# Knowledge, attitude and practice of epilepsy in Uttarakhand, India

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#### Abstract

**Objectives:** This study was conducted to find out knowledge, attitude and practice (KAP) of epilepsy among 12<sup>th</sup>-class students in Uttarakhand state. Secondly data of Uttarakhand was compared with KAP study from other parts of the country. **Materials and Methods:** All 12<sup>th</sup>-class students studying in six schools of randomly selected 36 villages in Chakrata block of Dehradun district of Uttarakhand state were provided a printed questionnaire having answer as "yes or no". This questionnaire used was used previously by various authors and validated for KAP analysis. These filled questionnaires were collected by village health workers and medical officer. **Results:** This study conducted on 219, 12<sup>th</sup>-class students revealed that epilepsy was heard by 98%, 74.9% thought epilepsy a mental disease and 4.8% believed that it is contagious. Negative attitude showed as nearly 2/3<sup>rd</sup> students stated that epilepsy is hindrance in marriage and occupation. Nearly 41% would use onion or shoe for terminating seizure attack. Ayurvedic treatment was preferred over allopathic drugs. **Conclusions:** Study on 12<sup>th</sup>-class students of Uttarakhand revealed poor knowledge, attitude and practice for epilepsy and needs special education program to dispel these misconceptions.

#### **Key Words**

Epilepsy, knowledge, attitude and practice, epilepsy in India

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### Introduction

Knowledge, attitude and practice (KAP) studies have now become an integral part of community management of chronic illnesses associated with high level of stigma such as leprosy and epilepsy.<sup>[1]</sup> Our state of Uttarakhand is the youngest in India. Hilly areas in this state are poorly supported by healthrelated services and old traditional practice for health-related issues are very common. We have stared our comprehensive rural epilepsy surveillance program (CRESP) in year 2007.<sup>[2]</sup> Under this program we first planned to get the KAP study in this region. Findings of this study will provide the base for our strategy regarding epilepsy awareness programme in this region. Schools in this region were our target for such

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education programme. Only two among seven KAP studies in India were conducted on people without epilepsy.<sup>[3]</sup> Only one KAP study had included school children from Kerala having highest literacy rate.<sup>[4]</sup> Thus we selected 12<sup>th</sup>-class students for KAP study to assess baseline KAP for epilepsy in hills of Uttarakhand. Additionally, KAP for epilepsy in Uttarakhand was compared with other parts of the country.

### **Materials and Methods**

This community-based cross-sectional study was conducted in Chakrata block of Dehradun district in Uttarakhand. The selected Chakrata block of Dehradun district is having lowest composite block index (CBI) among six blocks of Dehradun district. Basic unit of the block is Nyaya Panchayat (NP) and this block is divided into nine NP. All 152 villages from nine NP were sorted in ascending order of population. Four villages from each NP were randomly selected on the basis population size. Finally 36 villages were randomly selected to cover about 14000 (25%) population.

Thirty-six community health workers (CHW) were appointed to cover all selected villages. In addition two medical officers (medical graduate) were appointed to supervise CHW. Whole of the staff was trained for a week at our institute on survey techniques, orientation to seizure disorders, method of interview and recording of data. There were only six schools up to 12<sup>th</sup> standard in these 36 villages. Class 12<sup>th</sup> students studying in these six schools were our target for KAP analysis. After official permission by the principals of these schools printed questionnaire for KAP was given to the students. Students have to fill this questionnaire and have to submit it back to our medical officer. If any question was not clearly understood by the students then medical officer had helped them.

KAP Questionnaire – Based on previous study the questionnaire having 23 questions with yes or no response was utilized.<sup>[5]</sup> Questions 1-7 for knowledge, Q8-Q14 for attitude and Q15-Q23 were there for testing the practice about epilepsy. Since selected area belongs to Hindi-speaking conservative society, this questionnaire was translated in local Hindi language and then back translated for final analysis. In 23<sup>rd</sup> question, option "D" was additional part as this was routine custom to use onion for termination of epileptic fit in local population. The survey was conducted by medical officer and field supervisors who were specially trained to this purpose. Prior permission was taken from principal and class teachers of respective school.

### Result

A total of 219 class  $12^{\text{th}}$  students from six schools (mean age 16.8 ± 0.9) were participated the study. There were 130 (59.3%) boys and 89 (40.7%) girls, all belonging to the Hindu community. Responses to KAP questionnaire are summarized in Table 1.

#### Knowledge (Q1-7)

About 98% students had heard or read about epilepsy. Fortyeight percent knew of at least one person with epilepsy. One hundred and thirty-seven students (64.9%) believed correctly that epilepsy is an organic brain disorder although, 2/3<sup>rd</sup> also believed that epilepsy is mental problem. Prevalent misconceptions were that epilepsy is hereditary disorder (31.8%), is contagious (4.7%) and is a result of previous life sin (5.2%).

#### Attitude (Q8-14)

Nearly 3/4<sup>th</sup> students thought that epilepsy can interfere with study. Majority of them believed that epilepsy is a hindrance to happy married (76.3%) and sexual life (75.4%). Nearly 75% believed that person with epilepsy cannot work normally as non-epileptic. Fifteen percent had some reservations in sitting or playing with epileptic patients. More than a quarter (26.5%) believed that society had discriminative attitude for epileptic patients.

#### Practice (Q15-23)

More students (75.8%) believed that Ayurveda is a better option than allopathic (61.1%). A small proportion (17%) believed that holy treatment with worship is effective in treatment of epilepsy. Two-third of the students from Uttarakhand (75.4%) felt that epilepsy can be cured (Q20) but almost similar number (72.5%) thought that person with epilepsy has to take lifelong treatment. In response to first aid measures for epileptic fits (Q23), 49.8% preferred that they would take the person to a hospital, 40.8% said that they would put shoe or onion on nose, 23.2% would splash water over face and 1.4% would make the person hold a bunch of keys.

#### Discussion

Findings in our study were suggestive of worse pattern of KAP when compared with other studies from India [Tables 1 and 2]. Word epilepsy was heard by 98% of students similar to other studies. Nearly 5% students in Uttarakhand state believed that epilepsy is contagious and is due to sin of ancestors. Results from other regions also suggested that 1-14% persons believed that epilepsy is contagious.<sup>[3]</sup> Almost 3/4th believed that epilepsy is hindrance in marriage and occupation. This figure is very high when compared to other study from India (10-66%) but near to a study from China (87%).<sup>[3]</sup> Social discrimination with person having epilepsy was favored by 26.5% of students and 15.2% would avoid to play or study with a person with epilepsy. Other two studies which surveyed non-epileptic population found that 13% (Pandian et al.) and 43% (Gambhir et al.) will not like to play with child with epilepsy.<sup>[3]</sup> Similar to other study from Kerala 2/3rd students of Uttarakhand favored for Ayurvedic treatment as Ayurvedic system is very popular in both states of India.<sup>[4]</sup> As per usual practice in northern India, 40.8% students believed that acute attack can be terminated with smell of shoe or onion which was higher than other studies (12.5-33%).<sup>[3]</sup>

Most appropriate responses about KAP were found in study from persons with epilepsy from Delhi.<sup>[3]</sup> Very high proportion (74.9%) in Uttarakhand in comparison of Delhi persons (14.2%) believed that epilepsy is a mental illness. This reflects the greater level of misconceptions and stigma associated with epilepsy. Possibly social backwardness in comparison to Delhi is responsible for it and school level education is not able to correct this belief. Socially developed societies have better attitude toward diseases like epilepsy. Chinese has better knowledge of epilepsy than in many developed countries but attitude is more negative.<sup>[6]</sup> Moreover, attitude for epilepsy was found to be negative even in highly educated professionals like professors and medical staff of developing countries.<sup>[6]</sup> Ten times more students in comparison to Delhi (31.8% vs 3.3%) felt that epilepsy is hereditary in origin. That is why large number of students was of belief that a person with epilepsy should not marry (73.6%) and should not produce children (75.4%) in comparison to Kerala and Delhi. Regarding marriage issue, usual practice in many parts of India including Uttarakhand is that parents hide the information about epilepsy before marriage due to attached stigma with it.

On an average 2/3<sup>rd</sup> students in Uttarakhand believed that epilepsy results in interference for education, and occupation while this number was less in other part of India [Tables 1 and 2]. It is known that parents and school teachers compel the student with epilepsy to remain away from school.<sup>[6]</sup> In rural Tanzania, 68% and in India 40% of parents would not allow the child with epilepsy to go to school.<sup>[6]</sup> At times teachers had preferred to place students with epilepsy at special school. <sup>[6]</sup> Very low proportion (25.4%) in our study believed that a person with epilepsy can be employed when compared with

Table 1: Showing the	questionnaire and	I responses in current and	two other	studies from India <sup>[3,4]</sup>
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Question	Present study (Uttarakhand) ( <i>n</i> = 219) Yes (%)	Pandian <i>et al</i> ., (2006) Kerala <sup>[4]</sup> ( <i>n</i> = 1213) Yes (%)	Gourie Devi <i>et al</i> ., (2010) Delhi <sup>[3]</sup> ( <i>n</i> = 120) Yes (%)
Have you read/heard about epilepsy?	206 (97.6)	97.7	94.2
Do you know any person with epilepsy?	102 (48.3)	43.1	-
Is epilepsy a mental illness?	158 (74.9)	59.3	14.2
Is epilepsy an organic brain problem?	137 (64.9)	50.4	55
Is epilepsy known to occur in family?	67 (31.8)	34.1	3.3
Can epilepsy spread by contact?	10 (4.7)	13.9	0.8
Is an epilepsy result of previous life sins?	11 (5.2)	11.2	20.9
Epilepsy creates hindrance in normal life. Yes/no?	153 (72.5)	62.4	-
A person with epilepsy should not marry. Yes/no?	161 (76.3)	58.1	10.8
A person with epilepsy will not have normal sexual relations. Yes/no?	159 (75.4)	43.2	7.5
A person with epilepsy should not study. Yes/no?	153 (72.5)	40.8	18.3
A person with epilepsy should not work. Yes/no?	157 (74.4)	29	9.2
Society should behave differently with a person of epilepsy. Yes/no?	56 (26.5)	45.1	-
Would you like to object to play/study with an epileptic child?	33 (15.6)	13	5
Can epilepsy be treated with Allopathic medicine?	129 (61.1)	55.4	91.7
Is Ayurvedic treatment the only option for epilepsy?	160 (75.8)	59	2.5
Does an epileptic patient need lifelong treatment?	153 (72.5)	35	-
A person of epilepsy should not leave even a single tablet?	163 (77.3)	60.9	-
Drug used in epilepsy have many side effects. Yes/no?	124 (58.8)	55.1	-
Can epilepsy be cured?	159 (75.4)	47.3	-
Treatment with holy treatment e.g., tantric is good for epilepsy?	36 (17)	22.1	-
Priest can treat epilepsy better?	53 (25.1)	39.1	19.2
If you see a person with epileptic fit what you will do?	105 (40.0)	(0.0	0/ 7
Will go to hospital	105 (49.8)	62.3 7.5	96.7 5.8
Give a bunch of key in hands Will put some water on his face or	3 (1.4) 49 (23.2)	23.9	5.8
Will put shoe or onion on his nose	86 (40.8)	_	12.5

# Table 2: Comparative findings in current and oldKAP studies from India<sup>[3]</sup>

Parameters	Old studies (%)	Current study (%)
Heard or read epilepsy	92-99	97.6
Epilepsy is an organic brain disorder	15-68	64.9
Epilepsy is contagious	1-14	5
Epilepsy is due to supernatural cause	4-26	5
Hindrance to marriage	10-66	76.3
Person with epilepsy can be employed	54-91	25.6
Will not like to play with a child with epilepsy	13-43	15.2
Modern medicine is useful	50-92	55.4
Like to take a person having attack to hospital	57-97	49.8

national range of 54-91%.<sup>[3]</sup> Hypothetically negative perception for occupation by a person with epilepsy in our study is linked to geographical situation and difficult movement for any job in hilly areas.

One opposing finding is our survey was that 72.5% students from Uttarakhand believed that person with epilepsy need lifelong therapy and 75.4% also answered that epilepsy can be cured. Possibly students believed that allopathic treatment has to be taken for whole life but Ayurveda can cure epilepsy. To conclude findings from our study suggested that KAP for epilepsy in Uttarakhand is very poor in comparison to other parts of country. Large proportion of students in hills of Uttarakhand was of the belief that epilepsy is a mental disease, that runs in family and a person with epilepsy should not be married and employed. Wrong practices like use of onion and shoe for acute attacks were still common in this community. Requirement of special education programme for parents, school teachers and students was felt to dispel myths and misconceptions about epilepsy. Clinician in this region also needs to spend some extra time from their busy schedule while addressing the social issues to the people living with epilepsy.

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