

Original Research Article

Epilepsy: what do Indian public living in Jammu know?

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ABSTRACT

Background: Epilepsy, a neurological disorder, still remains one of the most stigmatising disease. Myths, beliefs and negative attitudes associated with the disease have been ascribed to the low levels of awareness and knowledge among the public. The present study aimed to assess the knowledge, attitudes and practices of the public regarding epilepsy visiting a tertiary care hospital in Jammu city of Jammu and Kashmir, India.

Methods: This cross-sectional study was conducted over a period of three months among adult persons (aged 18 years and above) visiting OPD in a tertiary care teaching hospital in Jammu city, J&K, India. A 29-item questionnaire was pilot tested and then distributed to 410 adults during the survey period and 30 of them were excluded as they had never heard about epilepsy.

Results: About 92.6% of the surveyed respondents had heard about epilepsy with mass media and family/ friends as the major sources of knowledge. 59.7% knew a person suffering from epilepsy and 30.7% had actually witnessed an attack of seizure. Only one-fourth of the respondents knew the disease to be a neurological disorder. More than half of the respondents would object to their children being associated with epileptic person in the school but surprisingly 63% would accept to work/become a friend with epileptic person. About 41% respondents would take patient in seizure to hospital while 43.5% would put a shoe on his nose.

Conclusions: The public knowledge was found to be reasonably good, but attitudes were found to be of mixed type while practices were also not up to the desired levels. Need is for persistent and effective information campaigns to change public attitudes towards person with epilepsy.

Keywords: Attitude, Epilepsy, Knowledge, Practices

INTRODUCTION

Epilepsy is considered among the most common neurological disorders across the globe and affects people of all ages.¹ As per estimates, the disease affects more than 50 million people worldwide, accounting for 0.5% of global burden of disease and 80% of the afflicted people are residing in the developing world.²

Despite being a common disease entity, epileptic patients suffer from public stigmas and discrimination due to erroneous belief widely prevalent in the communities.^{3,4} Inadequate knowledge about epilepsy along with myths and misconception also add to the stigma and discrimination.^{5,6} This translates into psychological and socio-economic obstacles for the epilepsy patients who have difficult in employment, education, socialization and reproduction life.⁷⁻¹⁰ Further these patients are

usually taken to faith healers for traditional remedies which is detrimental for their overall health.

Having proper knowledge and attitudes about the disease influences the perception as well as the attitudes of the community towards the patients as well as their respective families. In this context assessment of the public knowledge, attitudes and practices towards epilepsy is the first step to gain first hand information on the psychosocial and economic problems surrounding this disease.

The review of literature revealed that a few studies have been conducted in various parts of the country to evaluate knowledge and attitude towards epilepsy both among the patients as well as the public. But authors could not find any study in the state of Jammu and Kashmir regarding epilepsy. So, it was in this context that this study was planned to assess the knowledge, attitudes and practices of the public regarding epilepsy visiting a tertiary care hospital in Jammu city of Jammu and Kashmir, India.

METHODS

The present cross-sectional survey-based study was carried out in the period of three months from December 2017 to February 2018. The study was carried out among adults persons (18 years and above) who visited the OPD of Medicine and Surgery Department of Govt. Medical College, Jammu as accompanying attendants of the patients. The study was carried out three-days a week and a minimum of 10 respondents were interviewed on the particular day. Only those who were willing to give informed verbal consent and willing to participate were included in the study. Excluded from the study were non-consenting persons and people who were younger than 18 years of age.

The questionnaire for the present study was prepared by the authors after going through a review of literature of the pertinent studies conducted in India and abroad. The questionnaire so prepared underwent a forward and backward translation from English to Hindi and the reverse by a professional translator. It was followed by a pilot study on 30 individuals who were not part of the final sample. The feedback so obtained based on their culture and beliefs was incorporated into the final form of questionnaire.

The final questionnaire thus had four sections. The first section was meant to gather socio-demographic data of the respondents while the rest of three sections were meant for knowledge, attitude and practices of respondents towards epilepsy. Due permission was sought from Institutional Ethical Committee, Govt. Medical College Jammu before the study was conducted. The participation of respondents was voluntary and privacy ensured. The data thus collected was tabulated and analysed. Chi-square was used as test of significance

with P-value <0.05 was considered statistically significant.

RESULTS

During the course of the study, 410 respondents were interviewed, majority (51.2%) being males. About half of the respondents were in 31-50-year age group and three-fourth of them belonged to Hindu religion. According to literacy level of the respondents 39.7% of the respondents were literate upto matric while 13.6% were not able to read and write. 41.4% of the respondents were housewives while 15.6% of them were students. Three-fourth (75.6%) of them were married (Table 1).

Table 1: Socio-demographic profile of the respondents (n=410).

Parameter	N	%	
Gender	Male	210	51.2
	Female	200	48.7
Age groups	<30 yrs	130	31.7
	31-50 yrs	214	52.1
	>50 yrs	66	16.0
Religion	Hindu	314	76.5
	Muslim	56	13.6
	Others	40	09.7
Literacy level	Not able to read/write	56	13.6
	Up to primary level	103	25.1
	Up to matric level	163	39.7
Occupation	Above matric	88	21.4
	Student	64	15.6
	Employed	126	30.7
	Own business/Farmer	150	36.5
Marital status	House wife	170	41.4
	Married	310	75.6
	Unmarried	100	24.3

The results revealed that only 380 respondents had heard about epilepsy. Regarding source of information about the disease, mass media was the main source for male respondents while it was family/friends for the females ($p<0.05$). Higher proportion of males had known a person suffering from epilepsy and seen an epileptic seizure than female counterparts and this difference was found to be statistically significant ($p<0.05$). Only 20.11% males and 16.36% labelled epilepsy as a neurological disease. Higher proportion of females replied that the disease is caused by previous life's sins, creates hindrance in normal life, epileptic persons can't be employed, and epilepsy affects education of person ($p<0.05$). Majority (>90%) of the respondents replied in affirmative about discrimination of epileptic patients by the society. 56.46% of females correctly picked convulsion as the manifestation of epilepsy in comparison to 38.38% of male respondent ($p<0.05$). 45% of the male respondents knew drugs as treatment for epilepsy while only 25.74% female respondents knew about it ($p<0.05$) (Table 2).

Table 2: Knowledge of the respondents towards epilepsy (n=410).

Question		Male		Female		P value
		n=210	N %	n= 200	N %	
Have you ever heard the disease called epilepsy	Yes	200	95.23	180	90.00	0.04
	No	10	4.76	20	10.00	
If yes, source of epilepsy knowledge	Mass Media	78	39.00	42	23.33	0.00
	Family/ Friends	46	23.00	92	51.11	
	School/Teachers	36	18.00	08	04.44	
	Doctors/Health	40	20.00	38	21.11	
	Care Workers					
Do you know a person suffering from epilepsy	Yes	162	81.00	65	36.11	0.00
	No	38	19.00	115	63.88	
Have you ever seen anyone having an epileptic seizure	Yes	82	41.00	35	19.44	0.00
	No	118	59.00	145	80.56	
What sort of disease is epilepsy	Neurological	70	20.11	45	16.36	0.68
	Mental illness	190	54.5	156	56.72	
	Hereditary	56	16.09	46	16.72	
	Contagious	32	09.19	28	10.18	
Do you think epilepsy is caused by previous life's sins	Yes	112	56.00	146	81.11	0.00
	No	88	44.00	34	18.89	
Epilepsy creates hindrance in normal happy life	Yes	30	15.00	70	38.89	0.00
	No	170	85.00	110	61.11	
A person with epilepsy can't be employed	Yes	102	51.00	142	78.89	0.00
	No	98	49.00	38	21.11	
Epilepsy affects education of a person	Yes	92	46.00	159	88.33	0.00
	No	108	54.00	21	11.67	
Do you think society discriminates against person with epilepsy	Yes	187	93.50	171	95.00	0.53
	No	13	6.50	09	05.00	
What is the manifestation of epilepsy	Foaming from mouth	142	35.8	56	19.04	0.00
	Loss of consciousness	66	16.66	44	14.96	
	Screaming	36	09.09	28	09.52	
	Convulsions	152	38.38	166	56.46	
Epilepsy is Curable	Yes	176	88.00	139	72.22	0.00
	No	24	12.00	41	22.77	
Treatment for Epilepsy	Drugs	173	45.16	86	25.74	0.00
	Surgery	98	25.58	102	30.53	
	Don't Know	112	29.24	146	43.71	

Table 3: Attitude of the respondents towards epilepsy.

Question		Male		Female		P value
		N	%	N	%	
Would you object to having your children in school associate with persons suffering from epilepsy?	Yes	63	31.50	148	82.22	0.00
	No	137	68.50	32	17.77	
Would you object to having your son/daughter marrying a person who is epileptic?	Yes	162	81.00	150	83.33	0.55
	No	38	19.00	30	16.66	
Can a child with epilepsy be successful in a class with healthy children?	Yes	102	51.00	78	43.33	0.13
	No	98	49.00	102	56.66	
Would you reveal epilepsy of your daughter/son before marriage?	Yes	164	82.00	50	27.77	0.00
	No	36	18.00	130	72.22	
I would accept to work/become a close friend with epileptic person	Yes	155	77.50	85	47.22	0.00
	No	45	22.50	95	52.77	

Regarding attitudes, 82.2% of the females would object to her children being associated with an epileptic person in school in comparison to 31.5% of the male respondents ($p < 0.05$). More than 80% of male and female respondent would object to their son/daughter marrying an epileptic person. Higher proportion of males would reveal epileptic status of their son/daughter before marriage and also would prefer to work with an epileptic patient ($p < 0.05$) (Table 3). 57.5% of the male replied that allopathic medicines could treat epilepsy in comparison to 33.3% of

the female respondents ($p < 0.05$). Majority of the respondents replied that an epileptic patient needs a lifelong treatment. Higher proportion of female respondents would take an epileptic patients to a faith healer and this difference was statistically significant ($p < 0.05$). 42.78% and 38.8% of male and female respondents would take an epileptic person to a hospital on seeing him in an epileptic seizure while 47.7% and 39.8% of female and male respondent would like to put a shoe on his nose (Table 4).

Table 4: Practices of the respondents towards epilepsy.

Question		Male		Female		P value
		N	%	N	%	
Can epilepsy be treated with allopathic medicines	Yes	115	57.50	60	33.33	0.00
	No	85	42.50	120	66.33	
Does an epileptic need lifelong treatment	Yes	175	87.50	141	78.33	0.01
	No	25	12.50	39	21.66	
I would like to take my epileptic patient to a faith healer	Yes	45	22.50	70	38.88	0.00
	No	155	77.50	110	61.11	
Anti-epileptic drugs have many side effects	Yes	120	60.00	116	64.44	0.37
	No	80	40.00	64	35.55	
On seeing an epileptic person, I would	Take him to hospital	172	42.78	140	38.8	0.13
	Put some water on his shoe	40	9.9	26	07.2	
	Bunch of keys on his hand	30	7.4	22	06.11	
	Put shoe on his nose	160	39.8	172	47.77	

DISCUSSION

The present study revealed a high public awareness level as 92.6% (380/410) of the respondents had ever heard about epilepsy, 59.7% (227/380) knew a person suffering from epilepsy and 30.7% (117/380) had ever seen an epileptic seizure. These results are in agreement to those reported from Al-kharj, Saudi Arabia, Riyadh, Jordan and India but lower from the study performed in Cameroon.¹¹⁻¹⁵ The source of information about the disease among the respondents was primarily family/friends followed by mass media in the present study and for one-fourth of respondents; it was doctors/healthcare workers. In contrast to these results, none of the respondents had learnt about epilepsy from health worker or medical doctors in a study by Kaddumukara M et al, from Uganda.¹⁶

Despite good levels of awareness about the disease, there were misconceptions and myths also. Only 18.4% of the respondents identified the disease as neurological while majority thought it to be a mental disorder. Also, about two-third of respondent thought that the disease is caused by previous life's sins. Further majority of the respondents replied that society discriminates against

person with epilepsy. In contrast to the results of the current study, AL-Dossari KK et al, reported that 70% respondents cited epilepsy as a neurological disease while Kaddumukasa M et al, reported that 39% of the respondents replied that epilepsy was a neurological disorder.^{16,17} Krishnaih B et al, reported that only 36.5% of the respondents said that society discriminates people with epilepsy.¹⁸ Similarly, Pal VS et al, reported that only 21% respondents said that epilepsy was due to previous life's sins.¹⁴ Regarding treatment, 36% of the respondents in the present study replied for drugs while Al-Dossari KK et al, reported that more than half of the respondents replied medical treatment and follow up as most effective treatment.¹⁷ About manifestation of epilepsy, 45% of the respondents correctly identified convulsion as the presenting symptom in the present study.

The study result has shown generally a mixed attitude towards epilepsy as 82% of the respondents objected to marrying their son/daughter with epileptic person and more than half objected to their children associated with epileptic persons in school. However, 63% would work or became a close friend with epileptic person. Alhazzani AA et al, reported that 17% wouldn't allow their child to mingle with an epileptic child in school while 19%

were not willing to work with epilepsy persons.¹¹ In contrast to the results of current study, positive attitudes toward epilepsy were reported by Al-Dossari KK et al, where 62.5% respondents would allow offspring to play with epilepsy person, 59% would allow marriage and >80% agreed to work and become close friend with epileptic persons.¹⁷ Radhakrishnan K et al, also reported better attitudes among respondents as only 11% of them would object to having contact with epileptic children.¹⁹

About one third of respondents in the current study believed in a faith healer which are in agreement to those reported by Alhazzani AA et al.¹¹ Lower rate to the tune of 20% was reported by Pal VS et al, from India in this regard. In contrast, Al Dossari KK et al, reported this figure to be 41% in their study.^{14,17} On seeing a patients in seizure, 41% respondent would take him to the hospital while 43.5% would put a shoe on his nose.

In contrast, Kaddumukasa M et al, reported only 5.6% would take seizure patient to hospital and 6% would put an object between his teeth.¹⁶ Pal VS et al, reported that more than one third of respondents would use shoe or splash water on face to terminate the seizure episode.¹⁴

Among the limitations of the present study are its small sample size and its cross-sectional nature. Considering these limitations, the findings may lack generalizability.

CONCLUSION

The study has revealed that misconceptions about epilepsy are still widely prevalent in this societies which are responsible for socio-culture stigmata as well as discrimination against epileptic patients. Need is for persistent and effective information campaigns to change public attitudes towards person with epilepsy. Results have shown that current levels of education haven't influenced the prejudices against the epileptic persons.

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