depression and anxiety experienced by caregivers.
2. Caregivers of female patients with epilepsy will exhibit higher levels of depression and anxiety compared to caregivers of male patients with epilepsy.
3. Levels of depression and anxiety will be higher among caregivers of patients with epilepsy than among caregivers of non-epileptic children.
4. Caregivers of patients with epilepsy will experience a lower quality of life compared to caregivers of non-epileptic children.
5. The burden experienced by caregivers of epilepsy patients will be greater than that experienced by caregivers of non-epileptic children.

Methodology

Sampling and Inclusion/Exclusion Criteria

The study utilized a sample of 100 caregivers, equally divided into two groups: 50 were caregivers of epileptic patients and the remaining 50 were from the general population, managing care for either gender equally (50 boys and 50 girls in each subgroup). The data regarding caregivers of epileptic patients were collected from various hospitals in Multan and Lahore, whereas the data pertaining to the non-epileptic caregivers were sourced from the general community. The inclusion criteria specified that caregivers must have been engaged in their caregiving duties for at least one year and should be aged between 5 to 39 years. The exclusion criteria ruled out caregivers for adult patients older than 40 years, those caring for individuals with any chronic physical, psychotic disorders (other than epilepsy), cognitive disorders, or dementia, and patients who had not experienced a seizure in the past year.

Questionnaire

1. Caregiver Burden Inventory

Dr. Zarit and his team developed the 12-item Zarit Caregiver Burden Interview from a 29-item checklist (Zarit et al. 1980). A shorter scale assesses the impact of caregiving on financial issues, psychological suffering, quality of life, and social relationships, including role and personal strain. Total scores on a five-point Likert scale of 0 ("never") to 4 ("almost always") can range from 0 to

48; higher values indicate a greater burden. Cronbach's alpha for the confirmed and standardized scale is 0.78, showing that it is internally consistent.

2. Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS), created by Zigmond and Snaith in 1983, is a dependable self-assessment tool used in hospital medical outpatient clinics to diagnose depression and anxiety. The 14-item HADS questionnaire includes two subscales, each with seven items to assess anxiety and sadness. These items are rated 0–3 on a four-point Likert scale. A score of 11 or higher on any subscale indicates "psychological morbidity," 8-10 indicates "borderline" conditions, and 0-7 indicates normal. The HADS has high internal consistency, with a Cronbach's alpha of 0.85 (Lee et al., 2002). In this study, the internal consistency scores for the anxiety and depression subscales were 0.78 and 0.85.

3. Quality of Life Scale

This study assessed quality of life using the WHO QOL-BREF field trial version in Urdu. This shorter version of the WHO QOL-100, developed by the WHOQOL group and fifteen worldwide field centers, has twenty-six items in four domains: psychological, physical, social interactions, and environmental. The first two items assess health satisfaction and quality of life, while the rest assess capacity, intensity, and frequency using a five-point Likert scale. Scores were standardized from 0 to 100 using SPSS syntax for cross-domain comparison (Thi et al., 2014). Cronbach's alpha of 0.74 supported the scale's reliability, indicating that higher scores indicate better quality of life (Skevington et al., 2004). The scale in this study had strong internal consistency ($\alpha = 0.913$).

Procedure

The study recruited participants from the psychiatric and neurology departments of hospitals in Multan and Lahore. The control group consisted of individuals who were healthy and not impaired, selected from the general population. The process of gathering data started by obtaining written informed consent from every participant. Upon obtaining consent, participants were provided with a booklet containing three assessments and a demographic questionnaire to be completed. The process of data collection took a total of five months. The data was analyzed and correlated using descriptive statistics (percentage, frequency, mean, and standard deviation) and inferential statistics (independent sample t-test and Pearson's coefficient correlation) in SPSS version 20.

Results

Table 1 demographic Information (N=100)

Epileptic Caregiver (n=50)			**Normal Children Caregiver (n=50)**		
Variable	**f**	**%**	**Variable**	**F**	**%**
Father	22	44%	Father	17	34%
Mother	28	66%	Mother	33	56%
Number of Children			Number of Children		
1-3	15	33%	1-3	23	45%
4-6	35	57%	4-6	27	65%
Epileptic History in Family			Epileptic History in Family		
Yes	19	36%	Yes	7	14%
No	31	54%	No	43	86%

The demographic information summarized in Table 1 compares the profiles of caregivers for epileptic patients (n=50) and caregivers for non-epileptic children (n=50). In terms of the caregiver's relationship to the child, 44% of the caregivers in the epileptic group are fathers, compared to 34% in the non-epileptic group. Mothers represent 66% of caregivers in the epileptic group and 56% in the non-epileptic group. When considering the number of children, 33% of epileptic caregivers have between one and three children, whereas this figure is 45% for caregivers of normal children. The majority, 57% of epileptic caregivers, are responsible for four to six children, compared to 65% among caregivers of non-epileptic children. Regarding family history, 36% of epileptic caregivers reported a history of epilepsy in the family, significantly higher than the 14% reported by caregivers of normal children. Conversely, 54% of epileptic caregivers reported no such family history, compared to 86% of caregivers of normal children.

Table 2 Pearson Product Moment Correlation among Epileptic parents

Variables	**1**	**2**	**3**
1. Caregiver Burden	**-**	**.56****	**-0.43***
2. Hospital Anxiety		**-**	**-0.34****
3. Quality of life			**-**

Table 2 presents the Pearson Product Moment Correlations among variables related to epileptic parents. The correlation coefficient between caregiver burden (Variable 1) and hospital anxiety (Variable 2) is significantly positive at .56**. Conversely, caregiver burden is negatively correlated with quality of life (Variable 3) at -0.43*, indicating as caregiver burden increases, quality of life decreases. Hospital anxiety also shows a significant negative correlation with quality of life at -0.34**, suggesting that higher anxiety levels in hospitals are associated with lower quality of life scores.

Table 3 Independent Sample T-Test

Variables	**Epileptic Parents (n=50)**		**Normal Children Parents (N=50)**		**T**	**p**
	M	**SD**	**M**	**SD**		
Caregiver Burden	5.43	1.32	3.02	1.05	4.32*	0.032
Hospital Anxiety	4.76	2.03	2.01	0.43	10.32**	0.001
Quality of Life	5.21	3.44	2.17	1.01	7.48*	0.021

Table 3 illustrates the results from an Independent Sample T-Test comparing parents of epileptic children (n=50) with parents of children without epilepsy (n=50) on various psychological and quality of life measures. For caregiver burden, parents of epileptic children reported a significantly higher burden (M=5.43, SD=1.32) compared to parents of normal children (M=3.02, SD=1.05), with a t-value of 4.32* and a p-value of 0.032, indicating statistical significance at the 0.05 level. Hospital anxiety was also significantly higher among parents of epileptic children (M=4.76, SD=2.03) than among parents of normal children (M=2.01, SD=0.43), with a t-value of 10.32** and a p-value of 0.001, showing high statistical significance at the 0.01 level. Similarly, the quality of life was found to be significantly lower for parents of epileptic children (M=5.21, SD=3.44) compared to those of normal children (M=2.17, SD=1.01), with a t-value of 7.48* and a p-value of 0.021, significant at the 0.05 level. These results indicate substantial differences in the psychological impact and quality of life between the two groups of parents.

Discussion

Seizures are increasingly recognized as a serious neurological condition that may be accompanied by undiagnosed cognitive, behavioral, and mental health issues in patients. Families of epileptic patients often endure significant stress, depression, anxiety, and a diminished quality of life. This study explores the psychological distress and quality of life challenges faced by caregivers of epilepsy patients, hypothesizing that the severity of epilepsy correlates with increased caregiver depression and anxiety. Depression and anxiety were measured using the Hospital Anxiety and Depression Scale (HADS), and the severity of epilepsy was found to be significantly linked to these conditions in caregivers. This finding is consistent with Yong et al. (2008), who reported a positive association between epilepsy severity and parental anxiety and depression among 418 parents. Yang et al. (2021) also supported this, finding a notable correlation between caregiver anxiety, seizure frequency, and the age of the child in a study of 334 participants.

The study further hypothesized that female caregivers of epileptic patients experience greater depression and anxiety compared to their male counterparts. This was confirmed by significant disparities in emotional well-being between male and female caregivers, indicating that stigma and societal attitudes towards female epileptic patients exacerbate these challenges. These females are often stereotyped negatively, impacting their social and marital relationships and increasing their psychological burden.

Comparative data highlighted that caregivers of epileptic individuals exhibit significantly higher levels of depression and anxiety than caregivers of non-epileptic children, validating the study's premise. Research by Reilly et al. (2018) and Khajeh et al. (2017) further corroborated these findings, demonstrating elevated stress, anxiety, and depression among parents of young epileptic children.

This study also aligns with findings from Goti et al. (2020) and Cianchetti et al. (2015), which examined how epilepsy impacts the quality of life among caregivers and found that these caregivers generally experience a lower quality of life compared to the general population. This is due to the intense care requirements and emotional strain associated with managing epilepsy.

Finally, the study proposed that epilepsy caregivers face greater stress compared to caregivers of children with other conditions. This was evidenced by significant differences in stress levels and quality of life between these groups, with epileptic caregivers bearing a heavier burden and experiencing lower quality of life. This is particularly pronounced among caregivers of intractable epilepsy, as found by Hasen et al. (2018), who noted the profound impact of stigma on these individuals.

Conclusion

This study investigates the disparities in the quality of life, feelings of melancholy, anxiety, and the level of burden experienced by caregivers of individuals with epilepsy compared to those caring for individuals without epilepsy. Notable disparities were observed between the two groups, indicating that caregivers of patients with epilepsy experience heightened burden, anxiety, melancholy, and diminished quality of life. Caring for patients with epilepsy can be exceedingly challenging and demanding. This challenge is exacerbated by various factors, such as associated comorbidities, uncontrolled seizures in children, caregiver depression and anxiety, early onset of seizures in children, prolonged caregiver distress, and the responsibilities associated with medication management. All of these factors significantly diminish the caregivers' quality of life. The results confirm a strong correlation between caregivers' heightened levels of anxiety and despair and the seriousness of their epilepsy. Caregivers of individuals with epilepsy generally encounter greater challenges and a diminished quality of life compared to caregivers of individuals without epilepsy.

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