

Knowledge, attitude and practices among patients of epilepsy attending tertiary hospital in Delhi, India and a review of Indian studies

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Abstract

Stigmatized psychosocial perception poses a serious challenge and source of discrimination which impedes epilepsy patients from attaining a satisfactory quality of life. The present study was aimed to obtain information on knowledge, attitudes and practices (KAP) of epilepsy patients in Delhi and compare with the published data from India. We included 120 people with epilepsy (PWE) attending the Neurology outpatient services of the Institute of Human Behavior and Allied Sciences (IHBAS), Delhi. Demographic details and responses to a questionnaire assessing the knowledge, attitude and practices were recorded. Although majority of the patients belonged to low socioeconomic strata, the literacy rate was reasonably high (70%). A large majority (94%) of PWE had heard about epilepsy and 91% knew that epilepsy can be treated with modern drugs. Positive attitude was observed with respect to allowing a child with epilepsy to study (80%), not objecting children to play with a child with epilepsy (95%), marriage (89%) and having children (92%). Negative attitude was reflected in the belief that epilepsy is due to supernatural powers (16%) and sins committed by patient or ancestors (21%). Analysis of Indian data revealed regional differences in KAP which could be attributed to local factors, such as literacy, awareness about epilepsy, and practice of different systems of medicine. Some of the differences can also be attributed to category of study population whether it included patients or non epilepsy individuals, since the former are likely to have less negative attitudes than the public. There is a need to create awareness about epilepsy on a nation-wide basis to dispel the misconceptions and stigma through effective and robust programs with the aim to lessen the disease burden.

INTRODUCTION

Stigma attached to epilepsy and the misconceptions about the disease often contribute to a greater burden than the disease itself.¹⁻³ Stigma can have significant negative influence on treatment seeking behaviour, quality of life encompassing all spheres of life including education, employment, marriage, child bearing and accrual of social benefits.^{4,5} Discrimination at school, job and by friends, spouse and family members adds to the burden. Social ostracisation affects not only the person with epilepsy but also the family members.

The perception of stigma about epilepsy varies widely across countries and is considerably more in developing countries compared to the developed nations. In the developed nations high level of literacy, mass communication through media and wider reach of health care to the community have resulted in better understanding of the nature of epilepsy and remarkable decline in wrong perceptions and myths about the disease.^{6,7}

However, in countries with low resources, poor awareness about epilepsy, stigma associated with the disorder, ignorance that it is a treatable disorder and restricted access to health care have a negative influence on the quality of life.² Regional differences within a large country have also been reported.

Epilepsy is referred to as *Apasmara* in Ayurveda, the highly systematized ancient Indian Medical System, developed during the period 5000 to 4500 BC. Despite the long and hallowed history, myths and misconceptions about epilepsy abound and are deep rooted, resulting in considerable stigma and discrimination leading to a wide treatment gap in India ranging from 38% to 90%.⁸⁻¹¹ Community based epidemiological surveys in the last four decades have shown a prevalence rate of 2.2 to 11.9 per 1000 population in different regions of the country with an urban-rural divide.^{9,12-14} It is estimated that there are 6 to 8 million people with epilepsy with addition

of approximately 50,000 new cases annually and 3 to 4 million (assuming a national average treatment gap of 50 %) remain untreated.

In India a few studies have been published which examined the knowledge, attitude and practices (KAPs) among people with epilepsy¹⁵⁻¹⁹, and non epileptic population.^{20,21} The aim of the present study was to obtain information on KAPs of people with epilepsy in Delhi and compare with the Indian data.

METHODS

People with epilepsy (PWE) attending the neurology outpatient services of the Institute of Human Behaviour and Allied Sciences (IHBAS), a tertiary centre for mental and neurological disorders, in Delhi during the period 2007 to 2008 were included. After obtaining informed consent,

120 PWE were administered a questionnaire comprising of 25 questions assessing the KAPs by one of the authors, a clinical psychologist (VS) in English or Hindi, whichever the patient was proficient. The questionnaire was translated to Hindi and back translated and checked for accurate reproduction. The responses were recorded as 'yes', 'no' and 'don't know'.

RESULTS

Of the 120 patients, 27 (22.5%) came from urban areas and 39 (32.5%) from rural areas of Delhi, and 54 (45%) from villages of neighboring states of Uttar Pradesh and Haryana. The demographic characteristics of 120 patients are shown in Table 1. Young people under age of 30 years constituted the majority (70%) and the rest (28%), except for 4 subjects, were in the middle age

Table1: Demographic details of 120 patients with epilepsy

Parameter	N (%)
Age in Years	
<30	83 (69.2)
31 to 45	33 (27.5)
46 to 60	4 (3.3)
Gender	
Male	72 (60.0)
Female	48 (40.0)
Socioeconomic Status	
Low <Rs.3000	109 (90.8)
Middle >Rs.3001	11 (9.2)
Occupation	
Employed	29 (24.2)
Farmer	2 (1.7)
Student	37 (30.8)
Housewife	27 (22.5)
Education	
Illiterate	37 (30.8)
School	77 (64.2)
Graduate & above	6 (5.0)
Marital status	
Married	61 (50.8)
Unmarried	59 (49.2)
Religion	
Hindu	89 (74.2)
Muslim	31 (25.8)

(31 to 45 years). Although the majority (90%) of the patients belonged to the low socioeconomic strata, the literacy rate was reasonably high at 70%.

The responses to the questionnaire (Table 2) show that 94% had heard about epilepsy, 91% knew epilepsy can be treated with modern drugs and 96% mentioned that they would take a person having an epileptic attack to the hospital. While 55% considered epilepsy to be a brain disorder, 14% thought it was a mental disorder, 16% attributed the disease to supernatural powers and 21% thought that the disease is a result of sins committed by them or their parents in the present or previous birth. As a corollary to this presumption, 19% believed that epilepsy can be treated by faith healers. Certain practices during an epileptic attack such as making the afflicted person smell a shoe and putting the keys in the hand were mentioned by 12% and 5%, respectively.

Positive attitude was observed with respect to allowing a child with epilepsy to study (80%), play games (92%) and allow children to play with a child with epilepsy (95%). Similar encouraging responses were observed regarding marriage (89%), employment (90%) and having children (92%). However only 56 to 60% mentioned that they will disclose the information about their son/daughter has epilepsy before marriage. Discrimination by teachers in school, play mates and by spouse was reported by 14%, 16% and 15% respectively. A significant observation was that there was only one (0.8%) response to epilepsy being contagious.

Comparison with Indian data

From the review of published literature from 1973 to 2007, 7 studies^{8,15-20} were identified which dealt with myths and misconceptions about epilepsy, understanding the nature of the disease and treatment. This data is compared with our observations. In 6 of the 8 studies (including the present report), PWE¹⁵⁻¹⁹ and in 2, non-epilepsy population^{8,20} were included. In Table 3, the number and category of subjects, place of study, and the responses to 5 questions namely, i) Is epilepsy a brain disorder, ii) Is epilepsy due to supernatural powers, iii) Is it due to sins of patient/ancestors in past or present life, iv) Is faith healing or sorcery useful in treating epilepsy and v) Is epilepsy treatable with modern drugs, are shown. Understanding that epilepsy is caused by a brain disorder varied from 15 to 68%, that it may result from supernatural powers ranged from 4 to 26%,

from sins of patient/ancestors from 14 to 21%, that epilepsy can be treated by faith healing or sorcery from 6 to 58% and with modern drugs from 45 to 92%. The responses in our study were within these ranges. It is noteworthy that in the recent study by Surekha and Surekha¹⁹, intervention through health education led to positive changes in attitude towards epilepsy and decrease in misconceptions. The magnitude of change was more than 50% in the post-intervention phase compared to pre-intervention phase.

Data on the attitude and practices of epilepsy were available only in 2 studies, one from Kerala (Radhakrishnan *et al.*)⁸ and the second from Chandigarh (Gambhir *et al.*)²⁰. Comparison of our data with these studies is shown in Table 4. The obvious difficulty in drawing conclusions is that while our study included patients, the other two studies were conducted to evaluate public awareness. Some general inferences however can be drawn. Majority (92 to 99%) of the respondents had heard about epilepsy. While in our study only one (0.8%) individual considered epilepsy to be contagious, it is a matter of concern that a significant proportion in Kerala (12%)⁸ had negative attitude. In another study from Delhi done on patients also showed a high figure (13%).¹⁸ A large percentage objected to play with a child with epilepsy in the study reported by Gambhir *et al.*²⁰ while positive attitude was seen in our study and the one from Kerala.⁸ Issues regarding marriage and employment elicited higher positive response rates in our study compared to figures from Kerala⁸ and Chandigarh.²⁰ The response to question as to what should be done during an epileptic attack, almost all subjects (97%) in our study mentioned that the patient should be taken to doctor or shifted to hospital. However, in the studies from Kerala (80%)⁸ and Chandigarh (57%)²⁰, the figures were lower. Certain practices during the attack such as smelling shoe was observed in North India while keeping keys in the hand was reported from both North and South India.^{8,20}

DISCUSSION

An attempt has been made to assess the KAP of epilepsy in Delhi among patients with epilepsy and compare the data with 7 published studies from India. Five of the studies were on patients and other two were on non-epilepsy individuals in the community. The majority of patients in our study was in the low socioeconomic strata and came from the urban and rural Delhi and villages of neighboring states in North India. The myths

Table 2: Knowledge, attitude and practices among 120 persons with epilepsy

Question	Yes N (%)	No N (%)	Don't Know N (%)
1. Have you heard about epilepsy?	113 (94.2)	7 (5.8)	-
2. Is epilepsy a brain disorder?	66 (55.0)	27 (22.5)	27 (22.5)
3. Is epilepsy a mental disease?	17 (14.2)	92 (76.7)	11 (9.2)
4. Is epilepsy a hereditary disorder?	4 (3.3)	116 (96.7)	-
5. Is epilepsy due to supernatural powers?	20 (16.7)	99 (82.5)	1 (0.8)
6. Is it due to sins of/patient/ ancestors?	25 (20.9)	89 (74.1)	6 (5.0)
7. Is epilepsy contagious?	1 (0.8)	102 (85.0)	17 (14.2)
8. Is epilepsy treatable with modern drugs?	110 (91.7)	7 (5.8)	3 (2.5)
9. Is epilepsy treatable with Ayurvedic medicine?	3 (2.5)	59 (49.2)	58 (48.3)
10. Can faith healers treat epilepsy?	23 (19.2)	97 (80.8)	-
11. Is branding useful in treatment of epilepsy?	-	116 (96.7)	4 (3.3)
12. During an epileptic attack will you put keys in the hands of patients?	7 (5.8)	112 (93.3)	1 (0.8)
13. During an epileptic attack will you make the patient smell a shoe?	15 (12.5)	105 (87.5)	-
14. During an epileptic attack will you take the patient to hospital?	116 (96.7)	4 (3.3)	-
15. Can a child with epilepsy study?	97 (80.8)	22 (18.3)	1 (0.8)
16. Will you allow your child to play with a child with epilepsy?	114 (95.0)	6 (5.0)	-
17. Is the child discriminated by school-mates?	19 (15.8)	98 (81.7)	3 (2.5)
18. Is the child discriminated by teachers?	17 (14.2)	100 (83.3)	3 (2.5)
19. Can a child with epilepsy play games?	111 (92.5)	8 (6.7)	1 (0.8)
20. Can a person with epilepsy take up a job?	109 (90.8)	11 (9.2)	-
21. Can a person with epilepsy marry?	107 (89.2)	13 (10.8)	-
22. Will you reveal about the epilepsy of your daughter before marriage?	67 (55.8)	49 (40.8)	4 (3.3)
23. Will you reveal about the epilepsy of your son before marriage?	72 (60.0)	44 (36.7)	4 (3.3)
24. Can a person with epilepsy have children?	111 (92.5)	9 (7.5)	-
25. Are you discriminated by spouse?	18 (15.0)	98 (81.7)	4 (3.3)

Table 3: Comparison of knowledge of epilepsy in India

Author (year) Sample size (EP/NEP) Region	Brain disorder	Supernatural causes	Sins of patient / ancestors in present/past life	Faith healing /Sorcery	Modern drugs-AEDs
Samant <i>et al.</i> (1973) ¹⁵ 510 (EP) West India	NA	5.2	NA	38.8	50
Tandon (1989) ¹⁶ 2,519 (EP) North, South, East, West India	NA	11.8	NA	24.2	80
Gambhir <i>et al.</i> (1995) ²⁰ 1,000 (NEP) North India	15	4	NA	6	55
Desai <i>et al.</i> (1998) ¹⁷ 80 (EP) North India	63	9	NA	55	45
Radhakrishnan <i>et al.</i> (2000) ⁸ 1118 (NEP) South India	68	NA	15	NA	78
Khwaja <i>et al.</i> (2007) ¹⁸ 100 (EP) North India	NA	6	14	33	66
Surekha (2007) ¹⁹ 212 (EP) North west India					
Before intervention	23.5	26.4	NA	31.6	55
After intervention	57.5	11.2		10.0	67
Present study 120 (EP) North India	55	16.7	20.9	19.2	92

Figures are in percentages. Publications are listed in chronological order.

EP: Persons with epilepsy, NEP: Non epilepsy individuals, NA: Not available.

and misconceptions about the disorder particularly that epilepsy is due to supernatural causes (such as evil spirits, or curse) were recorded in 16.7% which was comparable with the observations (4 to 26%) of others from different parts of the country and also to the of study from Zambia of survey of KAPs among teachers (17% among 171 teachers).²² It is noteworthy that as against the expectation that patients will be better informed than the public, the study by Gambhir *et al.* on public surprisingly showed a very low figure of 4%. Interestingly in Pakistan, only 3% of 241

persons with epilepsy believed that epilepsy is due to supernatural causes.²³ Knowledge that epilepsy is a brain disorder was reported by 55% which was just 13% less than the observation of 68% in the population of Kerala⁸ with a high literacy rate (92% compared to 70% in our study) and also higher level of education (14% at graduate and above compared to 5% in our study). While 92% of our patients were aware that epilepsy is treatable with modern drugs, in the study from Kerala it was only 78%.⁸ This difference can be attributed to the fact that Ayurveda, the traditional Indian system

of medicine, is widely practiced and popular in Kerala and 64% felt that ayurvedic treatment is beneficial as against 2.5% in our study. Nearly one fifth of our patients believed that faith healing is effective in treatment although half of this group also stated that modern drugs are beneficial for control of seizures. In studies from India it is observed that faith healing is considered to cure epilepsy by 6 to 39% of responders.¹⁵⁻²⁰

A highly significant observation in our study was that just one patient (0.8%) felt that epilepsy is contagious as against high proportion of 12% and 13% in studies on public reported by Radhakrishnan *et al.* and on persons with epilepsy by Khwaja *et al.*, respectively.^{8,18} Of the 171 teachers surveyed in Zambia 28.2% considered epilepsy to be contagious.²² Another equally positive response was that only 5% of our patients responded that they would not allow their children to play with a child with epilepsy compared to 11 % reported by Radhakrishnan *et al.*⁸ and 43% by Gambhir *et al.*²⁰, both studies were conducted among non-epilepsy population. In other population surveys in developing countries such as in China²⁴ and in Kuwait²⁵, 57% and

28%, respectively, opposed playing with a child with epilepsy, while in developed countries (Finland²⁶, United states of America⁶, Italy²⁷) the figures ranged from 8 to 19%. In this respect our observations are similar to developed countries. In our study very few (10%) thought that people with epilepsy should not get married and this proportion was less than reported in Kerala (30%)⁸, Pakistan (21%)²³, Chandigarh in North India (66%)²⁰ and China (87%).²⁴ A negative aspect in our study was that more than half of our patients mentioned that they would not disclose the information that their son/daughter has epilepsy because of the fear of not finding suitable partner and difficulty in marriage negotiations. Santosh *et al.*²⁸ from Kerala reported that among 82 women attending epilepsy clinic, 55% concealed and 45% revealed the past history of epilepsy. It was observed that among those who did not disclose the information, divorce, separation and disturbed marriage were more common than those who revealed that they had epilepsy.

During a seizure the practice in many parts of India is to keep keys in the hands of the patient to terminate the attack. This aspect had been

Table 4: Comparison of attitude and practice of epilepsy in India

Parameter	Gambhir <i>et al.</i> (1995) ²⁰ Chandigarh NEP n=1,000	Radhakrishnan <i>et al.</i> (2000) ⁸ Kerala NEP n=1,118	Present study Delhi EP n=120
Heard <i>about</i> epilepsy	92	99	94
Epilepsy is <i>contagious</i>	--	12	1
Allow child to play with a child with epilepsy	57	89	95
Person with epilepsy can marry	44	71	90
Person with epilepsy can be employed	--	54	91
Take a person having an attack to hospital/doctor	57	80	97
During the attack to make the patient smell shoe	33	--	12
During an attack keep keys in the hands	--	55	6

The figures are in percentage

EP: Persons with epilepsy, NEP: Non epilepsy individuals

included only in the study from Kerala in addition to our study with responses of 55% and 5.8%, respectively.⁸ Yet another custom, seen only in North India, is to make the patient to smell a shoe and this was observed in 12.5% in our study and 33% in another study from Chandigarh in North India.²⁰ The responders did not offer any explanation as to why they perform this act and mentioned that they just followed the commonly observed practice.

In our study there was positive correlation of literacy with the understanding that epilepsy is a brain disorder ($p=0.001$), disclosure of information about the history of epilepsy of the daughter before marriage ($p=0.001$), and negative correlation with belief that faith healing can cure epilepsy ($p=0.001$). Similar observation of level of education and attitude toward epilepsy has been reported from other studies from India^{8,20}, China^{24,29}, Nigeria³⁰, Pakistan²³ and Sri Lanka.³¹

Change in public attitudes about epilepsy does occur, albeit slowly. This is exemplified by the serial surveys conducted of adults throughout United States over thirty years from 1949 to 1979. In 1949, 57% would not object to their children playing with a child with epilepsy compared to 89% in 1979; and 59% in 1949 and 92% in 1979 did not think that epilepsy is a form of insanity.⁶ Similarly, in Jaipur, North-West India an improvement of positive attitude was observed over a period of 4 years in people with epilepsy who were regularly provided health education at follow up visits (Table 3).¹⁹ In the present study, favorable opinion of the responders could be attributed to the ongoing intense awareness programs regularly conducted during the last 10 years by the neurologists of this institute at the epilepsy clinic of the hospital, in the schools and in the community

In the overall analysis it can be stated that in India, a third or more of patients with epilepsy have religious beliefs and erroneous perception of the disease which adversely influence the management of epilepsy and contribute to the wide treatment gap. However religious beliefs do not necessarily have negative influence. It may be used to advantage in reducing psychological stress and improve control of seizures as elegantly described by Pal *et al.*³²

In the national programs envisaged for control of epilepsy through district model of providing epilepsy care³³, the data emerging from the Indian studies should provide guidance to the policy makers, planners and administrators. They should incorporate awareness programs to enhance

understanding of nature of the disorder, and focus on issues related to schooling, marriage, having children and eliminate negative attitudes towards people with epilepsy.³⁴

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