Stigma and Level of Dysfunction among Individual with Epilepsy

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ABSTRACT

Background: In this study, we assessed the Stigma and dysfunction in the Individual with epilepsy as compared to normal control. Objective: To examine level of dysfunction of the Individual with epilepsy and normal control and to examine perceived stigma of the Individual with epilepsy and normal control. Sample: The present study conducted at Out Patient Department of Epilepsy Clinic of the Central Institute of Psychiatry, Ranchi, included 60 Individual, among which 30 Individual were diagnosed with epilepsy and 30 normal Individual as control group. Design: The present study was cross-sectional hospital based and single contact study. The study assessed the level of dysfunction and perceived stigma in the Individuals with epilepsy as compared to normal control. Tools: Socio Demographic & Clinical Data Sheet, Stigma and Dysfunction Analysis Questionnaire were used for the assessment. The Statistical Package for Social Sciences (SPPS) 16.0 for windows was used for statistical analysis. Results: Dysfunction Analysis Questionnaire revealed severe level of dysfunction in the area of social, vocational, personal, family and cognitive area and personal area' in the domain of disability analysis questionnaire in Individual with epilepsy. There were no significant differences of stigma for epilepsy in the both group. Conclusion: It can be concluded that majority of patients was male, belonging to joint family and was from rural background and result of the study revealed severe level of dysfunction in the all domain of Dysfunction Analysis Questionnaire but there was absence stigma for epilepsy in both group.

Keywords: Stigma, Dysfunction, Epilepsy

INTRODUCTION

Epilepsy is one of the most common serious neurological disorders affecting. It affects 1% of the population by age 20 and 3% of the population by age 75. (Neligan, 2012). It is more common in males than females with the overall difference being small (Newton, 2012). Most of those with the disorder (80%) are in the developing world. The estimated prevalence of active epilepsy (as of 2012) is in the range 3–10 per 1,000, with active epilepsy defined as someone with epilepsy who has had at least one unprovoked seizure in the last five years. Epilepsy begins each year in 40–70 per 100,000 in developed countries and 80–140 per 100,000 in developing countries. Poverty is a risk and includes both being from a poor country and being poor relative to others within one’s country. In the developed world epilepsy most commonly starts either in the young or in the old (Newton, 2012). In the developing world its onset is more common in older children and young adults due to the higher rates of trauma and infectious diseases. In developed countries the number of cases a year has decreased in children and increased among the elderly between the 1970s and 2003. This has been attributed partly to better survival following strokes in the elderly (Neligan, 2012). Epilepsy is the second most common chronic neurological condition. It is estimated (Sridharan, 2002), that there are 55,00,000 persons with epilepsy in India, 20,00,000 in USA and 3,00,000 in UK.
Three to five per cent of the populations have a seizure sometime in their life and half to one per cent of the population have ‘active epilepsy’. The incidence of epilepsy ranges from 40 to 70 per 100,000 in most developed countries and from 100 to 190 per 100,000 in developing countries. In most countries worldwide, the prevalence of active epilepsy ranges from 4 to 10 per thousand populations. Higher prevalence rates ranging from 14 to 57 per thousand have been reported from some African and South American countries (Hauser & Annegers, 1980; Palcencia et al., 1992; Nicoletti et al., 1999; Sander, 2003). In India the incidence rate of epilepsy is roughly 49.3 per 100,000 and the number of new Individual with epilepsy in India each year would be close to half a million (Mani, 1997).

The incidence of epilepsy in developed countries is around 50 per 100 000 people per year, and is higher in infants and elderly people (MacDonald, 2000; Sander, 2003; Forsgren, 2005). Less wealthy people show a higher incidence, for unknown reasons (Heaney, 2002). Poor sanitation, inadequate health delivery systems, and a higher risk of brain infections and infestations could contribute to a higher incidence—usually above 100 per 100 000 people per year—in resource-poor countries where most people with epilepsy usually do not receive treatment (Sander, 2003; Sander, 2004). Childhood incidence has fallen over the past three decades in developed countries, which could be a result of adoption of healthier lifestyles by expectant mothers, improved perinatal care, and immunization programs. A parallel rise in incidence in elderly people could be related to improved survival in people with cerebrovascular disease and cerebral degeneration (Sander, 2003).

The prevalence of epilepsy is between 4 and 10 per 1000 people per year (Sander, 2003; Forsgren, 2005). A few (typically small) studies from isolated geographical areas with unique genetic or environmental factors have shown higher rates. Lifetime prevalence rates are much higher than rates of active epilepsy, even in resource-poor countries where most people do not have access to antiepileptic. This difference is mainly explained by the cessation of seizures in most people who develop the disorder, but also partly by increased mortality in epilepsy (Morgan, 2002).

In epilepsy, the stigma has been considered to be one of the most important factors that have a negative influence on the people with epilepsy and their family. Despite commendable achievements in the field of neuropharmacology as well as introductions of newer antiepileptic medications still common people reckon epilepsy to be a disorder with contagiousness, or having some demonical influences or problems lie on the suffered so on. Still people could not get out from the misconceptions and prejudices related to epilepsy. This way people who have epilepsy do not get the social acceptance and image what others do and these peoples’ social connectivity and repertoire tend to become limited and indeed restricted. Epilepsy is a common neurological condition, frequently associated with psychosocial difficulties. Prejudice and discrimination often have a greater impact on the daily lives of people with epilepsy than seizures. Previously done studies on epilepsy suggest that the stigma of epilepsy is one of the most important negative influences on the subjective well-being or life satisfaction of people with epilepsy. Epilepsy is known as a stigmatizing condition, as people with epilepsy sometimes cannot conform to usual social norms as a result of the unpredictable nature of seizures; consequently, society may fear dealing with someone who is having an epileptic seizure. From the patient’s point of view, the diagnosis of epilepsy challenges self-perception, and causes concern about ability to function in normal social roles, such as getting a job or having a family. The perception of epilepsy is often negative, which impairs the patient’s quality of life and reinforces the stigma. Stigma associated with epilepsy has been related to poor psychosocial health outcomes, such as low self-esteem, worry, negative feelings about life, and depression (Jacoby, 2002; MacLeod & Austin, 2003; Fernandes et al., 2007). Poor subjective well-being is also found in person with epilepsy (Kumar, P. et al., 2013). Finding indicated that severe level of dysfunction has been found in all functional area like social, vocational, personal, family and cognitive area in the patients with epilepsy as
compared to normal control (Prakash et al., 2013). People with epilepsy are also reported to perceive psychosocial adjustment as severe as perceived by patients having an impairing illness like schizophrenia in an earlier study from India (Kumar & Verma, 2006). It has found also that there were no significant differences of social support and stigma of epilepsy in the both group, epilepsy and normal control (Prakesh et al., 2014). The concept of stigma emerged as an important factor related to subjective wellbeing as well as development of positive self-esteem in persons with epilepsy. To develop both individual and broad social interventions to decrease the impact of stigma, it is important to understand how people of all ages with epilepsy experience and cope with this problem in their lives.

Epilepsy affected people often develop marked dysfunctions in many areas of life activities which could limit their socio-occupational functioning up to a great extent. Previous studies showed that there is a definite relationship between clinical variable like current seizure frequency and levels of anxiety and depression, perceived impact of epilepsy, perceived stigma, and marital and employment status. Another important variable like age at epilepsy onset may also have some relationship with psychosocial dysfunctions of these people (Jacoby et al., 1996). In addition to those above issues people with epilepsy may also face a number of complex and interacting problems and barriers related to employment. Factors like gender, number of antiepilepsy medications used, seizure frequency, and reported interference in daily functioning created by seizures can be the best predictors of employment of these people (Bishop, 2004). Despite significant progress in neuro-pharmacology, over 30% of people with epilepsy tend to have refractory seizures which will never achieve remission with antiepileptic drug therapy. These individuals are often severely disabled by their condition, have an unsatisfactory quality of life, and are at increased risk of sudden unexpected death. Recent studies have discovered that patients who have had symptomatic or cryptogenic epilepsy, experience of multiple seizures before antiepileptic drug treatment initiation, and those with febrile convulsions, a family history of epilepsy, or psychiatric comorbidities are least likely to respond to drug therapy and would likely to have higher degree of socio-occupational and psychosocial dysfunctions (Brodie, 2005).

**OBJECTIVES**

- To examine level of dysfunction of the Individual with epilepsy and normal control.
- To examine perceived stigma of the Individual with epilepsy and normal control.

**METHOD**

**Sample:**

The present study conducted at Out Patient Department of Epilepsy Clinic of the Central Institute of Psychiatry, Ranchi, included 60 Individual, among which 30 Individual were diagnosed with epilepsy and 30 normal Individual as control group.

**Inclusion Criteria of Patients:**

- Patients diagnosed with epilepsy as per International League against epilepsy (ILAE, 1989)
- Both sexes (male & female)
- Age more than 18 years
- Those who gave written informed consent for the participation in study

**Exclusion Criteria of Patients:**

- History of any chronic physical illnesses, mental illness, organic brain syndromes, and substance abuse/dependence.
- Co morbid significant psychiatric illness.
- Mental retardation, History of learning disorder, conduct disorder, ADHD.
- Age less than 18 years

**Inclusion criteria for normal controls:**

- No history of any chronic physical illnesses, mental illness, organic brain syndromes, and substance abuse/dependence
• Age more than 18 years
• Age, Sex and education Appropriately matched with the patients' group
• Those who gave written informed consent for the participation in study

Exclusion criteria for normal controls:
• Having significant physical illness, substance addiction (except moderate use of tobacco and caffeine)
• Having significant psychiatric illness
• Not willing to participate in the study
• Age less than 18 years

Design:
The present study was cross-sectional hospital based and single contact study. The study assessed the level of dysfunction and perceived stigma in the Individuals with epilepsy as compared to normal control.

Tools:
• A socio demographic and clinical data sheet was made for the study to obtain the socio-demographic and clinical information from the participants of the study.
• Dysfunction Analysis Questionnaire (DAQ) (Pershad et al., 1985)
• Stigma Scale of Epilepsy (SSE) (Fernandes et al., 2007).

Brief Description of Tools:
• Socio-Demographic & Clinical DataSheet
  A socio demographic data sheet was developed for this study which included variables like age, sex, education, income, occupation etc. for both groups, and illness related parameters (illness duration, number of episodes, frequency of seizures).
• Dysfunction Analysis Questionnaire (DAQ) (Pershad et al., 1985)
  The DAQ (Pershad et al., 1985) developed at PGIMER, Chandigarh, primarily for the measurement of the dysfunction in various areas of persons with psychiatric illnesses. This scale has 50 items grouped under 5 areas, viz., social, vocational, personal, family and cognitive. Each area which the scale assesses has 10 items and each item has 5 alternative answers indicating the same, better or worse level of functioning compared with the premorbid level of functioning. Rating of 1 indicates better than premorbid level of functioning and rating of 4 indicates rapid deterioration of functioning. Some items may not be applicable to a particular patient. An attenuated percentage score is calculated by the following formula:

  \[
  \text{Attenuated percentage score} = \frac{100 \times \text{obtained raw score}}{\text{Total no. of items attempted by the patient} \times 5}
  \]

  An attenuated percentage score of 40 in each scale means no dysfunction compared with a reference point of premorbid level. A score <40% means better level of functioning whereas score >40% means dysfunction.

• Stigma Scale of Epilepsy (SSE)
  This scale was developed by Fernandes et al, (2007). This scale identifies the perception of epilepsy stigma by a subject. This scale contains 24 items, each with a 4-point scale. Individuals are asked to indicate the most suitable answer for each item from the following options: 1 = not at all, 2 = a little, 3 = a lot, 4 = totally. Higher scores indicate more level of stigma. SSE score calculation

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  \text{SSE Score} = \frac{\text{Sum of all answered items} - \text{number of answered items}}{\text{Maximum score possible} - \text{Minimum score possible}} \times 100
  \]

  The scores of two items (1 and 4) were inverted when the scores were added.

Procedure:
The patients were selected based on inclusion and exclusion criterion through purposive sampling from
epilepsy clinic of Central Institute of Psychiatry, Kanke, Ranchi. Normal controls were selected from adjoining area of Kanke Block. Informed consent was taken from all the participants after providing detailed information about the study. After filling of the socio-demographic data sheet, dysfunction analysis questionnaire, and stigma scale for epilepsy were administered on the patients with epilepsy and normal control individuals.

**Statistical Analysis:**
The Statistical Package for Social Sciences (SPPS) 16.0 for windows was used for statistical analysis. Both descriptive and inferential statistics were used for analyzing data. Chi square test was used for comparing categorical variables and t-test was used for comparing continuous variables.

**RESULTS**

| Table-1  |
|------------------|--------|------|--------|
| **Comparison of Socio-demographic variables of Experimental (Epilepsy) and Control Group (Normal)** |
| **Variable** | **Group N=60** |  |  
|  | **Epilepsy** | **Control** | **df** | **χ²** |
|  | (N=30) (%) | (N=30) (%) |  |  |
| **Sex** |  |  |  |  |
| Male | 22 (73.3%) | 24 (80%) | 1 | .373 |
| Female | 8 (26.7%) | 6 (20%) |  |  |
| **Domicile** |  |  |  |  |
| Rural | 21 (70.0%) | 27 (90.0%) | 1 | 3.750 |
| Urban | 9 (30.0%) | 3 (10.0%) |  |  |
| **Marital status** |  |  |  |  |
| Married | 12 (40.0%) | 20 (66.6%) | 2 | 4.815 |
| Unmarried | 17 (58.6%) | 10 (33.3%) |  |  |
| Divorced | 1 (3.4%) | - |  |  |
| **Education** |  |  |  |  |
| Up to Class-V | 5 (16.8%) | - | 3 | 5.798 |
| Class-VI-XII | 18 (60.0%) | 20 (66.6%) |  |  |
| Graduation | 5 (16.8%) | 8 (26.6%) |  |  |
| Post-Graduation | 2 (6.4%) | 2 (6.6%) |  |  |
| **Occupation** |  |  |  |  |
| Unemployed | 1 (3.3%) | - | 4 | 6.526 |
| Student | 15 (50.0%) | 10 (33.3%) |  |  |
| Service | 1 (3.3%) | 1 (3.3%) |  |  |
| Self-employed | 8 (26.6%) | 17 (56.6%) |  |  |
| Housewife | 5 (16.8%) | 2 (6.6%) |  |  |
| **Religion** |  |  |  |  |
| Hindu | 21 (70.0%) | 25 (83.3%) | 3 | 1.191 |
| Islam | 4 (13.3%) | 2 (6.6%) |  |  |
| Christian | 2 (6.7%) | 1 (3.3%) |  |  |
| Others | 3 (10.0%) | 2 (6.6%) |  |  |
| **Family Type** |  |  |  |  |
| Joint | 28 (93.3%) | 23 (77.6%) | 3 | 3.268 |
| Nuclear | 2 (6.7%) | 7 (23.3%) |  |  |
Table 1 shows the comparison of two groups, i.e. experimental group (persons with epilepsy) and normal controls in relation to socio-demographic parameters. These two groups did not have any significant difference on any other socio-demographic parameters. In case of categorical variables Chi-square test was used for Group comparison.

Table 2 shows comparison of severity of dysfunction (scores of dysfunction analysis questionnaire) between patients with epilepsy and normal persons. There were significant differences in all the domains of dysfunction analysis questionnaire between two groups and there was no significant difference in any of the scores of Stigma Scale of Epilepsy.

DISCUSSION

Present study was a cross sectional comparative study on the level of dysfunction and perceived stigma between Individual with epilepsy and normal controls. The study sample comprised of 60 individuals (30 epilepsy patients and 30 normal individuals). The researcher of the present study could not find any similar study which has seen level of dysfunction and stigma together in a single sample, but many studies have conducted having different variables(like, subjective well being, dysfunction, social support, stigma etc.) at one time in a larger sample (Collings, 1990; Sunmonu, et al., 2009). A study done having 60 epileptic patients for investigating the relationship between subjective feeling of stigmatization and a tendency to conceal the presence of the disorder, but they didn't compare patient group with the normal controls (Janzik, et al., 1988). In another study 40 epileptic patients were studied to examine how they face stigmatization at their respective work place. In that study researcher found that 21 samples out of total 40 samples reported that they did not disclose their disorder to their employer because of fear of being stigmatized by office administration and colleagues (Cambler& Hopkins 1980). Though the sample size of the present study was comparatively less (N=60; Epilepsy patients (n)=30 and Normal Persons(n)=30]. These could be stated as the strengths of the present study. In the present study the epilepsy group consists of 73.3% males and 26.7% females and the control group consist
of 80.0% males and 20.0% females. The average age of the epilepsy patients was 28.30± 9.62 (in years) and that of the normal controls was 30.27 ± 8.71 (in years). There was no significant difference found in age distribution between the two groups. In the present study did not show any significant difference in stigma between epilepsy patients and normal controls. Study done by Fernandes et al., investigated stigma among patients with epilepsy by applying the same tool used in the present study, and found epilepsy as a stigmatizing condition, and various factors such as education, socio-economic class can influence the stigma level in epilepsy patients (Fernandes, 2007). The present study failed to replicate similar finding, can be because of the lesser sample size (n=30) compared to the sample size of the study done by Fernandes et al (n=1850). It may also be that the number of educated patients were high in number thus less stigma (Fernandes, 2007). The present study (Table-2) showed a significant difference in all the domain of dysfunction analysis questionnaire between epilepsy patients and controls. In the social area, there was significant difference between epilepsy patient and normal control (p=.000***). This indicated that the patient group had severe level of poor social relationship. This can be due to high stigma level in the community towards people with epilepsy due to a socially relevant and significant difference between them and normal people, which results in status loss and discrimination (Link & Phelan, 2006). In vocational area, there was significant difference between epilepsy patients and normal control (p=.007**). It indicated that the patient group had poor vocational relationship, which can be due to status loss and discrimination. In personal area there was a significant different between epilepsy patients and normal control (p=.000***). This indicated that the patient group had poor personal relationship. In family area at here was significant difference between epilepsy patients and normal control (p=.015*). This indicated that the patients group had poor family functioning. In cognitive area, there was significant difference between epilepsy patients and normal control (p=.000***). Study done by Sunmonu et al (2009) showed that patients with epilepsy performed poorly when compared to normal controls in the domains of language, memory, attention and calculation and praxis. The findings of this study support the findings of the present study that severe level of cognitive dysfunction is present in epilepsy patients when compared to normal controls.

**CONCLUSION**

It can be concluded that majority of patients was male, belonging to joint family and was from rural background. Dysfunction Analysis Questionnaire revealed severe level of dysfunction in the area of social, vocational, personal, family and cognitive area and personal area’ in the domain of disability analysis questionnaire in Individual with epilepsy. There were no significant differences of stigma for epilepsy in the both group.

**LIMITATIONS**

1. This study was a cross sectional design hence patients were assessed only once.
2. The sample used for the present study may not represent the entire Population from which it has been drawn because of the small sample size and heterogeneity in relation to various socio-demographic and cultural variables.
3. Both sexes were not equally represented in the selected samples.

**FUTURE DIRECTIONS**

1. In future, a similar type of study can be conducted on a larger sample with a prospective design.
2. In future stratification can be done to ensure appropriate representation of people of all socio-economic class.
3. Both sexes should be equally represented in the study sample.
4. To get the actual representation of the epilepsy patient and normal control, sample should be collected from community.
REFERENCES


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