

Clinical Study

Assessment of Psychological Distress in Epilepsy: Perspective from Pakistan

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The unpredictable nature & elongated course of epilepsy affect all dimensions (physical, psychological, and social) of an individual's life. People with the diagnosis of epilepsy are a high-risk group for different psychiatric problems that is anxiety, depression as well as social problems (marriage, education, and daily activities). The findings of present research revealed high rate (70%) of psychological distress among fifty adult individuals with epilepsy. It was also found that people with uncontrolled epilepsy experience high level of psychological distress (100%) as compared to those with controlled (42%). Demographic and clinical factors associated with distress include lack of occupation, the presence of an underlying disabling condition (with treatment), and the severity of epilepsy. The finding generated here showed that 13 out of 19 females with epilepsy reported psychological distress. It was also found that none of these women was employed (a cultural specific phenomenon) with a slightly high number of unmarried females (74%). So by understanding the relationship between clinical and psychosocial variables, a good management plan can be devised with a focus on social and gender differences. The present research can also help to increase the awareness and to lower the stigmatization related to epilepsy.

1. Introduction

The present research is a small contribution in understanding the psychological disturbances in epilepsy. Studies have reported the prevalence of psychological distress and psychiatric comorbidity in patients with epilepsy [1–4]. There are several factors that cause psychological distress in epilepsy. Seizure activity, poor seizure control, and kindling-like phenomena may be causes of depression. Sometimes depression may be a side effect of anticonvulsant medication [5, 6]. Psychosocial factors predisposing to depression in people with epilepsy include adjustment difficulties, limitations and restrictions in social settings which the disorder imposes, as well as the unpredictable nature of the seizures and the associated feelings of helplessness and loss of control over one's life. The unpredictability limits mobility, hinders the work and education, and may lead towards the psychological disorders. These issues gain more importance when there is limited knowledge about the disorder especially in the case of developing countries with low level of education and poor health care system.

Three quarters of the 50 million people with epilepsy live in developing countries and 94% of them are untreated [7]. This large percentage raises many questions related to the treatment facilities as well as the societal attitude towards the disorder. Several studies from developing countries have reported more negative attitudes and stigma about epilepsy as compared to the developed countries [8–10]. This situation is not different in Pakistan as well. In Pakistan overall prevalence of epilepsy is estimated to be 9.99 per 1000 population with the highest rate in young adulthood [11]. Here the burden of epilepsy is twice as high in rural areas (14.8/1000) as compared to urban areas (7.4/1000) [12]. This high rate of PWE in rural areas increases the need to investigate more about the disorder with a focus on cultural variation and psychosocial variables to help in the treatment and management.

It is reported that up to half of people with uncontrolled epilepsy experience depression [13]. Factors associated with depression include lack of occupation, the presence of an underlying disabling condition (with treatment), and the severity of epilepsy [14–17]. In one study by the authors of

[18, 19] it was found that women with epilepsy of child-bearing age are at high risk of depression. Sometimes depression may be a side effect of anticonvulsant medication or from combinations [5, 6].

A number of researches have reported the comorbidity of anxiety along with depression in patients with epilepsy [20–22]. The most common emotional responses of people with epilepsy include fear of the unexpected seizure, humiliation after a seizure, particularly if incontinence occurs, and feelings of alienation at work and social situations [23]. These emotional responses are not limited to cognitive impairments, but also affect the social domain of functioning. Since the person who has seizures has no control over other people's reactions during a seizure, therefore they prefer solitary activities or reduce their social contacts. It has been reported that people with epilepsy have feelings of low life satisfaction in the areas of employment, peace of mind, and social relationships [24]. In one study it was found that the family dysfunction contributes to psychiatric, emotional, and behavioral problems, to be worse in those with epilepsy than in the control group of patients with other chronic diseases [25]. A research conducted by Aziz, Akthar, and Hasan [26] from Pakistan reported that PWE face difficulty performing activities of daily living and find it hard to make decisions about whether to marry or to have children. However new researches on social domain are limited.

It is therefore important to consider the above-mentioned clinical (seizure frequency) and demographic variables (gender, education, occupation) in assessment of psychological and social well-being in epilepsy. The existing literature suggests that in Pakistan studies on epilepsy are mainly limited to distribution, prevalence, etiology, and biological aspect of the disease. Therefore it is necessary to assess the psychological, social, and behavioral aspects of epilepsy so the improvement can be made in the management plan keeping in consideration the cultural aspects.

Based on the above-mentioned literature the following hypotheses have been formulated.

1.1. Hypotheses

- (a) There exists a significant relationship between seizure frequency and psychological distress.
- (b) Female with epilepsy as compared to males experience high level of psychological distress.

2. Method

2.1. Participants. In this study, a total 50 individuals (31 males and 19 females) with epilepsy were selected as participants. The age range of participants was 18 to 45 years. Patients with a confirmed diagnosis of epilepsy were included with the help of psychiatrists or neurophysicians. Patients who had a diagnosis of epilepsy for more than 1 year were included in the sampling frame. Participants with tonic-clonic seizures and partial complex seizure were selected because these types are common among adults with epilepsy in Pakistan.

Patients were excluded from the sampling frame if they had serious physical or mental limitations that did not allow them to complete the questionnaire. In addition, patients with psychiatric or neurological disorders that would impair judgment or impact quality of life beyond the effects caused by epilepsy, including mental retardation, stroke, head injury, brain tumor, and cerebral palsy, were excluded from the sampling frame.

Participants were divided into three categories: mild, moderate, and severe which is based on the number of seizures over the past 6 months. Individuals who had only one or no seizure in the past 6 months were categorized as being in the *mild seizure state*. Patients with one seizure in the past 3 months were included in the *moderate state*. Patients who had one or more seizures during the past month were categorized as being in the *severe or uncontrolled state*.

2.2. Instruments

2.2.1. Data Demographic Sheet. The demographic information included name (optional), age, gender, education, occupation, area of residence, and monthly income (personal or family). The epilepsy-related variables included current medications and number of seizures during the last 6 months.

2.2.2. General Health Questionnaire-28 [27]. General Health Questionnaire-28 (GHQ-28) developed by Goldberg and Hillier in 1979 is widely used instrument in detecting the psychological distress among clinical and nonclinical population. In Pakistan this questionnaire has been translated in Urdu and this Urdu version has found to be valid and reliable [27]. There are four dimensions in assessing the psychological distress. These are

- (1) somatic symptoms,
- (2) anxiety/insomnia,
- (3) social dysfunction,
- (4) depression.

Each item has four response choices ranging from “better than usual” to “much worse than usual.” A total score is computed by adding all 28 items. In the present research the scoring of GHQ-28 followed the test manual recommendations (0, 0, 1, 1) using the binary scale method. A cut-point of 5 is used to detect psychological distress. Higher score on GHQ-28 subscales reflect poorer functioning, psychological distress, and psychiatric problems [28]. The scale is a valid and reliable instrument; in the present study the alpha reliability coefficient was computed to be 0.80. The internal consistency reliability levels for the subscales is reported to be 0.74 (somatic complaints), 0.75 (anxiety/insomnia), 0.72 (social function), and 0.76 (depression) in this research.

2.3. Procedure. The data was collected from outdoor patients department at neurology and psychiatry departments of three government hospitals from Rawalpindi and Islamabad. Informed consent was taken from concerned authorities

and participants before test administration. It took 10–15 minutes for each participant to complete the questionnaire. Further questions related to day-time activity, seizure effects, medication effect, and treatment options tried before were also catered. After the data collection results were analyzed by using Statistical Product for Social Sciences (SPSS v.17). Descriptive (mean, standard deviation, cross-tabulation) and inferential statistics (independent sample *t*-test, multiple regression analysis) were computed and will be discussed in Section 3.

3. Analysis

3.1. Sample Characteristics. The sample comprises of 50 adults including 31 men (62%) and 19 women (38%). The age range of participants was 18–42 years. The mean age of respondent was 24.22. Majority of the participant had education up to matriculation ($N = 23$, 46%). Seventy-two percent were single and 28% were married. Forty-two percent of participants were unemployed and 38% were employed. Thirty-eight percent of patients were in mild seizure category, 26% fall in moderate seizure category, and 36% had severe seizures.

Table 2 has indicated significant difference between employment status of male and female. None of the female participants was employed. Furthermore no significant differences are present in seizure frequency, mean age, marital status and education.

Table 3 indicates a significant relationship between psychological distress and seizure frequency. The table further indicates positive relation between seizure frequency and subscales of GHQ-28. Only the anxiety/insomnia subscale is found to be non-significant. There are different reason for a nonsignificant relationship between anxiety and seizure frequency. The most important is the medication side effects. Antiepileptic drugs cause drowsiness, lethargy, and sleep. So epilepsy patients did not show the symptoms of anxiety like insomnia, sleep disturbances, and irritability as reported by the participants. There is need to assess anxiety particularly related with epilepsy, its characteristics and medication side effects.

In regression enter method was used to predict psychological distress based on clinical and demographic variables. Seizure frequency is found to be a significant predictor of psychological distress ($B = 1.20$, $P = .001$) accounting for 42% variance in psychological distress (Table 4). The results further indicate that education is also found to be predictor for psychological distress ($B = -1.19$, $P = .01$). Gender, occupation, and age are found to be non-significant in predicting psychological distress among patients with epilepsy.

In order to identify gender differences independent sample *t*-test has been applied.

Table 5 indicates no gender differences in males and females experiencing psychological distress. A further analysis comprising cross-tabulation was also computed to see gender differences (see Table 7), and results show that 68% female and 71% males with epilepsy experience psychological

distress. Furthermore a descriptive analysis of mean scores was also computed to see the gender differences in psychological distress and the subscales of GHQ-28.

Table 6 indicates mean differences in psychological distress. As the table shows females have higher mean score on the total as well as all subscales except somatic complaints. The highest difference is reported on social dysfunction subscale which indicates high level of psychological distress in females as compared to males.

4. Discussion

The present study was aimed to explore psychological distress among people living with epilepsy. The demographic profile of the participants has revealed that most of them were experiencing severe or uncontrolled epilepsy ($n = 18$, 36%). It has also been identified that none of female participant was employed (Table 2). This condition is cultural specific because in Pakistan it is preferable for women to stay in their homes, so they are totally depending on their families for financial support and long-term treatment of the disorder. This condition may hinder their social mobility and increase restrictions. It is also evident from the results of Table 6 where female as compared to males had high mean scores in social dysfunction. The social dysfunction in people with epilepsy has increased the risk of accidents and unexpected sudden death especially in the communities where a great deal of social activities takes place around the fire. It is further reported that PWE face difficulty in performing activities of daily living and find it hard to make decisions about whether to marry or to have children [26].

This social dysfunction is further linked to psychological morbidity, that is, presence of psychological disorders. It has been reported that depression is the most commonly reported problem in epilepsy. Factors associated with depression include lack of occupation, antiepileptic medications, and the severity of epilepsy [18]. Psychosocial factors predisposing to depression in PWE include adjustment difficulties, the limitations and restrictions which the disorder imposes, as well as the unpredictable nature of the seizures and the associated feelings of helplessness and loss of control over one's life. The present research has also investigated the relationship between these clinical and demographic variables with psychological distress including depression and anxiety (Tables 3 and 4) which has supported the first hypothesis. In the present study participants have reported that they experience severe headache, drowsiness and lethargy for one to two days after a seizure.

There are several reasons of psychological distress in patients with epilepsy. Society's lack of understanding of epilepsy is a psychosocial burden that is strongly felt, and many people with epilepsy try to keep their condition a secret. Feelings of anger, frustration, embarrassment, and vulnerability may develop as a result of society's attitude towards the illness. Other demographic variables leading to psychological distress include lack of education, unemployment, and age. The present study has also included regression analysis for these variables and the results indicate that

TABLE 1: Frequency and percentages of demographic and clinical characteristics of participants ($N = 50$).

Characteristics	Total (50)		Mild seizure state (19)		Moderate seizure state (13)		Severe seizure state (19)	
	<i>f</i>	%	<i>f</i>	%	<i>f</i>	%	<i>f</i>	%
Age (mean years \pm S.D)	24.2							
Male	31	62	12	63.2	7	53.8	12	66.7
Female	19	38	7	36.8	6	46.2	6	33.3
<i>Marital status</i>								
Married	14	28	4	21.1	6	46.2	4	22.2
Unmarried	36	72	15	78.9	7	53.8	14	77.8
<i>Employment status</i>								
Unemployed	21	42	5	26.3	4	30.2	12	66.7
Employed	19	38	8	42.1	6	46.8	5	27.8
Student	6	12	4	21.1	1	7.7	1	5.6
Housewives	4	8	2	10.5	2	15.4	0	00
<i>Education status</i>								
Uneducated	9	18	1	5.3	2	15.4	6	33.3
Up to primary	11	22	5	26.3	1	7.7	5	27.8
Up to matriculation	23	46	12	63.2	6	46.2	5	27.8
Above matriculation	7	14	1	5.3	4	30.8	2	11.1

TABLE 2: Frequency and percentages of demographic and clinical characteristics of participants based on gender.

Characteristics	Total (50)		Male (31)		Female (19)	
	<i>f</i>	%	<i>f</i>	%	<i>f</i>	%
Age (mean years \pm S.D)	24.2(6.02)		25.39 (6.16)		22.32(5.41)	
<i>Marital status</i>						
Married	14	28	9	29	5	26.3
Unmarried	36	72	22	71	14	73.7
<i>Employment status</i>						
Unemployed	21	42	9	29	12	63.2
Employed	19	38	19	61.3	0	
Student	6	12	3	9.7	3	15.8
Housewives	4	8	0	0	4	21
<i>Education status</i>						
Uneducated	9	18	5	16.1	4	21.1
Up to primary	11	22	7	22.6	4	21.1
Up to matriculation	23	46	16	51.6	7	36.8
Above matriculation	7	14	3	9.7	4	21.1
<i>Seizure frequency</i>						
Mild	19	38	12	38.7	7	36.8
Moderate	13	26	7	22.6	6	31.6
Severe	18	36	12	38.7	6	31.6

education has inverse relation with psychological distress (Table 4). Patients with epilepsy in Pakistan do not appear to be highly stigmatized, but their education and grades are affected by the disorder. They have difficulty performing activities of daily living and find it hard to make decisions about whether to marry or to have children [26].

Previous researches have reported that employment is a significant predictor of psychological distress [24, 29]. Table 1 also shows that even though 46% of the participants have education up to matriculation, however the unemployment rate is high (42%). There are number of factors related to this high unemployment rate. In one research by

TABLE 3: Pearson product correlation between seizure frequency and psychological distress ($N = 50$).

	Seizure frequency	P
Psychological distress	0.55	0.001
Somatic symptoms	0.37	0.01
Anxiety/insomnia	0.18	0.20
Social dysfunction	0.45	0.001
Depression	0.36	0.01

TABLE 4: Regression analysis of clinical and demographic variables with psychological distress ($N = 50$).

Variable	B	SE	B	t	sig
Seizure frequency	1.20	0.35	0.42	3.45	0.001
Gender	1.17	0.82	0.17	1.43	0.16
Education	-1.19	0.43	-0.34	-2.78	0.01
Occupation	-0.57	0.55	-0.14	-1.04	0.30
Age	0.10	0.07	0.17	1.31	0.19

TABLE 5: Independent sample t -test of psychological distress based on gender ($N = 50$).

		Mean	St. dev.	t	P
Gender	Male ($n = 31$)	7.32	3.27	0.69	0.49
	Female ($n = 19$)	8.00	3.59		

TABLE 6: Mean and standard deviation of scores on GHQ-28 subscales based on gender ($N = 50$).

GHQ-28	Total	Male (31)	Female (19)
Total score	7.58 \pm 3.38	7.32 \pm 3.27	8.00 \pm 3.59
Somatic symptoms	4.04 \pm 1.79	4.19 \pm 1.80	3.79 \pm 1.81
Anxiety/insomnia	1.62 \pm 1.24	1.48 \pm 1.21	1.84 \pm 1.30
Social dysfunction	1.64 \pm 1.35	1.39 \pm 1.33	2.05 \pm 1.31
Depression	0.28 \pm 0.61	0.26 \pm 0.56	0.32 \pm 0.67

Data are expressed as means \pm standard deviation.

TABLE 7: Cross-tabulation of psychological distress based on gender ($N = 50$).

Variables	Categories	f (%)	
		No psychological distress	Presence of psychological distress
Gender	Male	9 (29)	22 (71)
	Female	6 (31.6)	13 (68.4)

Chung et al. [9] 31% of respondents from the community believed that PWE should not be employed in jobs as other persons are.

Depression is also affected by a number of demographic variables. In one study by Beghi et al. [18] it was found

that women with epilepsy of childbearing age are at high risk of depression. The similar finding has been generated in the present research in which 13 out of 19 females with epilepsy have reported to suffer from psychological distress. It was also found that none of these women was employed (a cultural specific phenomenon) with a slightly high number of unmarried females (74%) as compared to males (71%). These gender differences reveal that women carry with themselves not only a diagnosis of epilepsy but relatively low position in the society especially with reference to decision making in major life events.

In Pakistan the work limitations for PWE are similar to other developing countries. However there are some positive aspects of cultural beliefs and practices related to epilepsy. People with epilepsy in Pakistan may have strong primary support group. They receive assistance and help from their families. It is also evident from the present research where 42% unemployed participants are solely dependent on their families for maintenance and treatment expenditures. It has also been reported in one community-based research in Karachi, Pakistan that PWE do not appear to be highly stigmatized. It may be helpful in devising a treatment and management plan for PWE.

The results further indicate that seizure frequency is the most significant predictor in epilepsy (Table 4). These findings are consistent with previous researches [30, 31]. Furthermore it is also reported that quality of life can be improved by controlling seizure frequency [15, 32]. It has also been reported that treating comorbid depression in epilepsy increases psychological well-being. Therefore it is important to assess psychological distress in epilepsy and to incorporate this component in treatment plan.

5. Conclusion

On the basis of present study findings it can be concluded that seizure frequency is a significant predictor of psychological distress. Increase in seizure can also increase psychological problems such as depression and anxiety. Furthermore the social dysfunction and somatic complaints are also reported. It can be better understood in realm of physical as well as in psychological, social, and behavioral domains. This finding may help in management and rehabilitation of patients with epilepsy in developing countries. The finding can be used by health care providers and policy makers to propose interventions such as improved access to mental health care, job training, and self-management programs to improve health outcomes in people with epilepsy especially by using the knowledge of indigenous practices and social structure. So by understanding the relationship between clinical and psychosocial variables in epilepsy a good management plan can be devised for the patients with epilepsy with a focus on social and gender differences. The present research can also help to increase the awareness and to lower the stigmatization related to epilepsy.

5.1. Limitations and Suggestions. This is a small-scale research focusing on four major domains of psychological

well-being. It is therefore suggested to conduct research on larger sample for result generalization and to cooperate other factors such as age at onset of illness, treatment mode, and perceived social support.

The issues highlighted by this research are the gender differences especially in terms of work status and difference in depression. An in-depth analysis is required to see the economic hardships faced by the patient and its correlate with their social status.

Moreover this research will be beneficial for health professionals to consider the societal attitude with reference to stigmatization, as this present research has included only those patients coming to hospitals not the traditional healers.

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