

An Indian Study on Perceptions of Patients of Epilepsy and Their Family to Stigma and Its Impact on Quality of Life

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Abstract

Background: Epilepsy 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. This research was undertaken to study the perceptions of epileptic patients and their family to the disease and its associated stigma and the impact of stigma on the quality of life of patients with epilepsy. **Material & Method:** Informed consent of 50 patients of epilepsy and 50 relatives coming to a tertiary care hospital was taken. A semi structured proforma along with the Stigma Scale of Epilepsy and QOLIE-31 were used to assess the stigma in medical, social and personal domains and quality of life on 7 subscales in the patients. Stigma Scale of Epilepsy for community was used to assess the perceptions of stigma expressed by the relatives of the epileptic patients. **Results:** Out of 50 patients stigma was perceived by 15 patients. Both patients and relatives said that epilepsy was caused by a problem in the brain and more than 70% expressed difficulties faced by a person with epilepsy at work, in marriage, driving, relationships and religion along with discrimination. Fear, pity and dependence were the feelings expressed by both patients and relatives. A highly significant difference was seen on the various subscales of QOLIE viz emotional well being, energy/fatigue, cognitive functioning, social functioning and overall quality of life with the non stigmatized patients having a better quality of life than the stigmatized patients. **Conclusions:** This study helps in sensitizing clinicians to the problems faced by the patients of epilepsy & in creating awareness about the same in the society in general, so that the epileptic patients are not ostracized. It would provide direction for any modification in the management protocol of epilepsy.

Keywords

Epilepsy, Stigma, Quality of Life, Perceptions, Family

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1. Introduction

Epilepsy is the world's most common neurological disorder affecting 50 million people worldwide with three-quarters of them living in poor countries, and more than 80% living in the tropics.^{1,2} It has an incidence of 20-70 per 100,000 and a prevalence of 4-10 per 1000 & causes cognitive, psychiatric and behavioural disorders.³

Despite the significant clinical and therapeutic progress

achieved in the treatment of epilepsy, the label of epilepsy is still considered by many, both with and without the condition, as stigmatizing and carries with it, both statutory and informal restrictions. Factors contributing negatively to psychological well being include a sense of not being in control of one's life, feeling stigmatized,^{4,5} having problems related to quality of life such as co morbid depression and anxiety and problems connected with work, financial situation and stress inducing events in life.⁶ Patients with epilepsy experience more problems in social functioning and

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psychological well being than peers in general⁷ and these are often considered to be even more handicapping than seizures themselves.⁸ Research has shown that people who reported higher levels of perceived stigma were more likely to report lower levels of self efficacy in dealing with epilepsy, long term health problems, injuries as a result of seizures, increased side effects from medications, non-adherence to anti-epileptic drug treatment and low satisfaction as patients.^{9,10}

The situation of people with epilepsy in the developing countries remains even more problematic. India being a culturally diverse country with several religious practices has several misconceptions related to various illnesses, one of them being epilepsy. The misinterpretation of epilepsy often causes people with the condition being socially ostracized. Furthermore, as a consequence of both stigma and economic circumstances, most people with epilepsy do not receive the treatment they actually require. The purpose of understanding stigma is to provide the means to overcome it. We undertook this study in order to understand the perceptions of the Indian patients to epilepsy as well as the attitudes of their family to the disease, the associated stigma and its impact on the quality of life of the epileptic patient.

2. Methods

The study was conducted in the out-patient department of neurology of a tertiary care general municipal hospital over a period of 2 months. It was a clinical and instrument rated, cross sectional study. The study was approved by the Institutional Ethics Committee in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki. All the subjects were informed about the study and were recruited only after taking a written informed consent.

2.1. Sample Characteristics

75 patients and their relatives attending the epilepsy OPD of the neurology department and diagnosed by the neurologist as having any seizure disorder of any semiology (complex partial / generalized /simple partial) on a regular follow up & treatment were initially screened for the study. Of them 50 patients and relatives who satisfied the inclusion criteria and gave written informed consent were then recruited for the study.

Inclusion in the study for the patient required epilepsy of any semiology diagnosed by the neurologist, with the duration of epilepsy more than 2 years, with regular treatment and seizure control on medication with the age range from 18-45 years. Inclusion in the study for the relative required the person to be aged 18 years and above with no history of epilepsy and staying with the patient.

2.2. Tools

All the patients were interviewed with the help of the following tools:

- i). *Semi structured proforma*: A semi structured proforma was designed to include the socio demographic data, relevant details about epilepsy, medication history and family history of seizures.
- ii). *Stigma Scale of Epilepsy*^{11, 12} is an exploratory open questionnaire which has two versions: for the community and for the patients. The participants answer all the questions as per their understanding. The questionnaire used for the community has 16 questions and the patients' questionnaire has 4 additional questions about self perception of epilepsy. Both questionnaires have 3 domains- medical, social and personal.
 - The medical area refers to clinical aspects of epilepsy as type of epilepsy, frequency and severity of seizures, medical treatment.
 - The social area refers to behaviours, attitudes and relationships in general.
 - The personal area deals with feelings, beliefs, and perceptions about epilepsy.

The relative group were only administered the Stigma scale for community. The scale therefore provides a clue based on the specific domains (medical, social and personal) about felt and enacted stigma.

Based on the stigma scale the patient group was then divided into 2 groups:

Group A: Patients who felt stigmatized due to epilepsy

Group B: Patients who did not feel stigmatized due to epilepsy

iii). *Quality of Life in Epilepsy Inventory: QOLIE-31*¹³

Quality of life in epilepsy (QOLIE-31) is a 31 item self-administered questionnaire specifically designed to measure quality of life of people with epilepsy derived from the QOLIE-89. The QOLIE-31 has seven of the 17 QOLIE-89 subscales. The QOLIE-31 measures health related quality of life across seven domains such as seizure worry, overall quality of life, emotional wellbeing, energy-fatigue, cognitive functioning, medication effects, and social functioning. Responses are summed to supply subscale scores and a total score, with higher scores indicative of better functioning. The QOLIE-31 has demonstrated good psychometric properties with internal consistency reported as Cronbach's $\alpha = .85$ and test-retest reliability of $r = .85$.

3. Statistical Analysis

Statistical analyses were performed using Statistical Package for Social Sciences (SPSS) for Windows version 16.0. The demographic variables and stigma perceived by the patients and their relatives were studied using frequency distribution. Chi square (χ^2) test was used for comparing the perception of stigma between patients and relatives. The impact of stigma on the quality of life of patients in stigmatized and non-stigmatized patients was studied using unpaired t-test. Two-tailed "P" values below 0.05 were considered significant.

4. Results

4.1. Demographic and Clinical Characteristics of the Patients

Table 1. Socio-demographic and epilepsy characteristics of the patients.

Variable	Patient group (n = 50)
Gender	
Male	36 (72%)
Female	14 (28%)
Religion	
Hindu	45 (90%)
Muslim	5 (10%)
Marital status	
Married	30 (60%)
Unmarried	20 (40%)
Education	
Primary	10 (20%)
Secondary	32 (64%)
Graduate	8 (16%)
Occupation	
Unemployed	6 (12%)
Employed	27 (54%)
Housewife	8 (16%)
Student	9 (18%)
Type of seizures	
GTC	38 (76%)
Complex partial seizure with or without secondary generalization	12 (24%)
Family history of seizures	
Present	10 (20%)
Absent	40 (80%)
Seizure frequency	
None in the past year	26 (52%)
<1 seizure per month	19 (38%)
>1 seizure per month	5 (10%)

The mean age of all the patients was 36.5 ± 10.4 years. Males were predominant, with the male: female ratio being 3:1. Majority of the patients were Hindus. About 60% were married and nearly 80% had secondary and higher education with 54% being employed. 76% had generalized seizures and 24% had complex partial seizures. Family history of seizures was documented in only 20% of the sample. The mean duration of seizures in patients was 10.6 ± 7.89 years. The

patient group was on regular treatment and seizures were controlled on medications, with nearly 50% having no seizure in the last one year. (Table 1)

4.2. Perception of Stigma in Patients and Relatives

The responses given by the patients and relatives were analyzed. The patients having negative attitudes in regard to the items like work/job possibilities, social relations and those who felt discriminated were considered to have a high perception of stigma. The prevalence of stigma was seen in 30% (n=15) of the patient population whereas it was not felt by 70% (n=35) of them. In keeping with the applied questionnaire, the main results obtained were grouped in three main domains: medical, social and personal areas and were studied for the patient and relative groups.

• Medical Area-

The questions for this domain were about knowledge of epilepsy, including causes, types of treatment for epilepsy and source of information. Majority of both the patients and relatives felt that epilepsy occurred due to problem in the brain and they believed that medication was necessary for treatment of epilepsy. No significant difference was observed in the views of both patients and relatives. (Table 2a)

• Social Area-

The questions for this area were about difficulties faced by a person with epilepsy, such as discrimination & difficulty in work, marriage, driving, relationships and religion. 76% of the patients and 88% of the relatives pointed that it was more difficult for people with epilepsy to get a job due to prejudice and risk of accidents. 94% patients and 98% relatives felt that patients with epilepsy could not drive or travel alone because it was considered dangerous. About 60-70% of patients and relatives felt that patients with epilepsy had memory impairment. When asked about hiring someone with epilepsy to work at their home, 96% of patients and 84% of relatives answered in the affirmative. They felt that all individuals had the same rights. When enquired about marrying someone with epilepsy, then 78% patients said that epileptics were normal people and expressed in affirmative while only 30% of the relatives answered 'yes' to this question. The relatives were of the view that marrying someone with epilepsy would pose problems in maintaining healthy social relationships.

On asking the relatives what they would do if they saw someone having a seizure, then most of them answered that they would help and take the patient to a nearby hospital (82%), calm the patient down, hold him/her tightly and pull the tongue (72%), would be afraid of the patient (12%) and would not know how to act (6%). When the patients were asked what people did when they had a seizure, then the

responses were that they would be helped (70%), people would go away (35%) or would be scared / fearful (20%).

In response to the question on religion and the beliefs of the religion about the disease, 90% of the patients were Hindus and 10% were Muslims. People of both the religions considered epilepsy to be a normal disease and only 4% people highlighted it as a spiritual disease. The suggestions given by the subjects to improve the negative aspects were: role plays about epilepsy (20%), psychological follow up (15%), and establishment of laws for safeguarding the rights of epileptic patients (5%) whereas about 60% of them did not know how to change the situation. (Table2b)

● Personal area:

This domain highlighted the feelings when a seizure occurred and the daily feelings of people with epilepsy. The feelings expressed by the patients during a seizure were of uneasiness (60%), sadness (40%), fragility, weakness (30%). When they were asked what people thought, when they had a seizure then 26% thought there was pity, 24% thought people had fear while 50% felt that they did not know what other people thought in such a situation. When the relatives were enquired about the feelings of a patient with epilepsy, their views were fear (60%), dependence (54%), and pity (52%). When the relatives were asked whether they would allow someone next to them to have friends with a patient of epilepsy then all of them answered in affirmative. (Table2c)

Table 2(a). Stigma Expressed by Patients and Relatives on Stigma Scale: Medical Domain.

Medical domain	Number of patients (n=50)	Number of relatives (n=50)	Chi square statistic	p value
Meaning of epilepsy				
Convulsion/attack	13 (26%)	20 (40%)	$\chi^2 = 4.2$ df = 3	0.24
Fainting episode	9 (18%)	12 (24%)		
Problem in the brain	17 (34%)	10(20%)		
Do not know	11 (22%)	8(16%)		
Causes of epilepsy				
Traumas	4 (8%)	10(20%)	$\chi^2 = 3.6$ df = 5	0.607
Psychological factors	20 (40%)	25(50%)		
Lack of blood supply to the brain	7 (14%)	8(16%)		
Lack of proper nutrition and sleep	12 (24%)	18(36%)		
Exertion	15 (30%)	20(40%)		
Do not know	14 (28%)	10(20%)		
Type of treatment				
Medication	35 (70%)	30(60%)	$\chi^2 = 1.76$ df = 3	0.622
Surgery	6 (12%)	5(10%)		
Religious approach	3 (6%)	6 (12%)		
Do not know	14 (28%)	17 (34%)		
Got the information				
Doctors	23 (46%)	18(36%)	$\chi^2 = 3.18$ df = 3	0.364
Other patients	10 (20%)	15(30%)		
Television	3 (6%)	1(2%)		
Do not know	11 (22%)	15(30%)		

(Multiple responses)

Table 2(b). Stigma Expressed by Patients and Relatives on Stigma Scale on Social Domain.

Difficulties	No. of patients n=50	No. of relatives n=50	Chi square statistic	p value
Work/job opportunities	38(76%)	44 (88%)	$\chi^2=23, df= 7$	0.0017***
Prejudice	39(78%)	10 (20%)		
Discrimination	13(26%)	5 (10%)		
Marriage	21(42%)	30 (60%)		
Relationships	13(26%)	7 (14%)		
Driving and traveling	47(94%)	49 (98%)		
Memory	34(68%)	30 (60%)		
Leisure	4 (8%)	2 (4%)		

(Multiple responses)

Table 2(c). Stigma Expressed by Patients and Relatives on Stigma Scale on Personal domain.

Feelings about epilepsy	No. of patients (n=50)	No. of relatives (n=50)	Chi square statistic	p value
Sadness	20 (40%)	12 (24%)	$\chi^2 = 15.57$ df = 5	0.008***
Inferiority	15 (30%)	7 (14%)		
Insecurity	5 (10%)	3 (6%)		
Fear	20(40%)	30 (60%)		
Pity	13 (26%)	26 (52%)		
Dependence	12 (24%)	27 (54%)		

(Multiple responses)

Table 3. Comparison of the impact of stigma on the quality of life of patients.

Variable	Group A = patients who were stigmatized (n = 15)		Group B=patients who were non-stigmatised (n = 35)		t test	P value
	Mean	Standard Deviation	Mean	Standard Deviation		
Seizure worry	3.24	2.44	4.52	2.103	1.88	0.065
Emotional well being	6.64	2.38	8.93	2.22	3.26	0.002**
Energy/Fatigue	4.84	2.88	7.21	2.69	2.802	0.0073**
Cognitive functioning	14.09	6.78	18.03	4.82	2.338	0.023*
Medication side effect	1.78	0.823	1.793	0.964	0.013	0.989
Social functioning	12.15	5.08	16.17	3.49	3.233	0.002**
Overall QOL	6.13	2.21	9.94	2.52	5.058	0.0001***
Total score	48.89	15.64	66.61	12.165	4.32	0.0001***

4.3. Impact of Stigma on the Quality of Life of Patients

The impact of stigma on the various domains of quality of life was compared in patients who felt stigmatized and those who did not. A highly significant difference was seen on the various subscales of QOLIE viz emotional well being ($t = 3.26$, $p < 0.002$), energy/fatigue ($t = 2.802$, $p < 0.0073$), cognitive functioning ($t = 2.338$, $p < 0.023$), social functioning ($t = 3.233$, $p < 0.002$) and overall quality of life ($t = 5.05$, $p < 0.0001$) with the non stigmatized patients having a better quality of life than the stigmatized patients ($t = 4.32$, $p < 0.0001$). However, on the subscales of seizure worry and medication side effects, no significant difference was seen between the two patient groups. (Table 3)

5. Discussion

5.1. Demographic and Clinical Characteristics of the Patients

It is understood that people with epilepsy and especially those in developing countries are known to experience problems with marriage, education, social isolation and employment. A study by Joseph et al¹⁰ noted a marriage rate of 70% which was similar to our finding of 60% whereas a lower rate of 46% was noted by Agarwal et al 2006.¹⁴ Separation from spouse due to seizures was seen in 4% of patients in a study by Joseph et al¹⁰ which was similar to other studies.¹⁵ Several studies have reported unemployment among epileptic patients.¹⁶⁻¹⁸ Our finding of 54%

employment in epileptics was more than the findings of 23% by Baker et al¹⁵ and 17% by Djibuti&Shakarishvili.¹⁹ Joseph et al¹⁰ in their study however reported that none of the patients in their sample were unemployed because of their illness. Unemployment and lower rates of marriage among epileptic patients lead to greater social isolation which may further depress the lives of these patients.

Education is often hindered due to seizure frequency especially with an early onset of seizures. However all our patients had some form of education with nearly 64% having secondary education and 14% being graduates. Joseph et al¹⁰ also found high school education in 45-50% of their patients and graduation in about 8% which is in keeping with our findings.

Commonest type of seizure seen in our study was generalized seizure seen in nearly two-thirds of the sample. Similar findings have been noted by other researchers.^{10,15,16,20} Shetty et al²¹ found that only 10 patients of their sample had no seizures in last 20 months whereas 50% of our patients were well controlled and had no seizure in last one year.

5.2. Perception of Stigma in Patients and Relatives

• Medical Area

When the responses to the items comprising the perceived stigma scale were analyzed, it was observed that epilepsy is not universally stigmatizing. In this study, 30% of the patients had feelings of stigma associated with their epilepsy compared with 70% of their counterparts who did not feel

stigmatized because of the condition. This could be due to increasing awareness regarding epilepsy and its acceptance as a medical illness. This is in keeping with other studies that have found lower levels of stigma. Both Westbrook et al²² and Buck et al²³ found that greater than 60% of participants did not report feeling stigmatized by their epilepsy as compared to a study conducted by Baker et al²⁴ where 51% of the patients felt stigmatized because of epilepsy. Epilepsy as a stigmatizing condition has also been reported in other studies as well.^{25,27}

In the medical domain it was observed that about 60% of both patients and relatives felt that epilepsy was an attack related to a problem in brain. They attributed their understanding of epilepsy to information received from other patients and doctors. Very few said that media was a medium of information. It therefore would be essential to impart information through radio, television and advertisements to reach out to millions suffering from epilepsy. This shows that there is increased awareness amongst the society in general about epilepsy and the need for treatment and very few people corroborated to religious mishap. In the Indian culture there are several superstitious beliefs among people that evil spirits or Gods curse is usually responsible for causing seizures but it was not corroborated by our sample. Similar findings about awareness of epilepsy was reported by an Indian study²⁸ where 92% had heard about epilepsy but 85% public were not aware of the cause of epilepsy and had several wrong beliefs. In another study, 87% people reported that they had read or heard about epilepsy, 70% knew someone who had epilepsy & 56% had seen someone having a seizure.²⁹

- Social Area

In the social domain the exploratory questionnaire showed that the most affected areas for epileptic patients were difficulties in work/job opportunities, marriage, social relations, memory impairment, restriction of activities (to drive and travel alone) and prejudice which was equally expressed by patients as well as their relatives. Studies have reported that prejudice and discrimination often have a greater impact on the daily lives of people with epilepsy than seizures.^{9,30}

Negative stereotypes of people with epilepsy have been so ingrained in the collective belief system that they have become an accepted part of many people's concept of the disorder,³¹ including patients themselves.²⁶ People with epilepsy may feel and be discriminated, but they do not believe in changing this situation. These aspects have a great impact on the felt stigma and make it difficult to distinguish felt and enacted stigma.

A number of variables can explain the differences in the

perception of stigma.³² These are:

- Psychosocial variables such as fear of seizure, feelings about life as a whole, general health.
- Epilepsy variables such as age at onset, duration of seizures, seizure type, seizure severity.
- Medication variables including medication type and number.

Other significant predictors of stigma include educational status, socio-cultural bias against epilepsy, cultural norms for concealment or disclosure of the condition. Ryan et al³³ proposed two alternative models that postulate the causes of stigma. The medical model assumes that if epilepsy is stigmatizing, then the perception of stigma will increase as the seizure severity increases. In contrast to this medical model, the socio-psychological model assumes that other individual characteristics like age, sex, education, perception of discrimination etc also affect the degree to which persons with epilepsy feel stigmatized by the disorder.

The place of the worker often speaks volumes about a society's views. Our study points out that out of the total 50 respondents, majority of the patients (76%) were of the view that epilepsy did impose certain restrictions in the job opportunities available to them but 54% were employed in occupations suitable to their health state. Many of them were not satisfied with their current employment status and attributed occasional discrimination at work. Only 12% of the patients reported that epilepsy was the reason they were not working. About 12% were unemployed but stated they were actively seeking work. Previous studies have highlighted the employment difficulties faced by the persons with epilepsy^{34,35} with unemployment identified as one of the most serious problems they face.³⁶ Epilepsy is a commonly associated with psycho-social difficulties³⁷⁻³⁹ and prejudices and discrimination which have an impact on daily life of people with epilepsy.^{9,40}

- Personal area:

Researchers in the past have shown that attitudes towards persons with epilepsy are influenced by the degree of the knowledge of the condition.^{37,41} People with epilepsy are prone to poorer self-esteem and higher levels of anxiety and depression than people without epilepsy.⁴² There has been an increasing recognition that seizures might be less disabling than their psychosocial correlates. It is more often the "normal" people, who in their ignorance and apprehension about epilepsy, tend to maintain social distance with the epileptics through discriminatory practices in both public and private spheres.²⁶ In India the culture is patriarchal with decisions taken by the head of family and hence there is often overprotection of the epileptic patient or over involvement by

the family resulting in feelings of fear, insecurity and indecisiveness with dependence on family members for even activities of daily living. The patients are often not allowed to go out to work or meet friends or go to school or play especially children for fear of getting seizures. This could give rise to anxiety and depression in these patients.

In our study sample, most of the patients and their relatives had adequate knowledge about epilepsy. Nonetheless, we are still far from fully demythologizing epilepsy and debunking long held prejudices, myths and misconceptions about the condition. Sustained efforts by professional and voluntary organizations as well as concerned individuals, have made major contributions in improving public perception about the condition and there is evidence that progress is being made. But favourable court rulings, supportive legislations and enlightened administrative decisions cannot, by themselves undo centuries of effect of stigmatization.^{5, 32, 43}

5.3. Impact of Stigma on the Quality of Life of Patients

We found in our study that the patients who experienced stigma had a poor quality of life on the various subscales of emotional wellbeing, energy/fatigue, cognitive functioning, social functioning and overall quality of life as compared to then on stigmatized patients. This shows that stigma affects several spheres of life and carries a negative impact. Feeling good about life, being happy would lead to an overall feeling of being energetic and full of pep which was missing in the stigmatized patients. This, thus affected their social functioning and overall quality of life and could also lead to psychopathology. All the patients included in the study were well controlled for seizures and were on regular follow up in the epilepsy outpatient department and therefore no significant differences were seen in the 2 groups on the subscales of seizure worry and medication side effects.

Several researchers have reported that the issues faced by people with epilepsy are common across cultural boundaries and the negative effects of epilepsy have an impact on patients' quality of life. Age, educational level, income, and frequency of seizures were significant determinants of quality of life.⁴⁴⁻⁴⁶ Other studies have found an impact on quality of life in spheres of uncertainty of seizures and the social meaning associated with this disease.⁴⁷⁻⁵⁰ Baker et al¹⁵ reported that 44% of respondents worried a lot about possible side effects of their medication and 47% reported that it substantially affected their plans and ambitions for the future. Dilorio et al⁴⁸ found that participants reporting higher levels of perceived stigma also reported lower levels of self-efficacy to manage epilepsy; more negative outcome expectancies related to treatment and seizures; and lower levels of medication management, medication adherence and

patient satisfaction. Poor seizure control with high seizure frequency also affects quality of life.^{15, 19, 51-53} Hence reducing the stigma and handicap associated with epilepsy are key to improving the quality of life as is reducing the side effects and achieving better control of seizures.

6. Conclusions

Our study findings emphasize the importance of more effective treatment of epilepsy and continuing education of the public about the nature and implications of the condition. The findings also emphasize the importance of empowering people with epilepsy so that they are better able to accommodate their condition and to maximize the quality of their lives with the help of psychological interventions, rehabilitation and educational programs.

We need to challenge the current social construction of epilepsy as a disability and stigma and aim to reduce existing treatment gaps. People with epilepsy deserve well-formulated legislative support. These measures will help the epileptic patients to become self-reliant. Finally, we need to champion a better resourced research agenda into the social realities of epilepsy, and the ways by which, these can be improved.

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