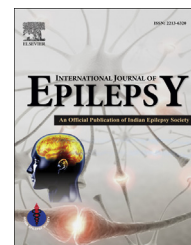


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## Original Article

# Knowledge about, attitudes towards, practices regarding *Taenia solium* cysticercosis among people attending an epilepsy clinic in India

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## ARTICLE INFO

## Article history:

Received 21 January 2014

Accepted 11 March 2015

Available online 6 May 2015

## Keywords:

Cysticercosis

Knowledge

Attitude

Practices

*Taenia solium*

## ABSTRACT

**Background:** *Taenia solium* cysticercosis is one of the commonest, but potentially eradicable, causes of seizures in India. Eradication and appropriate control should incorporate educational interventions regarding the infestation and this requires an assessment of knowledge about, attitudes towards and practices (KAP) regarding the disorder.

**Aim:** We undertook a KAP survey regarding *T. solium* cysticercosis in a hospital-based population with seizures in order to determine the existing knowledge and attitudes regarding the disorder and practices regarding its prevention and treatment.

**Methods:** One hundred and eighty two people attending an epilepsy clinic were administered a validated 16-item KAP questionnaire, the responses of which were assessed against responses obtained from experienced neurologists.

**Results:** Of the 182 respondents, 22 (12%) believed that a worm was responsible for their seizures, while 94 (52%) were aware of the link between worms and epilepsy in general. Despite this 150 (82%) were unsure about the name and nature of the worm. In fact 89 (49%) believed that the worm was acquired by eating cabbages rather than by consuming pork and by poor personal hygiene. Only 14 (8%) had ever consumed pork. Of note, 56 (31%) admitted visiting unqualified quacks who sucked out the worm through the nose.

**Conclusions:** In conclusion although the population was highly sensitized to the association between worms and epilepsy they did not appreciate its mode of transmission. Moreover the practice of visiting quacks to remove worms was quite prevalent.

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## 1. Introduction

The parasitic infestation of human brain, neurocysticercosis (NCC), caused by the larval stage of the pork tapeworm, *Taenia*

*solium*, is endemic in most parts of India and much of South and Central America, and parts of sub-Saharan Africa.<sup>1</sup> Only recently, few community-based studies have documented transmission of the parasite and the high prevalence of its infestation in selected locations within India.<sup>2–4</sup>

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<http://dx.doi.org/10.1016/j.ijep.2015.03.003>

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The International Task Force for Disease Eradication has recognized *T. solium* cysticercosis as one of the six disorders that are potentially eradicable.<sup>5</sup> The control or eradication of any infectious disorder requires an assessment not only of the prevalence of infection in the community but also of knowledge about, attitudes towards and practices regarding (KAP) the disorder among members of the community. Control can be effectively implemented when the attitude of the community is scientifically appropriate and community members are supportive of the measures taken towards control or eradication. Hence, we undertook a knowledge, attitudes, and practices (KAP) survey that specifically addressed issues related to *T. solium* cysticercosis among people with epilepsy attending a specialized epilepsy clinic in a hospital in North-west India in order to determine aspects of prevention that need to be stressed in health education campaigns.

## 2. Material and methods

### 2.1. Study sample

The study sample comprised 182 consecutive people with epilepsy attending the adult epilepsy clinic of Dayanand Medical College, Ludhiana, India between 1st January 2007 and 30th June 2007. Informed consent was obtained from all study subjects. The project was approved by the Institutional Ethics Committee.

### 2.2. Design and administration of questionnaire

Questions and their answers were formulated by two neurologists with experience in the care of patients with NCC. They provided 10 questions each, of which identical items were omitted, leaving behind 16 questions. The questions were oriented towards the awareness of the nature of epilepsy in the subjects, awareness about NCC and the mode of acquisition, transmission and prevention of cysticercosis, available treatment options, and risk practices and behaviors that might facilitate transmission of the parasite. All questions were provided with multiple response answers of which only one response was deemed to be correct. The questions were then administered to another neurologist in order to determine appropriate responses.

The questionnaire was administered by a student investigator in the study team in strict confidentiality in a private room away from the epilepsy clinic in either English language or Punjabi, which is the vernacular language in the state of Punjab. Responses were also recorded by the student investigator.

## 3. Results

### 3.1. Demographic characteristics of sample population

The KAP questionnaire was administered to 182 patients [125 (69%) males] [mean ( $\pm$ SD) age: 24 ( $\pm$ 14 years)]. The cohort included 44 (24%) students, although, most had completed their studies with 158 (87%) being matriculate or under-

matriculate (Table 1). Four of the respondents were medics or paramedics.

### 3.2. Epilepsy characteristics

Of the 182 respondents, 35 (19%) presented with new-onset seizures, and 147 (81%) had chronic epilepsy. Imaging (either CT or MRI) was undertaken in all patients and 31 (17%) had evidence of NCC on their imaging studies.

### 3.3. Knowledge about relationship between helminths and epilepsy and transmission of cysticercosis

Regardless of presumed etiology of their epilepsy, 22 (12.1%) respondents believed that a worm was responsible for their epilepsy (Table 2). However, 88 (48%) were unsure regarding the cause of their epilepsy and considered hereditary factors ( $n = 10$ ; 6%), accidents ( $n = 25$ ; 14%) and stress ( $n = 37$ ; 20%) to be causally linked to their infirmity. Ninety four (52%) respondents were aware that worms might be responsible for epilepsy. The majority (150; 82%) were however unsure about the name or nature of the worm (i.e. tapeworm). Eighty nine (49%) believed that the worm was found in cabbages and therefore could be acquired by eating raw cabbages. Only 14 respondents (8%) held the view that the tapeworm could be acquired by consuming pork and 28 respondents (15%) believed that infestation was associated with poor personal hygiene. According to 57 (31.2%) respondents, the infestation could be diagnosed using a computerised tomographic scan (Tables 3, 4).

### 3.4. Attitudes towards and knowledge about prevention of cysticercosis (Table 5)

In all, 122 (67%) respondents were willing to participate in a community program for screening or controlling *T. solium* infestation. In the views of 68 respondents (37%), good

**Table 1 – Demographic characteristics of the study sample.**

Demographic Characteristics	Responses
<b>Gender</b>	
Male	125 (69%)
Female	57 (31%)
Age (in years) (Mean $\pm$ SD)	24 $\pm$ 14
<b>Educational qualification</b>	
Under-matriculate	73 (40%)
Matriculate	85 (47%)
Graduate	17 (9%)
Post graduate	3 (2%)
Higher	3 (2%)
<b>Profession</b>	
Medical/paramedical	4 (2%)
Teacher	1 (1%)
Business	31 (17%)
Student	44 (24%)
Professional	6 (3%)
Farmer	15 (8%)
House wife	28 (15%)
Others	53 (29%)

**Table 2 – Epilepsy characteristics.**

	Responses
<b>Epilepsy code</b>	
New-onset epilepsy	35 (19%)
Prevalent epilepsy	147 (81%)
Duration of seizures (in months) (mean $\pm$ SD)	70 $\pm$ 74
<b>Seizure frequency</b>	
Single	25 (14%)
Sporadic	47 (26%)
Annual	17 (9%)
Biannual	26 (14%)
Monthly	39 (22%)
Weekly	11 (6%)
Daily	17 (9%)
<b>Aetiology</b>	
Neurocysticercosis	31 (17%)
Other	151 (83%)

personal hygiene could prevent transmission, though 42 (23%) were of the impression that transmission could be prevented by avoiding consumption of cabbages and salad. The majority (101; 55%) were unsure of the community-level measures required to prevent transmission of *T. solium*.

### 3.5. Risk behaviors

Although 89 (49%) respondents consumed animal products and meats, only 14 (8%) admitted to pork consumption ever. Many (82; 45%) believed that free-ranging pigs were the source of pork for human consumption and 57 (31.3%) practiced open defecation albeit only occasionally. Personal hygiene was claimed to be good by 171 (94%) respondents (Table 6).

### 3.6. Myths associated with treatment of NCC

Fifty six (31%) respondents (including both, those diagnosed with NCC as well as others) admitted to visiting an unqualified

**Table 3 – KAP items and response.**

	Responses
<b>Relationship between helminths and epilepsy</b>	
<b>What do you think has caused your epilepsy?</b>	
Hereditary factors	10 (6%)
Worms	22 (12%)
Accidents	25 (14%)
Stress	37 (20%)
Not sure	88 (48%)
<b>Can worms cause epilepsy?</b>	
Yes	94 (52%)
No	30 (16%)
Not sure	58 (32%)
<b>If worms can cause epilepsy, do you know the name of the worm that can cause epilepsy?</b>	
Roundworm	0 (–)
Boll worm	1 (1%)
Tapeworm	1 (1%)
Hookworm	0 (–)
Not sure	150 (82%)
Not applicable	30 (16%)

**Table 4 – Knowledge about transmission of cysticercosis.**

	Responses
<b>How does one get infected with this worm?</b>	
By eating raw cabbages	71 (39%)
By eating chicken	3 (2%)
By contact with dogs	3 (2%)
By poor hygiene	28 (15%)
Not sure	47 (26%)
Not applicable	30 (16%)
<b>Where is this worm normally located?</b>	
Cabbages	89 (49%)
Pigs	14 (8%)
Buffaloes	0 (–)
Eggs	3 (2%)
Not sure	46 (25%)
Not applicable	30 (16%)
<b>If one person in the family has worms, can this be passed on to other persons in the family?</b>	
Yes	26 (14%)
No	79 (44%)
Not sure	77 (42%)

individual (quack) who claimed to be able to suck out the worm with the help of a thin suction tube applied to the nose of the subject (Table 7). However, the majority (103; 57%) were of the view that medications were nevertheless required in order to treat the disorder and only 7 (4%) held the belief that

**Table 5 – Knowledge about and attitude towards preventing cysticercosis.**

	Responses
<b>What methods best prevent from developing cysticercosis?</b>	
Avoid eating cabbages and salads	42 (23%)
Maintain good personal hygiene	68 (37%)
Do not eat any type of meat	10 (6%)
Avoid eating pork	9 (5%)
Not sure	53 (29%)
<b>If there were a mass screening program for cysticercosis that involved giving stool and blood sample, would you participate?</b>	
Yes	143 (79%)
No	39 (21%)
<b>If there were a community based intervention program that required certain medicines to be taken for 1–2 days as a mass program to eliminate worm infestation, would you participate in such a program?</b>	
Yes	122 (67.0%)
No	60 (33.0%)
<b>At the community level, what can be done to prevent transmission of cysticercosis?</b>	
Ensuring meat inspection	38 (21%)
Banning the use of all meats	23 (13%)
Banning the cultivation of salads in the fields	13 (7%)
Disallowing pig farming	7 (4%)
Not sure	101 (55%)
<b>What else can be done at community level to prevent transmission of cysticercosis?</b>	
Improving public awareness about the transmission of the disorder	76 (43%)
Police checking of pork vendors	17 (9%)
Microscopic screening of food material	54 (29%)
Not sure	35 (19%)

**Table 6 – Personal habits and hygiene.**

	Responses
<b>What is the usual source of pork that is used for human consumption?</b>	
Free ranging pigs	82 (45%)
Pigs from pig farms	61 (33%)
Both	21 (12%)
Not sure	18 (10%)
<b>Have you ever consumed non vegetarian foods apart from eggs?</b>	
Yes	89 (49%)
No	93 (51%)
<b>Do you/did you ever eat pork?</b>	
Yes	14 (8%)
No	165 (91%)
Not sure	3 (1%)
<b>Do you ever defecate in the open?</b>	
Yes	57 (31%)
No	125 (69%)
<b>Are you aware of free ranging pigs in your locality?</b>	
Yes	59 (32%)
No	123 (68%)
<b>Do you wash hands with soap before having your meals?</b>	
Always	81 (45%)
Mostly	68 (37%)
Sometimes	27 (15%)
Never	6 (3%)
<b>Do you wash hands with soap after defecating?</b>	
Always	171 (94.0%)
Mostly	4 (2%)
Sometimes	6 (3%)
Never	1 (1%)

removal through the nose was the only method of removing the worm from the brain.

#### 4. Discussion

*Taenia solium* cysticercosis is one of the preventable causes of seizures and epilepsy. In order to reduce the burden of epilepsy attributable to cysticercosis, the transmission of *T. solium* needs to be controlled.<sup>6</sup> A number of control interventions have been suggested to interrupt transmission of the parasite, but these are unlikely to be successful without positive change

in knowledge about, attitudes towards, and practices regarding the parasite and the disorder it causes.

Very few studies have evaluated the status of knowledge about, attitudes towards and practices concerning transmission of *T. solium*.<sup>7–10</sup> One community-based survey in rural Mexico examined this aspect before and after an educational intervention oriented towards improving knowledge about and practices regarding *T. solium*. Before the intervention, 26% of the population sampled was aware about human cysticercosis but immediately following the educational intervention, the proportion rose to 57%.<sup>9</sup> The socio-cultural setting of the Mexican survey was different from the population in our study. The majority of the households in rural Mexico reared pigs as a source of pork. Nearly 97% of the respondents in the Mexican survey were able to recognize pork infested by cysticerci. In comparison, only 7.7% of the respondents in our study remembered consuming pork ever.

Over half the respondents in our study were aware of the association between worms and epilepsy. This shows that the sample population was sensitized to the association between worms and epilepsy. One reason for this familiarity could be that the sample was drawn from a specialized epilepsy clinic and individuals with epilepsy attending the clinic often seek and are offered information about the link between helminths and epilepsy as a part of usual care.

A previous KAP survey in people with NCC also found that respondents were aware of the association between worms and epilepsy.<sup>11</sup> In a different population comprising school teachers, the awareness of the association was only 26%.<sup>8</sup>

In association with two previous surveys in selected populations from India,<sup>11,8</sup> this study uncovered gaps in knowledge about the parasite and the disorder. A unique finding in the present survey however, was that nearly half of the respondents (89; 49%) held the belief that the worm responsible for epilepsy was found in cabbages and that the consumption of raw cabbages, other vegetables and salads could lead to worm infestation of the brain. As if to reinforce this belief, a number of subjects visited quacks in the countryside, who specialized in removal of worms using a mouth-held small, suction tube applied to the nose of people affected by epilepsy. The quacks then presented a cabbage bollworm to the subjects giving them the false impression that the cabbage bollworm was responsible for brain infestation. Some of the respondents visited these quacks despite having been provided counsel about the pointlessness of the exercise as part of usual care. The practice is not only unethical and scientifically baseless but also an unnecessary burden on the time and money of the people who visit these quack clinics. There is dire need for mobilizing public opinion and political and legal measures against this practice.

One limitation of this study was that it was undertaken in a highly-specialized population and hence its results may not accurately reflect community beliefs and practices. Furthermore, the benefits of recording community knowledge and practices should be reviewed in light of the failure to demonstrate sustainability and relevance of health and safe practices educational intervention in settings, where *T. solium* cysticercosis is endemic.<sup>9</sup> For instance, in the Mexican study, the immediate benefits of the health education intervention were evident, a survey of knowledge, attitudes and practices

**Table 7 – Knowledge about treatment of cysticercosis and associated myths.**

	Responses
<b>How would one treat this worm?</b>	
Removal through the nose by persons specializing in this job	7 (4%)
Medications	103 (57%)
Surgery	6 (3%)
It resolves spontaneously	2 (1%)
Not sure	34 (19%)
Not applicable	30 (16%)
<b>Have you been to a person or heard about a person who removes worms through the nose?</b>	
Yes	56 (31%)
No	126 (69%)

six months later revealed that the benefits were not sustained.<sup>11</sup> Similarly, a survey in Peru demonstrated that the practice of allowing pigs to stray away from enclosures freely for feeding on human faeces is difficult to change because this practice saves pig-rearing peasants the expenditure incurred on procuring food material for the pigs.<sup>12</sup> The farmers optimize their profits by keeping investments to a minimum. Thus the driving force behind peasant's practices and attitudes to *T. solium* is economic benefit with total indifference to health, hygiene and safe practices.

In conclusion, this descriptive study demonstrates the prevailing state of knowledge about, attitudes towards and practices regarding the transmission and treatment of *T. solium* cysticercosis. Although, there is a high level of awareness of the relationship between helminths and epilepsy, there are misconceptions regarding the transmission and treatment of the disorder, which need to be corrected.

### Conflicts of interest

All authors have none to declare.

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