

Original article

Knowledge, attitude and stigma in epilepsy: a study from a tertiary care centre in Nepal

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Abstract

Introduction: Epilepsy is a common health problem which engenders a variety of medical, social, psychological and economic burdens. Stereotyped assumptions about people with conditions such as epilepsy are inherent in many cultures and Nepal is not an exception. Better information about epilepsy among the people can remove the stigma associated with it. **Objective:** The aim of the present study was to assess the knowledge, attitude and stigma regarding epilepsy among patients with epilepsy. **Methods:** It is a hospital based, cross-sectional descriptive study of 47 patients visiting BPKIHS psychiatry OPD. A semi structured Proforma, knowledge attitude questionnaire and the Stigma Scale developed by M. King et.al. was administered to collect the data. **Results:** Majority (66.0%) of subjects were male. Generalized seizure (76.6%) was most common presentation. Majority of subjects believed that their disease should be kept secret. Almost 81% subjects thought they could work with persons suffering from epilepsy whereas 23.4% subjects objected even to travel together with them. About 32% subjects felt bad about having epilepsy, 40.4% agreed that they were angry the way people react to their illness, and 76.6% thought that they would have had better chances in life if they did not have epilepsy. **Conclusion:** Knowledge about epilepsy is still patchy among patients. Despite this, attitude towards epilepsy is generally positive. Still there is significant stigma attached to this illness. These findings call for comprehensive educational program aimed at improving the knowledge and reducing the stigma in the population at large.

Keywords: epilepsy, generalized seizure, stigma

Introduction

Epilepsy is a common health problem which engenders a variety of medical, social, psychological and economic burdens. The impact of the disease is felt, noticed and experienced in all spheres of the patient's life and also to some extent in patient's family. Stereotyped assumption about people with conditions such as epilepsy are inherent in many cultures, based in old superstitions and beliefs and, often reinforced through disabling portrayal in literature and media.¹ The attitude of the general public towards epilepsy has

still not improved significantly. Also a strong stigma is attached to this disease.² This has led to psychological stress among the person suffering from epilepsy. Though there are numerous studies done on epilepsy throughout the world only few had addressed the issue of the Knowledge Attitude Practice and stigma in epilepsy, making awareness; even more fewer are in Nepal. This study has been undertaken to highlight the need of disease to be taken seriously for implementing it in the national health policy making which will help in empowering the general public with the positive knowledge regarding the disease which will reduce the various complications that a person with epilepsy and also the family has to suffer in their life.

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Methods

It a hospital based cross-sectional descriptive study of patients attending psychiatry OPD during one year duration (Jan 2008 to Jan 2009). All consecutive patients visiting psychiatry OPD of BP Koirala Institute of Health Sciences, Dharan were screened for potential enrolment based on the inclusion and exclusion criteria. Written informed consent was taken from each patient and the information was kept confidential and used for research purpose only. A semi structured Proforma developed and approved by the department was used to record the basic socio-demographic details. Separate questionnaire for knowledge and attitude, and questionnaire for stigma was administered to collect the data. Lab investigation was done for the management of the case as per the need.

Results

A Total of 47 consenting patients were enrolled in the study. The result are as follow

Demographics

Among the patients, the age ranged from 16-50 years with mean age being 26 years. Male subjects were 31(66%) and 25(53.2%) were married. Majority of the subjects were Hindu and educated up to secondary level. (Table 1)

Table 1: Socio-demographic profile of subjects with epilepsy

Profile	Category	Frequency (f)	Percentage (%)
Age (in years)	≤19	16	34
	20-29	17	36.2
	30-39	7	14.9
	40-49	7	14.9

Sex	Male	31	66
	Female	16	34
Marital Status	Unmarried	25	53.2
	Married	22	46.8
Religion	Hindu	31	66
	Kirat	13	27.7
	Christian	2	4.3
	Muslim	1	2
Education	Illiterate	4	8.5
	Primary	4	8.5
	Secondary	27	57.5
	Intermediate	11	23.4
	Graduate	1	2.1
Occupation	Business	5	10.6
	Farmer	8	17.0
	Housewife	2	4.3
	Idle	7	14.9
	Service	7	14.9
	Labourer	3	6.4
	Painter	1	2.1
	Student	14	29.8
Family type	Joint	2	4.3
	Nuclear	45	95.7
Monthly Income	≤10000	36	76.6
	11000-20000	10	21.3
	≥21000	1	2.1

Clinical description of epilepsy

Majority i.e. 36(76.6%) patients had primary generalized seizure, 5(10.6%) had complex-partial seizure and 4(8.5%) had partial seizure with secondary generalization in 4(8.5%) patients. Among 47 patients, 8(17.0%) had positive family history for epilepsy. (Table 2)

Table 2: Distribution of subjects by types of seizure based on (International league against epilepsy) classification and family history of seizure

Character	Category	Frequency (f)	Percentage (%)	
Types of Seizure	Partial	SPS*	2	4.3
		CPS**	5	10.6
		PS# with secondary generalization	4	8.5
	Primary Generalized	Atonic	1	2.1
Tonic Clonic		35	74.5	
TOTAL		47	100	
Family History	Present	8	17	
	Absent	39	83	
TOTAL		47	100	

*Simple Partial seizure, **Complex Partial Seizure, #Partial Seizure

Knowledge about epilepsy

Among the patients, 21(44.7%) believed that person with epilepsy (PWE) are violent and dangerous and 16(34.0%) had opinion that PWE are mentally ill. However, majority i.e. 22(46.8%) think that PWE can return to their pre-morbid state and treatment should be continued as per doctors advice. Almost half of the subjects were not ready to marry their children with PWE. Majority i.e. 44(93.6%) opined that presence of epilepsy in the family should be kept a secret. However more than half i.e. 27(57.4%) knew that epilepsy can occur due to physical and chemical changes

in the brain. Majority i.e. 28(59.6%) think that PWE can take care of themselves and their family but 15(31.9%) think that PWE cannot work responsibly. A significant number of subjects also think that alternative measures like yoga, meditation worshipping god and local herbal medication are also effective. Majority i.e. 39(83.0%) opined that treatment by a psychiatrist is very effective. On scoring the knowledge, the mean score was 13.38±3.6. Maximum score was 20 and minimum score was 6. (Table 3)

Table: 3 Showing some items of knowledge regarding epilepsy in subjects with epilepsy

S.No	Questions	Yes n (%)	No n (%)	Can't say n (%)
1.	Epileptic Patients are violent and dangerous	21 (44.7)	16 (34)	10 (21.3)
2.	Epileptic patients are mentally ill	16 (34)	20 (42.6)	11 (23.4)
3.	Epileptic patients can never return to premorbid state	10 (21.3)	22 (46.8)	15 (31.9)
4.	The only place to treat epileptic patients is mental hospital	36 (76.6)	2 (4.3)	9 (19.1)
5.	Epilepsy gets improved after marriage	6 (12.8)	29 (61.7)	12 (25.5)
6.	Most of the epilepsy can be treated at home	10 (21.3)	29 (61.7)	8 (17)
9.	Are you ready to marry your children with person with epilepsy	6 (12.8)	23 (48.9)	18 (38.3)
10.	We should keep the fact secret, if anybody has epilepsy in the house	2 (4.3)	44 (93.6)	1 (2.1)
15.	Epilepsy can be hereditary	13 (27.7)	19 (40.4)	15 (31.9)
17.	Epilepsy can occur due to physical & chemical change in brain	27 (57.4)	8 (17)	12 (25.5)
18.	Epileptic patients can take care of themselves	28 (59.6)	17 (36.2)	2 (4.3)
19.	Epileptic patients can take care of the family	29 (61.7)	10 (21.3)	8 (17)
20.	Epileptic patients can maintain their relation with others	29 (61.7)	12 (25.5)	6 (12.8)
21.	Epileptic patients can work responsibly	29 (61.7)	15 (31.9)	3 (6.4)
22.	Epileptic patients can plan about the future	27 (57.4)	13 (27.7)	7 (14.9)

Attitude towards epilepsy

Of all respondents while asking ‘if you can work with an epileptic patients’, 38(80.9%) subjects answered affirmatively. All of the subjects did not have any problem in sitting and talking to PWE. Majority i.e. 45(95.7%) subjects say that they can stay together in the same house with PWE. Most of the subjects i.e. 36(76.6%) agreed that they can travel together with an epileptic patient but 11(23.4%) objected in doing so.

Stigma regarding epilepsy

Among the patients, about one-third i.e. 15(31.9%) patients felt bad about having had epilepsy. Nineteen (40.4%) patients agreed

that they were worried about telling people that they had received psychological treatment. Nine (19.2%) patients agreed that they have been discriminated against by employers because of epilepsy. High majority of subjects i.e. 36(76.6%) believed that they would have had better chances in life if they did not have epilepsy. Nineteen (40.4%) patients agreed that they are angry with the way people have reacted to their illness. Thirteen (27.7%) patients agreed that they have been avoided by people because of their illness. On stigma scoring, the mean score of patients was 46.34±16.25. Maximum score was 75 and minimum was 4. (Table 4)

Table: 4 showing some of the items of stigma perceived by patients with epilepsy

Statements	Agree/ Strongly Agree	Neither Agree nor Disagree	Disagree/ Strongly Disagree
I do not feel bad about having had epilepsy	27(57.7)	5(10.6)	15(31.9)
Some people with epilepsy are dangerous	23(48.9)	11(23.4)	13(27.6)
Very often I feel alone because of epilepsy	18(38.3)	2(4.3)	27(57.5)
I am scared of how other people will react if they find about my epilepsy	24(51.0)	3(6.4)	20(42.6)
I would have had better chances in life if I had not had epilepsy	36(76.6)	4(8.5)	7(14.9)
I worry about telling people that I take medicines for epilepsy	21(44.7)	3(6.4)	23(48.9)
Peoples reaction to my illness make me keep myself to myself	25(53.2)	4(8.5)	18(38.3)
I am angry with the way people have reacted to my epilepsy	19(40.4)	2(4.3)	26(55.3)
People have avoided me because of my epilepsy	13(27.7)	5(10.6)	29(61.7)
People have insulted me because of my epilepsy	15(31.9)	6(12.8)	26(55.3)
Having had epilepsy makes me feel that life is unfair	24(51)	2(4.3)	21(44.7)
I find it hard telling people I have epilepsy	22(46.8)	3(6.4)	22(46.8)

Discussion

Age of the subjects

In our study, the age of the patients ranged from 16-50 years with the mean of 26.7±10.2 years. In a study conducted by Upadhyaya et.al.³ at four village health posts in Kaski district, a western part of Nepal, the mean age was 26 years which coincides with our finding.

Gender and marital status

Most of the studies have reported epilepsy to be more common in males. In our study, out of 47 patients 31(66%) were male and 16(34%)

were females. In a similar study conducted by P. Rajapakse et.al. male constituted 55% (males) and 45% females.⁴ Slightly higher male dominance than other studies in our study might be due to the fact that our society is still a male dominated society with women’s secondary social position. Male family members get more attention than females for treatment. This being hospital based study, so it may not necessarily reflect the situation in the general population.

Clinical profile

In developed countries, patients with partial seizure or localization-related epilepsies account for 33-65% of the epilepsy population and those with generalized seizure account for 17-60% and 2-8% are unclassified.⁵ In our study, primary generalized seizure (76.6%) was the most common seizure followed by partial seizure (13.4%). Almost similar finding was reported by D-S Tran et.al. where 84.3% cases were generalized seizure and 15.7% were partial seizure.⁶ The variation may be related to lower level of case ascertainment of partial seizures and misclassification. Geographically relevant risk factors such as neurocysticercosis and birth and accident related head trauma might contribute to the high prevalence of partial epilepsies in some tropical countries.⁷

In our study, 17% patients had positive family history for epilepsy. In a similar study conducted by Upadhyaya et al. 15.9% patients had positive family history for epilepsy.³ The reason for this slight higher positive family history is unclear though it is possible that untreated infectious diseases like typhoid or tuberculosis are more readily transmitted between family members and, especially in cases of childhood illness, might have caused or later led to seizure disorder.⁸

Knowledge about epilepsy

The success of programs aiming at improving quality of life of people with epilepsy will depend on their knowledge and attitude towards this illness.

In our study, significant numbers of subjects (44.7%) believed that patients with epilepsy are violent and dangerous. Similar view was found in a study by H. Aziz et al. in Pakistan where 8.9% subjects believed that patients with epilepsy are violent and dangerous.⁹ Higher rate in our study might be due the prevailing belief that mental illness and epilepsy are similar illnesses. A sizeable number (21.3%) believed that patients with epilepsy cannot return to their normal state of this may lead to delay in treatment and poor

compliance. The majority felt that marriage could not cure epilepsy rather they should be taken to a specialist for the treatment. In contrast to the general public's prevailing view about epilepsy, majority of subjects believe that it cannot be due to sin, religious or other mistakes, witchcraft, poverty, strained interpersonal relation and unsafe sexual relation. Most of the subjects (57.4%) knew that epilepsy occurs due to physical and chemical changes in the brain. This is comparable to the views found in a study in Pakistan.⁹ However significant numbers of subjects (48.9%) were not ready to marry their children with epileptics, reflecting associated prevailing stigma. This finding is supported by the study conducted by Pongkiat where 36.3% subjects were not ready

to marry their children to a person with epilepsy.¹⁰ More than half of the subjects responded that these patients can take care of themselves and their family; they can work responsibly and maintain their relation with others. A study from Sri-lanka showed that 80.2% subjects believed that they can live a normal life.⁴ However, respondents with opposite view maintained that they cannot do so i.e. (20-30%). This is consistent to the finding by K. Radhakrishnan et al. where it was found that one third subjects believe that persons with epilepsy cannot have a happy married and sexual life.⁽⁷⁾ This attitude in the subjects might be related to their belief that epilepsy is a hereditary disease and that epilepsy and mental illness are perceived as similar. Significant number believes that other traditional system of treatment are effective. This reflects the traditional view and beliefs which are still prevalent in the society. Eighty three percent believed that treatment by a psychiatrist is 'very effective' followed by general practitioner. While scoring the knowledge about epilepsy on the scale, it was found that majority of the subjects (80.9%) had inadequate knowledge about epilepsy. The mean score was 13.38±3.6. It might be due to inadequate information about epilepsy and other health related issues in the general population.

Attitude towards epilepsy

In our study, high majority of subjects had positive attitude towards epilepsy. However 19.1% of subjects stated that they cannot work together with person having epilepsy and a sizeable number of subjects expressed unwillingness to travel together with them. In a similar study in Senegal, 40% of subjects would mind if their child would play with person with epilepsy.¹¹ The majority of these problems is due to negative social attitude towards epileptic person. This study points that our subjects had less negative attitude towards epilepsy. This might be due to the frequent contact with the health professionals during the course of treatment.

Stigma

Stigma can be defined as a mark of shame, disgrace or disapproval which results in an individual being rejected against and excluded from participating in a number of different areas of society.¹³ It has long been recognized as a major source of distress /burden to people with epilepsy and their families.^{14,15} It has a profound impact on the quality of life of sufferers in developed as well as developing regions.¹⁶⁻¹⁹ In Nepal, though the stigma exists but is not so severe as in countries mentioned in other studies like in Ethiopia & Zambia. In our study, the stigma was felt more by the patients. About 32% patients felt bad about having had epilepsy. It is understandable that having an illness that requires medication for a longer duration is bothersome to anyone. Around one-fifth patients expressed bitterness that they were talked down because of epilepsy. Significant number of patients (46.8%) found it hard in telling other people that they have epilepsy. About 19% patients felt that they have been discriminated against by employers because of epilepsy. On comparing the stigma, 55.3% of patients felt stigmatized. It might be due to the fact that patients were the ones who directly faced the problems. Any critical comments and behaviours against their illness

will be perceived more by the patients. The findings from the study by G.A. Barker revealed that the most consistent predictor of stigma is associated with seizure frequency; people with high seizure frequency are more likely to report higher levels of stigma than people with low seizure frequency.²⁰ This

finding is not surprising given the results of previous studies showing that seizure frequency is highly correlated with and predictive of psychosocial impairment. Interestingly, knowledge contributes relatively little to the explained variance on scores of the stigma scale for the whole population.²⁰

Conclusion

In this study, it was found that the knowledge about epilepsy was patchy among the patients. Despite this, attitude towards epilepsy are generally positive, but there is still a strong feeling that persons with epilepsy are stigmatized. This study is important in providing baseline information about psychosocial aspects of epilepsy and also highlights the need for further research on the topic. Educational program and psychological interventions should be formulated with an aim of improving the knowledge about epilepsy and reducing the stigma in the population at large taking into account the belief and value system of the community.

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