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Stigma and Attitude toward Epilepsy

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ABSTRACT

Background: Epilepsy is a chronic disorder, by definition a condition of recurrent unprovoked seizures. In India there are approximately 5.5 million people with epilepsy. Stigmatization lead to discrimination and people with epilepsy have been the target of prejudicial behaviour in many spheres of life over in many cultures.

Aim: The study was carried out to assess the stigma, knowledge and attitudes with respect to epilepsy among general public in the area of Ranchi Jharkhand.

Methodology: A total 100 general public were selected with purposive sampling technique. A questionnaire on epilepsy which were taken from questionnaires used in other published surveys. It containing items that awareness, attitudes about epilepsy. All the questions were simple with yes answers and stigma scale of epilepsy were administered on sample and the responses were recorded.

Result: The findings of the study are although people are aware of epilepsy but they harbor negative attitude towards epilepsy. The findings support a need to promote epilepsy awareness programs as means of increasing public knowledge and decreasing level of stigma.

Keywords: Epilepsy, Stigma, Attitude,

INTRODUCTION:

Epilepsy is a chronic disorder, by definition a condition of recurrent unprovoked seizures. In India, there are approximately 5.5 million people with epilepsy, 4.1 million of whom reside in rural areas (Sridharan et al, 2002). It is a disorder associated with significant psychological and social consequences for everyday living (Baker et al, 1998). People with the condition report a significant impact of epilepsy in different areas of the patient's life. This may include physical, psychological, social, sexual, work, medication effect and treatment. Hermann & Whitman (1986) hypothesized three alternative groups of variables that contribute to understanding the impact of epilepsy: psychosocial variables such as fear of seizures, perceived stigma, and discrimination; degree of adjustment to the diagnosis; other life events and level of social support; neuroepilepsy variables such as age at onset, duration of epilepsy, seizure type, and seizure severity and medication variables including medication type and number.

Stigma is a major factor associated with the burden of individuals with epilepsy. For many patients, the fear of stigma makes them keep their disorder a secret. They refrain from discussing it openly and try to minimize their difficulties. Such people seek treatment from traditional healers or faith healers (Giri et al, 2006). Research shows that the stigma associated with epilepsy and social discrimination causes significantly more suffering for individuals with epilepsy than the seizures themselves (McLin et al, 1995).

The concept of stigma is described as "an attribute that is deeply discrediting," and in the case of epilepsy, it is true for every individual who is labeled an epileptic (Goffman et al, 1963). Scrambler and Hopkins described two types of stigma in terms of epilepsy. Felt stigma refers to the shame of having epilepsy and the fear of encountering epilepsy linked enacted stigma, whereas enacted stigma refers to actual episodes of discrimination because of epilepsy (Scambler et al, 1986).

In India the discrimination, social attitude and stigma is more devastating for the epileptics than the disease itself. Radhakrishnan et al (2002) conducted a door to door survey to ascertain the prevalence and pattern of epilepsy and to characterize and quantify knowledge, attitude and practice towards epilepsy among the people of Kerela. About 99% had heard or read about epilepsy. Thirty one and 27% thought epilepsy to be a heredity disorder and a form of insanity

respectively. About 40% of the respondents felt that individuals with epilepsy could not be properly educated or employed. Eleven percent would object to their children having contact with epileptic children, Hence it was reflected from the study that although the respondents had knowledge about epilepsy but the underlying attitude towards it was negative. Thacker et al (2008) conducted a study to assess the knowledge, attitude and practice about epilepsy amongst school teachers in Northeast Uttar Pradesh. It was found that about 97% of the school teachers were aware of epilepsy with majority including it as a brain disease. A substantial proportion was uncertain about relation of epilepsy and insanity and 31.7% felt epileptics to be of below average intelligence. Only about half of them preferred their children to play with an epileptic. An overwhelming no was obvious about marriage with an epileptic patient. Only 27.8% of the respondents had given any first aid measure to a seizing patient with only 16.3% giving it properly. Majority of the respondents felt that epilepsy is a brain disease and gave reasonable answers to the questions about the cause of epilepsy such as genetics (10.4%), trauma (8.5%), infections (3.3%) and tumour (3.5%). In Jharkhand especially in Ranchi and in neighboring areas, a number of cases of epilepsy are reported. In light of this, the main aim of the present study was to assess stigma and attitude towards epilepsy among the general population.

MATERIALS AND METHODS

Socio-demographic

A socio-demographic sheet were used to get some primary information regarding socio demographic variables like age, gender, education, occupation, marital status, religion, family income per month and family type.

Stigma Scale of Epilepsy (Fermandes et al., 2007)

It contains five domains with twenty-four items, each with a four-point scale: the individual are asked to indicate the most appropriate answer for that item, marking the number corresponding to the category (1 = not at all, 2 = a little, 3 a lot, 4 = totally). It covers area like difficulties faced by people with epilepsy, the main feelings highlighted by patients with epilepsy and prejudice related to epilepsy. This can be administered on patients as well as community. The raw scores are transformed, and gave scores lying between 0-100. Higher scores mean greater stigma. Reliability and validity evaluation depicts that the internal consistency of the SSE showed a general Cronbach's coefficient a0.88 for the patients with epilepsy and 0.81 for people in the community.

PROCEDURE

This study was conducted at the area of Ranchi Jharkhand. Informed consent was obtained from all participants after explaining the details of study. The objectives of the study were explained to the participant. The participants were told that the information would be kept confidential and would not be used for any commercial purposes.

After establishing rapport and the explaining the purpose of the study the details of the socio demographic variables were gathered from the participants. After collecting the demographic variables the stigma scale of epilepsy were administered and presented questionnaire on epilepsy which were taken from questionnaires used in other published surveys(Young GB et al,.2008, Chung MY et al,. 1995) to know the attitudes toward person with epilepsy.

RESULTS

Table-1: Responses of General public to questions on Knowledge, attitudes and practices.

S. No.	Question	Number responses (%)
1	Have you heard or read about epilepsy?(yes)	89 (89%)
2	Have you seen any one having epileptic seizure?(yes)	14 (14%)
3	What do you think causes epilepsy? a. Inherited diseases(yes) b. Accidents(yes) c. Brain tumers e. Insanity(yes) f. Stroke(yes) g. Don't know	 37 (37%) 9 (9%) 18 (18%) 25 (25%) 0 (0%) 11 (11%)
4	What do you think about treatment of epilepsy? a. Doctor b. Traditional faith healers c. Ayurvedic d. Don't know	 55 (55%) 19 (17%) 11 (11%) 15 (15%)

5	What do you do when you see a person having a seizure? a. Move objects such as furniture away from the person(yes) b. Move him from a dangerous place such as road or top of the staircase(yes) c. Avoide putting anything in his mouth(yes) d. Put some metallic object in their hand (yes)	 19 (19%) 43 (43%) 7 (7%) 31 (31%)
6	Do you think a person with epilepsy should have children?(yes)	68 (%)
7	Do you think that in general a person with epilepsy should be employed at the same jobs as other peoples?(yes)	19 (19%)
8	Would you object to a person with epilepsy marring a close relative of yours?(yes)	59 (59%)

Table-2: Stigme of general public

Variable	Score in range (0-100)	Number responding (%)
Stigma	0-25	2 (12%)
	26-50	17 (17%)
	51-75	23 (23%)
	76-100	58 (58%)

The mean age of general public was 34.46±7.84 years. Majority of person were Hindu (40%), male (43%), student (39%), educated up to Secondary and above (53%). Majority of person were married (59%) who belongs to Joint family (56%) in Urban area (50%).

The results shows that large number of participants (89%) had heard or read about epilepsy, (14%) had seen patients having epileptic attack. Participants (37%), (25%) and (18%) thought cause of epilepsy heredity, insanity and Brain tumor respectively. Participants (55%) were aware that epilepsy could be treated by Doctor, (31%) participants believed that when person having attack should be made to hold a sharp metallic object.

Participants (59%) responded that would disapprove of a close relative marrying a person with epilepsy, (68%) participants felt that a person with epilepsy could have children. Participants (19%) felt that a person with epilepsy should be allowed to continue with his or her job as any other normal. Most of participants (58%) have high score on stigma scale, which showed that stigma is present among them.

DISCUSSION

The study was investigated the stigma, awareness and attitudes toward epilepsy among general population in area of Ranchi Jharkhand. Our results indicate that though most of the participants were aware of epilepsy but their knowledge of the causes of epilepsy was poor. They aware about the treatment of epilepsy, (31%) participants believed that a person experiencing an epileptic attack should be made to hold a sharp metallic object. This is in accordance with the belief that sharp object help to dispel evil spirits and terminate the attack. Our finding is similar to the studies conducted on knowledge, attitudes and practices regarding epilepsy by Pandian et al., 2006, Sureka and Sureka, 2007, and Rajbhandari, 2003)

Participants (59%) said that would disapprove of a close relative marrying a person with epilepsy. The existence of belief may be due to the fact that people believe that epilepsy is genetic in nature and that after marriage it may pass on the generations to come, (68%) participants felt that a person with epilepsy could have children. Very few participants (19%) felt that a person with epilepsy would be allowed to continue with his or her job as any other normal. Most of participants (58%) have higher stigma toward person with epilepsy. Our finding is similar to the studies Rambe & Sjahri (2002) who found in their study that 16% of the respondent were well informed about epilepsy, 25% of the respondents objected their children playing with the child with epilepsy, 56% objected to their children marrying a person with epilepsy.

Radhakrishnan et al (2002) conducted a door to door survey to ascertain the prevalence and pattern of epilepsy and to characterize and quantify knowledge, attitude and practice towards epilepsy among the people of Kerela. About 99% had heard or read about epilepsy. Thirty one and 27% thought epilepsy to be a heredity disorder and a form of insanity respectively. About 40% of the respondents felt that individuals with epilepsy could not be properly educated or employed. Eleven percent would object to their children having contact with epileptic children, Hence it was reflected from the study that although the respondents had knowledge about epilepsy but the underlying attitude towards it was negative. Since earlier times, various authors had been assessing stigma in patients as well as in normal controls and

had found that the stigma equally existed in healthy controls as well as in patients (Fisher et al, 2000; Ratsepp et al, 2001; Fernandes et al, 2007). Thaker et al (2008) conducted a study to assess the knowledge, attitude and practice about epilepsy amongst school teachers in Northeast Uttar Pradesh. It was found that about 97% of the school teachers were aware of epilepsy with majority including it as a brain disease. A substantial proportion was uncertain about relation of epilepsy and insanity and 31.7% felt epileptics to be of below average intelligence. Only about half of them preferred their children to play with an epileptic. An overwhelming no was obvious about marriage with an epileptic patient. Only 27.8% of the respondents had given any first aid measure to a seizing patient with only 16.3% giving it properly. Majority of the respondents felt that epilepsy is a brain disease and gave reasonable answers to the questions about the cause of epilepsy such as genetics (10.4%), trauma (8.5%), infections (3.3%) and tumour (3.5%).

CONCLUSION

The general public are aware about epilepsy but harbor strong negative attitudes towards epileptic mainly due to old ideologies still vested in our society. Our finding support the need to promote epilepsy awareness programs as means of increasing public knowledge of epilepsy and undoing the myths and stigma present in society, as well as providing information about treatment and causes of the disease.

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