

*Full Length Research Paper*

# Public perception of epilepsy: A survey from the rural population in Northeastern Thailand

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Accepted 23 September, 2013

We conducted a survey to assess public awareness and attitudes towards epilepsy in five provinces of the Northeastern Thailand. A cross-sectional survey was conducted by using a face-to-face interview. There were 964 subjects who were randomly selected by a multistage sampling with a response rate of 86.9% (831 participants). There were 449 (60.0%), 102 (12.3%) and 127 (15.3%) participants who had heard of epilepsy, known someone with epilepsy, and witnessed a seizure, respectively. About 80 and 99% of the participants did not know the causes and types of epilepsy, respectively. More than half of the participants (58%) believed that epilepsy cannot be cured. The negative attitude rate ranged between 8 - 90%. The highest item was "persons with epilepsy cannot live in the society like other people." Age, gender, income, and provinces were significantly correlated with the negative attitudes. Six out of the ten questions regarding attitude toward epilepsy were significant correlated with knowledge. In conclusion, public perception of epilepsy is lacked and needs attention. Knowledge particularly regarding causes of epilepsy and attitudes toward epilepsy are closely related. Public education intervention is suggested to improve public attitudes of epilepsy.

**Key words:** Epilepsy, knowledge, attitudes, correlation.

## INTRODUCTION

Although knowledge, attitude and beliefs towards epilepsy have improved in most countries, there is still misperception about the disorder (Austin et al., 2002). Living in the society is more challenging than epilepsy itself (Austin et al., 2002). Fear and misunderstanding of epilepsy may lead to social stigma resulting social discrimination particularly in teenagers.

In Thailand, despite 1 - 2% of the population have epilepsy; it remains a mysterious disorder shrouded in myths and misunderstanding for most people. Persons with epilepsy face many interpersonal, emotional and social difficulties as in other countries. The rural areas of

the Northeastern, Thailand have unique cultures and tradition. In addition, beliefs and thoughts of people might be different from other areas in Thailand and the world. We therefore performed a survey to study the public knowledge and attitude towards epilepsy in these particular areas.

## MATERIALS AND METHODS

A cross sectional survey was conducted in 5 rural areas of 5 provinces in the Northeastern Thailand including Udon Thani, Khon Kaen, Chaiyaphum, Kalasin, and Maha Sarakham. A structural questionnaire was used to assess the public knowledge and attitude towards epilepsy.

## Instrumentation

The questionnaire was derived from literature reviews (Austin et al.,

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2002; Bener et al., 1998; Daoud et al., 2007; Demirci et al., 2007; Diamantopoulos et al., 2006; Fong and Hung, 2002; Hills and MacKenzie, 2002; Tuan et al., 2007) and some questions related to local belief were added. It assessed participants' demographic data, epilepsy familiarity, knowledge, and attitude. Epilepsy familiarity consisted of three questions including; "Have you heard of epilepsy?", "Do you know someone with epilepsy?", and "Have you ever witnessed a seizure?". There were 14 questions regarding knowledge of epilepsy concerning causes, treatments, and precipitation factors of epilepsy. In addition, 10 questions were asked about participants' attitude towards epilepsy. All questions regarding knowledge and attitude had two options; yes or no.

### Study population

The questionnaire was administered to 964 persons by multistage random sampling from September to November 2005. All participants were older than 18 years and gave an informed consent. This survey was a face-to-face interview at the participant's home. Ample time was allowed for completion of the questionnaire and the average time taken for a single interview ranged from 15 - 20 min.

### Data analysis

Analysis of the data was executed with descriptive statistics, and chi-square test with the STATA (version 9). Epilepsy familiarity, knowledge, and attitude data were correlated with demographic data. In addition, the association between knowledge and attitude was also performed. A probability value of less than 0.05 was considered significant.

## RESULTS

In this study a total of 831 subjects (86.9%) participated and completed the interview. The demographic data was presented in Table 1. The mean age (range) of subjects was 46.23 years (18 - 85). The majorities of the respondents were women (73%), had the education level of primary school (77.2%), and was farmers or employee (65%). The rest were businessman, government officials, retired, and students. The family income of 36,000, 36,001 - 100,000, >100,000 baht/year were categorized as low, average, and high income, respectively. There were 73.4% of participants with middle or high family income (Table 1).

### Epilepsy familiarity

There were 449 (60.0%), 102 (12.3%), and 127 (15.3%) participants who had heard of epilepsy, known someone with epilepsy, and witnessed a seizure, respectively. The sources of epilepsy knowledge were from health care personnels (35%), friends (31%), television (24%), books or magazines (10%), and radio (0.4%).

There were significant differences in numbers of participants who had heard of epilepsy by provinces ( $p = 0.001$ ), occupation ( $p = 0.018$ ), and family income ( $p =$

**Table 1.** General characteristics of study subjects (Total subjects = 831).

| Characteristics            | N (%)      |
|----------------------------|------------|
| <b>Age (years)</b>         |            |
| < 40                       | 273 (32.9) |
| 40 - 49                    | 222 (26.7) |
| 50 - 59                    | 197 (23.7) |
| 60                         | 139 (16.7) |
| <b>Gender</b>              |            |
| Male                       | 221 (27.0) |
| Female                     | 610 (73.0) |
| <b>Education</b>           |            |
| Primary school or lower    | 641 (77.2) |
| Secondary school or higher | 190 (22.8) |
| <b>Occupation</b>          |            |
| Unemployed                 | 101 (12.0) |
| Farmers or employee        | 539 (65.0) |
| Others                     | 191 (23.0) |
| <b>Provinces</b>           |            |
| Udon Thani                 | 101 (12.1) |
| Khon Kaen                  | 303 (36.5) |
| Chaiyaphum                 | 122 (14.7) |
| Kalasin                    | 131 (15.8) |
| Maha Sarakham              | 174 (20.9) |
| <b>Family income</b>       |            |
| Low                        | 221 (26.6) |
| Middle                     | 301 (36.2) |
| High                       | 309 (37.2) |

Note: Low, middle, and high family income defined by total family income equal, respectively

0.041). Gender and provincial differences were significantly correlated with variables "knows someone who had epilepsy" and "has witnessed a seizure" (Table 2). In addition, the oldest age group was more likely than other age groups to know someone with epilepsy ( $p = 0.038$ ) and farmers or employees had significantly witnessed a seizure.

### Knowledge about epilepsy

The knowledge about epilepsy was divided into four aspects as follows: causes, types, treatments, and precipitating factors (Table 3).

**Causes of epilepsy:** Almost 80% of the participants reported that they did not know what causes epilepsy. However, about 50% of participants believed that epilepsy is a brain disorder (Table 3). Participants with higher education or average income, and those who know someone with epilepsy were significantly associated with

**Table 2.** Significant factors correlated with epilepsy familiarity.

| Variables                          | N (%)      | p value |
|------------------------------------|------------|---------|
| <b>Had heard of epilepsy</b>       |            |         |
| <b>Provinces</b>                   |            | 0.001   |
| Udon Thani                         | 58 (54.7)  |         |
| Khon Kaen                          | 188 (62.1) |         |
| Chaiyaphum                         | 90 (73.8)  |         |
| Kalasin                            | 64 (48.9)  |         |
| Maha Sarakham                      | 99 (56.9)  |         |
| <b>Occupation</b>                  |            | 0.018   |
| Unemployed                         | 44 (43.6)  |         |
| Farmer or employee                 | 338 (62.7) |         |
| Others                             | 106 (55.5) |         |
| <b>Family income</b>               |            | 0.041   |
| Low                                | 120 (54.3) |         |
| Middle                             | 178 (59.1) |         |
| High                               | 201 (65.1) |         |
| <b>Knows someone with epilepsy</b> |            |         |
| <b>Gender</b>                      |            | <0.001  |
| Male                               | 12 (5.4)   |         |
| Female                             | 90 (14.8)  |         |
| <b>Age (years)</b>                 |            | 0.038   |
| < 40                               | 25 (9.2)   |         |
| 40-49                              | 32 (14.4)  |         |
| 50-59                              | 20 (10.1)  |         |
| ≥ 60                               | 25 (17.9)  |         |
| <b>Provinces</b>                   |            | <0.001  |
| Udon Thani                         | 12 (11.9)  |         |
| Khon Kaen                          | 26 (8.6)   |         |
| Chaiyaphum                         | 34 (27.9)  |         |
| Kalasin                            | 14 (10.7)  |         |
| Maha Sarakham                      | 16 (9.2)   |         |
| <b>Has witnessed a seizure</b>     |            |         |
| <b>Gender</b>                      |            | 0.01    |
| Male                               | 22 (10.0)  |         |
| Female                             | 105 (17.2) |         |
| <b>Occupation</b>                  |            | 0.03    |
| Unemployed                         | 15 (14.9)  |         |
| Farmer or employee                 | 94 (17.4)  |         |
| Others                             | 18 (9.4)   |         |
| <b>Provinces</b>                   |            | <0.001  |
| Udon Thani                         | 12 (11.9)  |         |
| Khon Kaen                          | 17 (5.6)   |         |
| Chaiyaphum                         | 54 (44.3)  |         |
| Kalasin                            | 25 (19.1)  |         |
| Maha Sarakham                      | 19 (10.9)  |         |

this response (p value = 0.001, <0.001 and = 0.001 respectively). Similarly, 54.9% of participants answered that epilepsy is a psychiatric disorder. This response was cor-

related with unemployment (p = 0.019). Participants with older age, lower education level, and low family income significantly thought that epilepsy is an infectious disease item (p = 0.003, 0.039 and 0.004 respectively). About 20 and 40% of participants believed that epilepsy is from evil or due to eating pork, respectively. The beliefs of evil or eating pork as causes of epilepsy were associated with unfamiliarity of epilepsy (p < 0.001 and p = 0.004). Approximately 43% of participants believed that epilepsy is an inherited disease. Though this belief had no association with any demographic variables, all other items regarding causes of epilepsy were found to be different among provinces.

**Types of epilepsy:** Almost all of participants (99%) declared that they were not able to identify type of epilepsy. In addition, 82% of participants perceived that epilepsy has only one type, which is generalized tonic-clonic seizure.

**Treatments of epilepsy:** More than half of the participants (58%) believed that epilepsy cannot be cured. This belief was associated with lower education level and unemployed status (p = 0.040, 0.032, respectively). Similarly, 56% of the participants responded that persons with epilepsy have to take antiepileptic medication lifelong. About one-fifth of the participant believed that epilepsy can be treated by a spiritual healer. Participants who believed that persons with epilepsy need to take medication forever or epilepsy can be treated by a spiritual healer were also heard about epilepsy (p < 0.001). The numbers of participants who responded to three questions regarding treatment of epilepsy were significantly different by participants' provinces (p < 0.001 for questions "epilepsy cannot be cured" and "person with epilepsy have to take antiepileptic medication lifelong" and p = 0.043 for question "epilepsy can be treated by a spiritual healer")

**Precipitating factors:** The three most common beliefs that precipitated seizure attacks were mental stress, hard-working job, and alcohol (Table 3). The participants who were unfamiliar with epilepsy significantly responded that sleep deprivation, alcohol consumption, and hard-working job were precipitating factors (p value = 0.001, 0.02 and 0.017 respectively). The participants with high family income also believed that alcohol consumption is a precipitating factor (p = 0.003). Farmers and employees reported that hard-working job is a significant precipitating factor for seizure attack (p = 0.049). Older age, low family income, and unfamiliarity with epilepsy were significantly associated with sexual activities as a precipitating factor for seizure (p value = 0.048, 0.007, and <0.001, respectively). Even though mental stress as a precipitating factor for seizure attack had the highest percentage, it was not correlated with any demographic variables.

**Table 3.** Responses regarding epilepsy knowledge in three aspects among 831 participants.

| Questions  | Yes, N (%) | No, N (%)  |
|--|------------|------------|
| <b>Causes</b>  |            |            |
| Epilepsy is a brain disorder   | 435 (52.4) | 396 (47.6) |
| Epilepsy is a psychiatric disorder   | 457 (54.9) | 374 (45.1) |
| Epilepsy is an inherited disorder  | 361 (43.4) | 470 (56.6) |
| Epilepsy is an infectious disease  | 199 (23.9) | 632 (76.1) |
| Epilepsy is caused by an evil  | 167 (19.9) | 664 (80.1) |
| Epilepsy is transmitted by eating pork                                       | 324 (38.9) | 507 (61.1) |
| <b>Treatment</b>   |            |            |
| Epilepsy can be cured  | 345 (41.5) | 486 (58.5) |
| <b>Persons with epilepsy need to take antiepileptic medications lifelong</b> |            |            |
| Epilepsy can be treated by a spiritual healer                                | 466 (56.0) | 365 (43.9) |
| What is/are precipitating factor (s) of epilepsy?                            | 167 (20.1) | 664 (79.9) |
| Sleep deprivation  | 458 (55.1) | 373 (44.9) |
| Mental stress  | 564 (67.9) | 267 (32.1) |
| Alcohol  | 513 (61.7) | 318 (38.3) |
| Hard-working job   | 531 (63.9) | 300 (36.1) |
| Sexual activity  | 242 (29.1) | 589 (70.9) |

### Attitude towards epilepsy

The negative attitude rate ranged between 8 - 90% (Table 4). The highest item was "persons with epilepsy cannot live in the society like other people". The second highest item was "epilepsy is a form of insanity" that was significantly related with lower education level ( $p = 0.011$ ). Participants who had lower income and never known persons with epilepsy were significantly related to the thought that persons with epilepsy have lower IQ ( $p$  value = 0.011, and 0.042, respectively). Nearly one third would not employ persons with epilepsy and this attitude was associated with the male sex ( $p = 0.017$ ), high family income ( $p = 0.003$ ) and provincial differences ( $p < 0.001$ ). More than 20% of respondents would not allow their son/daughter to marry an epileptic person and recommend children with epilepsy to study in a selected school. These two rejections were associated with unfamiliarity with epilepsy and provincial factor, respectively ( $p < 0.001$ , = 0.035, respectively). The participants who would not allow their children to play with an epileptic person were found 12.9% and related to older age ( $p = 0.003$ ) and low family income ( $p = 0.014$ ).

### The association of attitude and knowledge of epilepsy

The significant association of attitude and knowledge of epilepsy were shown in Table 5. Knowledge about causes of epilepsy was more related to attitude than other categories of knowledge; one item in treatment and another item in precipitating category. The rejection of

allowing their children to play or get married with persons with epilepsy was related to the perception that epilepsy is a psychiatric disorder or infectious disease. The epilepsy attitude of employed persons was also significantly correlated with knowledge regarding causes of epilepsy.

### DISCUSSION

Cross-cultural studies have shown that there is limited data on knowledge of epilepsy and the attitudes towards epilepsy can be varied (Gajjar et al., 2000; Lee et al., 2001). Some beliefs such as epilepsy are a neurological disease can lead to stigmatizing (Fatovic-Ferencic and Durrigi, 2001). Even though knowledge and attitudes have improved worldwide, there are differences among countries (Daoud et al., 2007).

Previous reports showed that knowledge about epilepsy was associated with age and education (Bener et al., 1998; Choi-Kwon et al., 2004; Kobau and Price, 2003). The level of knowledge regarding epilepsy was still inadequate even in medical students and teachers (Tiamkao et al., 2005; Tiamkao et al., 2007). We found differences among the provinces with respect to epilepsy familiarity, knowledge and attitudes. Moreover, knowledge regarding causes of epilepsy has drastically correlated with attitudes (Table 5).

Even though all study sites were in the Northeast, Thailand, there were significant differences in all three aspects of epilepsy familiarity by study provinces (Table 2). Regarding knowledge of epilepsy, only about half of participants answered the questions correctly in all categories (Table 3). Factors that correlated with knowledge

**Table 4.** Responses regarding epilepsy attitude among 831 participants, ordered by the most negative attitude item (bold numbers).

| Questions   | Yes, N (%) | No, N (%) |
|---|------------|-----------|
| Do you think persons with epilepsy can live in the society like other people?   | 83 (10.0)  | 748(90.0) |
| Do you think epilepsy is a form of insanity?  | 396 (47.7) | 435(59.3) |
| Is an average IQ of persons with epilepsy lower than normal population?   | 343 (41.3) | 488(58.7) |
| Do you agree that persons with epilepsy are dangerous persons?  | 338 (40.7) | 493(59.3) |
| Can women with epilepsy have their own children?  | 552 (66.5) | 279(33.5) |
| Do you think persons with epilepsy should be employed in the same jobs as other people?   | 571 (68.7) | 260(31.3) |
| Would you object to your son/daughter marrying a person who sometimes has seizure attack?   | 236 (28.4) | 595(71.6) |
| Should children with epilepsy study in a special school?  | 196 (23.6) | 635(76.4) |
| Would you object to your child playing with a person with epilepsy? If you or your family members have epilepsy, would you tell others? | 107 (12.9) | 724(87.1) |
|   | 765 (92.1) | 66(7.9)   |

**Table 5.** The significant correlation between attitude and knowledge among 831 participants.

| Attitudes   | p value |
|---|---------|
| Would you object to your child playing with a person with epilepsy?                       |         |
| Epilepsy is a psychiatric disorder  | 0.006   |
| Epilepsy is an infectious disease   | <0.001  |
| Sexual activity is a precipitating factor of epilepsy                                     | 0.002   |
| Would you object to your son/daughter marrying a person who sometimes has seizure attack? |         |
| Epilepsy is a psychiatric disorder  | 0.008   |
| Epilepsy is an infectious disease   | <0.001  |
| Sexual activity is a precipitating factor of epilepsy                                     | <0.001  |
| Should children with epilepsy study in a special school?                                  |         |
| Epilepsy is an inherited disorder   | 0.002   |
| Epilepsy is caused by an evil   | 0.005   |
| Epilepsy is transmitted by eating pork  | 0.005   |
| Is an average IQ of persons with epilepsy lower than normal population?                   |         |
| Epilepsy is an infectious disease   | 0.009   |
| Epilepsy can be cured   | 0.037   |
| Sexual activity is a precipitating factor of epilepsy                                     | 0.002   |
| Do you think epilepsy is a form of insanity?  |         |
| Epilepsy is a brain disorder  | 0.005   |
| Epilepsy is an inherited disorder   | <0.001  |
| Epilepsy is caused by an evil   | <0.001  |
| Epilepsy is transmitted by eating pork  | <0.001  |
| Epilepsy can be cured   | 0.021   |
| Do you think persons with epilepsy should be employed in the same jobs as other people?   |         |
| Epilepsy is a brain disorder  | 0.002   |
| Epilepsy is a psychiatric disorder  | 0.004   |
| Epilepsy is caused by an evil   | 0.001   |
| Epilepsy is transmitted by eating pork  | 0.001   |
| Sexual activity is a precipitating factor of epilepsy                                     | <0.001  |

ledge of epilepsy were age, education level, family income, epilepsy familiarity, and provincial differences.

Generally, the knowledge level in our participants was lower than other reports from Asian countries (Bener et

al., 1998; Choi-Kwon et al., 2004; Chung et al., 1995; Daoud et al., 2007; Demirci et al., 2007). Even though factors that correlated to knowledge of epilepsy were quite similar to previous reports, we added that living areas were also associated knowledge level.

Regarding attitudes towards epilepsy, 90% of participants believed that persons with epilepsy cannot live in the society like healthy people do. This attitude implied that epilepsy is a serious disease. While 9.3% of participants in Jordan reported that persons with epilepsy were insane (Daoud et al., 2007), the number in our study was surprisingly high at 45%. Gender, age, family income, epilepsy familiarity, and provinces were associated with the negative attitudes towards epilepsy. Compare to previous reports in Asia, our negative attitudes towards epilepsy rates were quite higher. This might be due to the sensitive personality of people in these areas.

Our analyses showed that participants' attitudes were significantly related to their knowledge about epilepsy; mostly causes of epilepsy. These findings may indicate that knowledge about causes of epilepsy is the main factor affecting participants' attitudes. Educational program, focusing on causes of epilepsy, may be helpful to improve public attitudes about epilepsy.

In conclusion, public perception of epilepsy is lacked and needs attention. Knowledge particularly regarding causes of epilepsy and attitudes toward epilepsy are closely related. Public education intervention is suggested to improve public attitudes of epilepsy.

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