

A Study to Find Out the Myths and Misconception Related to Epilepsy Among the Family Members of Patient With Epilepsy Attending OPD of Lgbrimh, Tezpur, Assam

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Abstract

Fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries. Some of the stigma continues today in many countries and can impact the quality of life for people with the disorder and their families. Non experimental descriptive study included 50 family members of patient with epilepsy attending OPD of Lokopriya Gopinath Bordoloi Regional Institute of Mental Health, Tezpur, Assam. Self-structured questionnaire was used to assess the myths and misconception related to epilepsy. The myths and misconception related Epilepsy among the family members of patient with epilepsy was assessed where the score is 38, the mean was 27.2 ± 4.49 and range was 19.0. Most of the respondents (96%) answered above 27 whereas only 4% of them respondent score below 27. The association of the myths and misconception related to Epilepsy with the selected demographic variables was assessed by using chi-square test and the finding shows there was no significant association between the demographic variables with the total score on myths and misconception related to Epilepsy at 0.05 significance. The study concludes that the family members of patient with epilepsy have less myths and conception and good knowledge regarding epilepsy. Whereas in certain areas like Epilepsy is uncommon, Epilepsy is not a medical disorder, Epilepsy result from the punishment from God and person with Epilepsy should not work which requires night duty where people have more misconception and understanding which needs awareness to clear these problems better.

Keywords: Myths; Misconception; Family member; Patient with epilepsy.

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Introduction

The word 'epilepsy' is derived from the Greek *epi* means *upon* and *labbanein* to *seize*. The suddenness of the attacks is emphasized in by the Greek.¹ In antiquity epilepsy was known as variety of folk names in different cultures such as the holy sickness, the divine disease, the falling evil, and the road Christ. Ancient culture believed that epilepsy was infliction or possession by a supernatural power.²

In some early societies, people with epilepsy

were considered to be under the influences of the changing phases of moon. This led to the term lunatic which in Latin means moon struck, or crazy.³

Myths and misconceptions have always existed in almost all the societies and through all ages. Myths are collectively shared fantasies that contribute to the psychological stability of both individual and society. There are many myths and misconceptions in the public mind that often have a negative impact on people with as well as on their families and friends.³

Misconceptions are the false impression and misapprehension. These could be mistaken thoughts, ideas or notions that develop and prosper in societies mostly leading to malpractices in terms of health beliefs and health seeking behaviors, such myths and misconception hinder the logical approach to seek appropriate health care, resulting in various health problems.³

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The WHO estimated the general population with active epilepsy (i.e. continuing seizures or the need for treatment) at a given time is 4 to 10 per 1,000 people. However, some studies in developing countries suggest that the proportion is 6 to 10 per 1,000. Around 50 million people in the world have epilepsy.⁴ According to Rural Community studies in India, reported the prevalence rate of epilepsy is about 3 persons/1000 population in rural Rajasthan; 4.7/1000 population in rural Bombay; and 4.74/1000 population in rural area of Kerala.⁵

Epilepsy is a misunderstood condition that has stigmatizing myths, perceptions, and incorrect knowledge surrounding it.⁶ It is a contagious disease and occurs due to previous life sin is a misconception in India.⁷ Evil eye, evil spirit and punishment from God causes epilepsy is still a believe among the public.⁸⁻¹⁰ Also people believe that it is a disease of insanity.¹¹⁻¹³ The choice of treatment was shaped by beliefs in an external spiritual cause of epilepsy and was commonly expected to be curative but not preventive. Treatment rarely led to the control of seizures, although when control was achieved, the level of community acceptance of people with epilepsy increased. Every person with epilepsy had sought traditional treatment.¹⁴

Epilepsy is a neurological disorder in which a person has repeated seizures (convulsions) over time. Seizures are episodes of disturbed brain activity that cause changes in attention or behavior.¹⁰

Epilepsy is common neurological condition affecting around 50,000,000 people worldwide. Epilepsy is universal in that it affects people of all ages, both sexes and unrelated to either the education or the financial position of the individual.¹¹ Person with epilepsy, fear rejection and often feel shame or loneliness from social stigma. Myths, misconceptions and misunderstandings about epilepsy continue and programs aimed at increasing knowledge and reducing negative public attitudes.¹³ The awareness of epilepsy in India is less and attitude towards epilepsy is much more negative.⁸ The social stigma attached to epilepsy very often constitutes a considerable problem and much private grief for patients and their relatives. Individuals who did not receive school education, those who had never known or seen an epileptic and those who thought that epilepsy is infectious were more likely to say that epileptics should be isolated from normal individuals, cannot receive academic education, cannot perform activities of daily life and cannot become useful members of the society. However, despite high awareness level, knowledge

level however was still very limited. Obviously, the main problem was lack of accurate knowledge regarding this illness. Moreover, the existence of incorrect knowledge plus false beliefs surrounding this disease has commonly been spread from person to person among the community, worsening the matter. This indicated that epilepsy education has been largely inadequate and ineffective especially in developing countries.¹⁶ It is known that society's attitudes and behaviors can be more adverse than the seizures themselves, in causing negative impact on the patients' daily lives.¹⁷

During a seizure the practice in many parts of India is to keep keys in the hand or making the person to smell shoe or onion^{4,8,18} Also majority of the people believe that the treatment of epilepsy is available in holy Quran.¹⁰ Holy water is opted by people (70.33%) to get rid of epilepsy.¹¹ People (44.78%) also believe that Faith healer are the best person to treat epilepsy.¹¹

After going through the above mentioned facts, it is clear that prevalence of epilepsy is very high throughout the world as well as in India. The thorough examination of many literatures shows that there is greater existing of myths and misconception among the family members and also among the general population

Methods

The research approach in this study was quantitative approach with non-experimental explorative research design to determine the myths and misconception among the family members of patient with epilepsy attending OPD of Lokopriya Gopinath Bordoloi Regional Institute of Mental health, Tezpur, Assam. Total samples consist of 50. Purposive sampling technique was used to collect the data. Content validation of tool to asses myths and misconception of epilepsy was done by four expertise in the area of psychiatric, psychiatric nursing, clinical psychology and psychiatric social worker. The tool is divided into two sections: section one comprised socio demographic data and section two comprised self structure knowledge questionnaire with 38 items. Written permission was taken from concerned authority and informed consent was taken from the subjects.

Results

The myths and misconception related Epilepsy among the family members of patient with epilepsy

was assessed where the score is 38 the mean was 27.2 ± 4.49 and range was 19.0. Most of the respondents (96%) answered above 27 whereas only 4% of them respondent score below 27 (Fig. 1). The association of the myths and misconception related to Epilepsy with the selected demographic

variables was assessed by using chi-square test and the finding shows there was no significant association between the demographic variables with the total score on myths and misconception related to Epilepsy at 0.05 significance. (Tables 1 and 2).



Fig. 1: Distribution of frequency and percentage of the family member based on total score of myths and misconception related to Epilepsy (N=50) . Score is divided in to below the mean score and above the mean score.

Table 1: Description of socio demographic variable of family members of patient with Epilepsy N=50

Variables	Frequency	Percentage (%)
Age	18-25 yrs	24%
	26-35 yrs	24%
	36-45 yrs	24%
	46-60 yrs	28%
Gender	Male	70%
	Female	30%
Marital status	Married	84%
	Single	16%
Religion	Hindu	52%
	Muslim	44%
	Christian	4%
Educational status	Primary	48%
	Middle school	34%
	Higher secondary	2%
	Graduation	16%
Monthly income	< Rs 5000/-	54%
	>Rs 5000-Rs 10,000/-	26%
	>Rs 10,000-Rs 20,000	8%
	>Rs 20,000	12%
Occupation	Unemployed	2%
	Daily wage earner	6%
	Business	14%
	Govt service	6%
	Private service	18%
	Home maker	28%
	Cultivator	16%
	Others	10%

Variables		Frequency	Percentage (%)
Relationship with the patient	Parents	25	50%
	Spouse	6	12%
	Children	4	8%
	Sibling	8	16%
	Others	7	14%
Duration of staying with the patient	1-5 yrs	5	10%
	5-10 yrs	14	28%
	10-20 yrs	11	22%
	>20 yrs	20	40%

Table 2: Distribution on frequency and percentage of individual item score on myths and misconception related to Epilepsy

Items	Score - 0		Score - 1	
	Frequency	Percentage (%)	Frequency	Percentage (%)
1. Epilepsy spread from one person to other	14	28%	36	72%
2. Epilepsy could be caused by black magic	9	18%	41	82%
3. Only kids get epilepsy	4	8%	46	92%
4. Person with epilepsy disable cannot work	12	24%	38	76%
5. Person with epilepsy should be restrain while having seizure	4	8%	46	92%
6. The teeth should be opened with object while having seizure	17	34%	33	66%
7. Epilepsy is the result of punishment from god	21	42%	29	58%
8. Person with epilepsy can get marry	20	40%	30	60%
9. Person with epilepsy can think and judge like other people	14	28%	36	72%
10. Person with epilepsy can control seizure voluntarily	4	8%	46	92%
11. When a person having seizure he should be made to smell shoe or onion	15	30%	35	70%
12. Epilepsy is not a medical problem	22	44%	28	56%
13. Marriage can cure epilepsy	4	18%	46	82%
14. Epilepsy run in the family	18	36%	32	64%
15. Children with epilepsy should not stop going school	26	52%	24	48%
16. Epilepsy is a result of bad parenting	4	8%	46	92%
17. A true religious believer can never suffer from an epilepsy	5	10%	45	90%
18. Epilepsy can spread by bad air	12	24%	38	76%
19. Pouring water in mouth during seizure will reduce the seizure	14	28%	36	72%
20. People suffer from epilepsy due to sins committed in their previous life	13	26%	37	74%
21. Epilepsy is uncommon	36	72%	14	28%
22. Person with epilepsy does not have the right to vote	7	14%	43	86%
23. Person with epilepsy should stay away from the community	2	4%	48	96%
24. Person with epilepsy should not visit the public places	13	26%	37	74%
25. Faith healer is the best person to treat epilepsy	3	6%	47	94%
26. Epilepsy is a form of insanity	11	22%	39	78%
27. Person with epilepsy need special education	16	32%	34	68%

Items	Score - 0		Score - 1	
	Frequency	Percentage (%)	Frequency	Percentage (%)
28. Person with epilepsy can lead a normal life	8	16%	42	84%
29. Children with epilepsy can be allowed to play outside	19	38%	31	62%
30. Person with epilepsy can learn new things	12	24%	38	76%
31. Seizure can occur during lunar/solar eclipse	11	22%	39	68%
32. Person with epilepsy become aware of seizure episode beforehand	31	62%	19	38%
33. Epilepsy is a form of demonic possession	14	28%	36	72%
34. Sleep disturbances increase the episode of epilepsy	22	44%	28	56%
35. Person with epilepsy can be allowed to run heavy machinery and drive vehicle	14	28%	36	72%
36. Epilepsy is treatable	6	12%	44	88%
37. Person with epilepsy is usually dangerous and violent	21	42%	29	58%
38. Person with epilepsy should not be in job which require night duty	32	64%	18	36%

Table 3: Chi square value showing association between myths and misconception related to Epilepsy and selected demographic variables

Variable	Myths and misconception-score		Calculated χ^2 value	df	Chi-square value	S*/NS At 0.05 level	
	0-27	28-38					
1. Age	18-25 yrs	6	9	0.17	3	7.82	NS
	26-35 yrs	4	7				
	36-45 yrs	3	6				
	46-60 yrs	6	9				
2. Gender	Male	13	22	0.036	1	3.84	NS
	Female	6	9				
3. Religion	Hindu	10	16	1.307	2	5.99	
	Muslim	13					
	Christian	2					
4. Marital status	Married	2	40	0.001	1	3.84	NS
	Unmarried	8					
5. Relationship with the patient	patient	8	17	1.595	4	9.49	NS
	Spouse	3					
	Children	3					
	Sibling	4					
	Others	4					
6. Occupation-of the family member	Unemployed	0	1	5.465	7	14.07	NS
	Daily wage earner	2					
	Business	5					
	Govt service	4					
	Private service	3					
	Home maker	9					
	Cultivator	3					
	Others	4					
7. Monthly income of the family member	>5000	6	21	8.535	3	7.82	NS
	>Rs5000-Rs 10,000/-	9	4				
	>Rs10,000-Rs20,000	2	2				
	>Rs 20,000	2	4				

	Variable	Myths and misconception-score		Calculated χ^2 value	df	Chi-square value	S*/NS At 0.05 level	
		0-27	28-38					
8.	Educational status of the family member	Primary	8	16	2.603	3	7.82	NS
		Middle school	9	9				
		Higher secondary	0	2				
		Graduation	2	4				
	Duration of staying with the patient	1-5 yrs	3	2	1.723	3	7.82	NS
		5-10 yrs	6	8				
		10-20 yrs	4	7				
		>20 yrs	6	14				

*p < 0.05 (significant at 0.05 levels) S- significant NS- not significant

Table 3 shows the association between the myths and misconception related to Epilepsy and the socio demographic variable.

There is no significant relationship between the total score on myths and misconception related to epilepsy and the socio demographic variable.

Discussion

Causes

The myths and misconception about the disorder particularly about the causes, in the present study shows that 42% family member mentioned that epilepsy is the result of punishment from God, 28% spread from one person to other, 28% by black magic only 36% believe that epilepsy may run in the family, 8% result from bad parenting, 26% due to sins committed in their previous live, 26% epilepsy is a form of insanity, 28% epilepsy is a form of demonic possession, 44% answered that sleep disturbances increases the episode of Epilepsy. Only 10% of the study sample believes that a true religious believer can never suffer from an Epilepsy.

The present study was comparable with the study conducted by Gouri *et al.*¹⁹ in Delhi which shows 16% attributed the disease caused supernatural power and 21% thought the disease is a result of sin committed by them and their parents.

The study conducted by Hashmi *et al.*²⁰ in Aurangabad, which report that only 4% believe that Epilepsy is contagious and 5% believe cause of Epilepsy is previous life sin, shows the low proportion of myths compare to the present study. Whereas 12% believe that epilepsy is contagious 31% believe that epilepsy is hereditary the result reported by Radhakrishnan *et al.*¹⁵ in Southern India.

Treatment

In the present study regarding the treatment (8%) mentioned to restrained while having seizure 32% to open the mouth in an object while having seizure, 44% will made to smell shoe or onion, 18% will pour water in mouth during seizure to reduce the seizure attack, 8% answered person with epilepsy can control seizure voluntarily. Only 6% believe that faith healer is the best person to treat Epilepsy and whereas 88% believe that Epilepsy is treatable. 18% of the study subject mentioned that marriage can cure epilepsy.

Radhakrishnan *et al.*¹⁵ reported that 55% of the respondents would make the person hold a bunch of keys to terminate the epileptic attack. Seventy-eight percent believed that an allopathic doctor should treat the person; 64% believed that Ayurvedic treatment for the treatment of Epilepsy which shows more misconception compare to the present study. Whereas the 91% knew that epilepsy is treated by modern drug. 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 affected person smell a shoe and putting the keys in the hand were mentioned by 12% and 5%, respectively which shows that more knowledge and less misconception of Epilepsy study conducted by Gouri *et al.*¹⁹ In the present study 8% believe that only kids get epilepsy, 24% have answered that person with epilepsy cannot work, 40% agreed that person with Epilepsy can get marry, 72% answered that person with epilepsy can think and judge like other people and 76% mentioned that person with epilepsy can learn new things. 84% mentioned person with epilepsy can lead a normal life.

Gouri *et al.*¹⁹ reported encouraging responses were observed regarding marriage 89%. Shows less misconception compare to present study.

Majority 52% of the present study subjects believe that children with Epilepsy should stop going school, 38% mentioned that children with epilepsy can be allowed to play outside .32% mentioned that person with epilepsy need special education. 42% mentioned that person with epilepsy can lead normal life.

Association of selected socio demographic variables with the myths and misconception related to epilepsy

This study discussed the findings of the association of the myths and misconception related to Epilepsy use in self-structured tools with the selected demographic variables by using chi-square value the present study, the finding show that there was no significant association between the demographic variable with the total score on myths and misconception related to Epilepsy at 0.05 significance.

In contrast to the present study Radhakrishnan *et al.*¹⁵ reported that the misunderstanding on cause of epilepsy is positively correlate with lower level of education ($p = 0.0001$) level.

Another study conducted by Gouri *et al.*¹⁹ which is in contrast to the present study shows that 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.

Conclusion

Epilepsy is a common episodic neurological condition that is heterogeneous in clinical presentation. One seizure does not signal epilepsy. Epilepsy is one of the world's oldest recognized conditions. The present study conducted in the intention to explore the myths and misconception related to epilepsy.

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