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Knowledge, attitude and practice of epilepsy among patients and family members attending urban health and training centre, Shahganj, Aurangabad, India

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ABSTRACT

Aims And Objective: To study knowledge, attitude and practice of epilepsy among patients and family members residing in urban slum. **METHODOLGY:** Study Design- Hospital based cross-sectional study. Study Place- UHTC, Shahganj, Aurangabad. Study Period- 1st to 29th Feb 2012(one month). Sample-KAP study was conducted by face to face interview of 100 persons including patients and family members of epilepsy using a predesigned and pretested questionnaire. **Results:** A large majority (95%) of PWE had heard about epilepsy and (53%) knew that epilepsy is an organic brain problem. Only 4% consider epilepsy as contagious. Negative attitude was observed with respect to not allowing a child with epilepsy to study in only (18%), objecting children to play with a child with epilepsy (12%), and unsuccessful marriage (19%) Negative attitude was reflected in the belief that epilepsy is due previous life sins (5%) About 73% people believed that allopath is a better option than ayurvedic (25%). A very small proportion, i.e. only 2% believed that holy treatment with worship is effective to treatment of epilepsy. About 40% felt that epilepsy can be cured, but almost 60% thought that a person with epilepsy has to take lifelong treatment. In response to first aid measures in response to epileptic fits, 60% preferred that they would take the person to a hospital, 23% felt that they would put a shoe or onion on nose, 15% would splash water over the face, and 2% would make the person hold a bunch of keys. **Discussion.** 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.

Key words: Epilepsy, Knowledge attitude practice(KAP),UHTC.PWE(patient with epilepsy).

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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 Aurangabad and compare with the Indian data.

Methods: People with epilepsy (PWE) and their relatives attending the Urban health and training centre, running weakly OPD for epilepsy associated with government medical college Aurangabad a tertiary health care centre were included. After obtaining informed consent, total of 100 subjects including patient and their relatives were included in the study. They were interviewed face to face by predesigned and pretested questionnaire comprising of 23 questions assessing the KAPs by students of government medical college Aurangabad. The responses were recorded as 'yes', 'no'.

Results: Out of total patients attending to Urban health and training centre, Shahgunj, 100 patients are involved in the survey. Responses to KAP questions are as follows:

Knowledge: About 95% people had heard about epilepsy. 66% knew at least one person with epilepsy. 60% people believed that epilepsy is a mental illness. 53% correctly believed that epilepsy is an organic brain problem. About 40% people were of the opinion that it was a hereditary disorder, 4% believed that it is contagious and 5% believed that it is a result of previous life sins.

Table.1: Comparison of knowledge from various studies in India.

Questions	Uttarakhand	Kerala	UHTC, Shahgunj, Aurangabad
Have you read or heard about epilepsy?	90%	97%	95%
Do you know any person with epilepsy?	48%	43%	66%
Is epilepsy a mental illness?	74%	59%	60%
Is epilepsy an organic brain problem?	64%	50%	53%
Is epilepsy known to occur in family?	67%	34%	40%
Can epilepsy spread by contact?	10%	13%	4%

Attitude: Nearly 18% people thought that epilepsy can interfere with study. About 19% believed that epilepsy is a hindrance to happy married life and 17% believed that epilepsy is a hindrance to normal sexual life. Nearly 14% believed that a person with epilepsy cannot work normally as a nonepileptic. 12% had some reservations in sitting or playing with an epileptic patient. More than a quarter (i.e. 2%) believed that society had a discriminative attitude towards the patients.

Table.2: Comparison of Attitude from various studies in India.

Questions	Uttarakhand	Kerala	UHTC, Shahgunj, Aurangabad
Epilepsy creates hindrance in normal life	72%	62%	18%
A person with epilepsy should not marry	76%	58%	19%
A person with epilepsy will not have normal sexual relations	75%	43%	17%
A person with epilepsy should not study	72%	40%	18%
A person with epilepsy should not work	74%	29%	14%
Society should behave differently with a person with epilepsy	56%	45%	2%

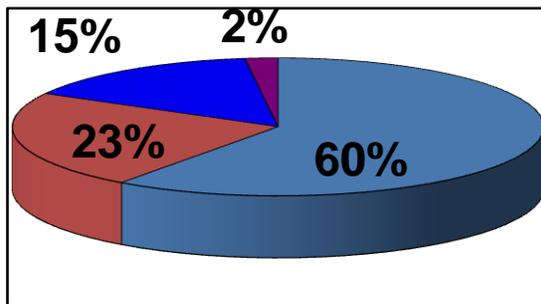
Practice: About 73% people believed that allopathic is a better option than ayurvedic (25%). A very small proportion, i.e. only 2% believed that holy treatment with worship is effective to treatment of epilepsy. About 40% felt that epilepsy can be cured, but almost 60% thought that a person with epilepsy has to take lifelong treatment. In response to first aid measures in response to epileptic fits, 60% preferred that they would take the person to a hospital, 23% felt that they would put a shoe or onion on nose, 15% would splash water over the face, and 2% would make the person

hold a bunch of keys.

Table3: Comparison of practice in various studies in India

Questions	Uttarakhand	Kerala	UHTC, Shahgunj, Aurangabad
Can epilepsy be treated with allopathic medicine?	61%	55%	73%
Is ayurvedic treatment the only option for epilepsy?	75%	59%	25%
Does an epileptic patient need lifelong treatment?	72%	35%	61%
A person of epilepsy should not leave even a single tablet	77%	60%	48%
Drugs used in epilepsy have many side effects	58%	55%	21%
Can epilepsy be cured?	75%	47%	39%
Is holy treatment good for epilepsy?	36%	22%	2%
Priest can treat epilepsy better	53%	39%	1%

Fig.1 Approach of the people towards an emergency attack



Discussion: 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, favourable opinion of the responders could be attributed to the ongoing intense awareness regularly conducted during the last 2-3 years by poster exhibitions in our centre by interns of GMCH Aurangabad and various community based projects by 2nd year students of GMCH. 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.

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