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# Public awareness, attitudes and understanding towards epilepsy in Kelantan, Malaysia

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*Abstract*

This is a survey on the public awareness, attitudes and knowledge toward epilepsy in Kota Bahru, Kelantan, Malaysia. Kelantan is a rural state with predominantly Malay population. The survey was based on a questionnaire conducted as one-to-one interview by medical students in the public places. There were 839 respondents, the mean age was 27 years, 65% were married. Sixty-eight percent had received secondary education or above. The respondents have high awareness of epilepsy, with 91% having heard or knew about epilepsy and 56% knew an epileptic person. The attitude towards epilepsy is more negative than similar studies done earlier among Malaysian Chinese. Twenty percent objected to their children associating with a person who sometimes had seizures, 48% objected to their children marrying someone who sometimes had seizures, and 58% thought that people with epilepsy should not be employed in jobs like other people. Only 30% identified epilepsy as a brain disease or disorder, and 69% identified hereditary as the cause. The respondents were not familiar with nonconvulsive form of epilepsy with only 18% identified transient change of behavior, and 16% identified loss of memory as manifestations of epilepsy. As for treatment, 52% advocated prayer, 44% asked for a alternative medicine practitioner, and 9% thought that epilepsy need not be treated or was untreatable. In *conclusion,* the survey of a predominantly Malay population in Malaysia showed that the respondents were familiar with epilepsy, but many maintained a negative attitude and had poor knowledge on causation and treatment of epilepsy.

*Key Words:* Epilepsy, awareness, attitudes, Kelantan, Malaysia

## INTRODUCTION

The public awareness and understanding of a medical illness is crucial in the prophylaxis, early treatment, and compliance of the modern therapy in a community. In epilepsy, the lack of it probably contributes to the high treatment gap seen in many developing countries.[1,2] The related phenomenon is that the patients may exhaust their limited resources in non-evidence based alternative therapies. The public awareness and understanding may also be important in the formulation of public health policy and allocation of fund. An accurate knowledge of the public attitude to epilepsy is also important as misconception and social misunderstanding may affect the quality of life of the patients more than the seizures itself.

In the recent years, surveys to assess the awareness, understanding and epilepsy have been done among the public in some of the Asian countries, including China[3], Taiwan[4], India[5,6], Malaysia[7], Singapore[8], among the school teachers in Thailand[9] and patients in Pakistan.[10] These studies generally showed a similar level of awareness, but more negative attitudes towards epilepsy when compared to the developing countries in the West. The previous Malaysian study was done among ethnic Chinese in an urban and rural area around Kuala Lumpur. As Malaysia is a multi-racial country where ethnic Chinese constitutes 25% of the population, it is important to extend the study to other population groups. This is the report of a survey done in Kota Bahru, Kelantan, in Peninsular Malaysia whose residents are predominantly Malays.

## METHODS

The study was performed in Kota Bharu, the capital of Kelantan state. The study consisted of a survey using a standard questionnaire of ten questions. To facilitate comparison, the questionnaire was similar to that used in the Gallup Poll[11] and the previous studies in China[3], Taiwan[4], Singapore[8] and Malaysia.[7] The

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questionnaire was translated into Malay. The survey was conducted as a one-to-one interview by medical students after a period of training. The interviewers were encouraged not to lead or coax the respondents in their answers and only explain the questions when it was necessary to clarify the points. The respondents were randomly selected at public places such as shopping complexes, hospitals and town halls. Subjects who were 13 years or above willing to participate in the questionnaire were recruited.

The data was analyzed using the SPSS version 6.0 with descriptive statistics and the level of significance was set at $p<0.05$.

## RESULTS

Eight hundred and thirty nine subjects participated in the survey. The mean age was 27 years. The male to female sex ratio was 1 : 1.6. The predominant languages spoken were: Malay (81%), Chinese (6.0%), Tamil (0.6%), English (4.3%) and Others (8.0%). Most of the subjects were married (65%), the remaining were single (33%) and divorced or separated (2%). For the married subjects, the number of children was: none (12.5%), 1-2 children (24%), 3-5 children (42%), 6-10 children (19%) and 11-12 children (1.7%). The distribution of the occupation was: secondary students (34%), traders (14%), teachers (6%), government servants (6%), medical students (4.5%), farmers (1.5%), fishermen (1.5%), factory workers (1.5%) and others (30%). The level of education was: secondary education (68%), university education (12%), primary education (6%), and no formal education (14%). The residence of the respondents was: in or around the town (74%), rural areas (16%) and unknown (9%).

### *Familiarity with epilepsy*

The responses to the questions related to familiarity with epilepsy are listed in Table 1. Ninety-one percent had heard or knew about epilepsy, 56% knew an epileptic person and 33% had witnessed an attack of epilepsy. Significantly greater number of respondents younger than 50 years and those with secondary or tertiary education have heard or read of epilepsy. Significantly greater number of those older than 50 years, the married and respondents with greater than three children have known someone with epilepsy. Significantly greater number of those older than 50 years and the married have witnessed an epileptic attack.

### *Attitudes towards epilepsy*

The responses to questions related to attitudes towards epilepsy are listed in Table 2. Twenty percent of the respondents objected to the possibility that their children might be playing with an epileptic. The objection was significantly higher among the respondents older than 50 years of age but less among those with tertiary education. Forty-eight percent objected to their children marrying a person who sometimes have seizure. The objection was significantly higher among those with tertiary education and those from the urban area. Fifty-eight percent of the respondents thought that people with epilepsy cannot be employed in jobs like other people. The attitude was significantly more favourable among those from the town area. Twenty-three percent of the respondents believed that epilepsy was a form of insanity.

### *Understanding of epilepsy*

The understanding of epilepsy elucidated was in the area of knowledge of its cause, presentation and treatment. The responses are as listed in Tables 3-5.

## DISCUSSION

This study was done in Kota Bharu, the state capital of Kelantan. Kelantan is located at the North Eastern part of Peninsular Malaysia. The state has a population of one and half million. Kota Bahru itself has 400,000 population. Ninety-five percent of the Kelantan population are Malays. Ethnic Chinese, Thais and Indians constitute the rest of the population. Whereas the urban and rural population are equally divided in Malaysia, two third of the population in Kelantan is rural. When compared with the states in the west coast of Peninsular Malaysia, the economy in Kelantan is also less developed. The study subjects in this study is thus representative of the town population from a rural Malay state in Malaysia.

The responses to questions related to familiarity with epilepsy show that the study population has high awareness of epilepsy. The high positive response rate of 91% for having heard or read about epilepsy is similar to the other Asian studies.[3-8] As for the question of whether the respondent has witnessed someone with a seizure, the positive rate was 33%. The corresponding figure in Henan, China was 72%. The disproportionately higher awareness in the Chinese population was attributed to the

**TABLE 1: Responses to questions related to familiarity with epilepsy**

| | No. of response | Q1 | | Q2 | | Q3 | |
|---|---|---|---|---|---|---|---|
| | | Yes % | No % | Yes % | No % | Yes % | No % |
| Total | 839 | 91 | 9 | 56 | 44 | 33 | 67 |
| Age of respondents (years) | | | | | | | |
| 13-29 | 565 | 91 | 9 | 52 | 48 | 30 | 70 |
| 30-49 | 181 | 91 | 6 | 61 | 39 | 37 | 63 |
| ≥50 | 93 | 84 | 16 | 68 | 32 | 47 | 53 |
| Sex of respondents | | | | | | | |
| Male | 320 | 90 | 10 | 57 | 43 | 33 | 67 |
| Female | 519 | 92 | 8 | 55 | 45 | 33 | 67 |
| Marital status | | | | | | | |
| Never married | 544 | 92 | 8 | 53 | 47 | 31 | 69 |
| Married[a] | 295 | 90 | 10 | 61 | 39 | 39 | 61 |
| No. of children | | | | | | | |
| 0 | 569 | 92 | 8 | 54 | 46 | 31 | 69 |
| 1-2 | 182 | 88 | 12 | 52 | 48 | 32 | 68 |
| ≥3 | 191 | 91 | 9 | 66 | 34 | 41 | 59 |
| Education level | | | | | | | |
| Primary[b] | 76 | 73 | 27 | 64 | 36 | 37 | 63 |
| Secondary | 567 | 91 | 9 | 51 | 49 | 29 | 71 |
| Tertiary | 196 | 95 | 5 | 67 | 33 | 45 | 55 |
| Residence | | | | | | | |
| Urban[c] | 625 | 91 | 9 | 59 | 41 | 33 | 67 |
| Rural | 213 | 91 | 9 | 47 | 53 | 32 | 68 |
| Occupation | | | | | | | |
| Students | 282 | 91 | 9 | 50 | 50 | 32 | 68 |
| Traders, medical students, teachers[d] | 252 | 92 | 8 | 72 | 28 | 40 | 60 |
| Farmers[e] | 52 | 93 | 7 | 50 | 50 | 40 | 60 |
| Others | 253 | 92 | 8 | 48 | 52 | 26 | 74 |

Three questions were asked. Q1: Have you ever heard of or read about the disease called 'epilepsy' or convulsive seizures (fits)? Q2: Did you ever know anyone who had epilepsy? Q3: Have you ever seen anyone having a seizure?

[a] Married include widow, widowers and divorcees

[b] Include those with no formal education

[c] Urban includes town and perimeter of town

[d] Include other government workers

[e] Include factory workers

**TABLE 2: Responses to questions about attitudes towards epilepsy**

| | No. of response | Q4 | | Q5 | | Q6 | | Q7 | |
|---|---|---|---|---|---|---|---|---|---|
| | | Yes % | No % | Yes % | No % | Yes % | No % | Yes % | No % |
| Total | 839 | 20 | 80 | 48 | 52 | 42 | 58 | 23 | 77 |
| Age of respondents (years) | | | | | | | | | |
| 13-29 | 565 | 20 | 80 | 50 | 50 | 42 | 58 | 25 | 75 |
| 30-49 | 181 | 17 | 83 | 45 | 55 | 44 | 56 | 17 | 83 |
| ≥50 | 93 | 30 | 70 | 34 | 66 | 38 | 62 | 21 | 79 |
| Sex of respondents | | | | | | | | | |
| Male | 320 | 21 | 79 | 45 | 55 | 40 | 60 | 16 | 84 |
| Female | 519 | 20 | 80 | 50 | 50 | 43 | 57 | 26 | 74 |
| Marital status | | | | | | | | | |
| Never married | 544 | 20 | 80 | 49 | 51 | 40 | 60 | 21 | 79 |
| Married[a] | 295 | 21 | 79 | 47 | 53 | 43 | 57 | 23 | 77 |
| No. of children | | | | | | | | | |
| 0 | 569 | 19 | 81 | 49 | 51 | 42 | 58 | 24 | 76 |
| 1-2 | 182 | 20 | 80 | 52 | 48 | 38 | 62 | 27 | 73 |
| ≥3 | 56 | 21 | 79 | 43 | 57 | 42 | 58 | 17 | 83 |
| Education level | | | | | | | | | |
| Primary[b] | 76 | 39 | 61 | 37 | 63 | 44 | 56 | 21 | 78 |
| Secondary | 567 | 19 | 81 | 47 | 53 | 40 | 60 | 22 | 77 |
| Tertiary | 196 | 16 | 84 | 59 | 41 | 48 | 52 | 24 | 76 |
| Residence | | | | | | | | | |
| Urban[c] | 625 | 21 | 79 | 54 | 46 | 44 | 56 | 24 | 76 |
| Rural | 214 | 16 | 84 | 31 | 69 | 34 | 66 | 21 | 79 |
| Occupation | | | | | | | | | |
| Students | 282 | 20 | 80 | 55 | 45 | 43 | 57 | 26 | 74 |
| Traders, medical students, teachers[d] | 252 | 23 | 77 | 53 | 47 | 48 | 52 | 22 | 78 |
| Farmers[e] | 52 | 20 | 80 | 55 | 45 | 40 | 60 | 22 | 78 |
| Others | 233 | 17 | 83 | 39 | 61 | 35 | 65 | 22 | 78 |

Four questions were asked. Q4: Would you object to having any of your children in school or at play associate with a person who sometimes had seizures (fits)? Q5: Would you object to having a son or daughter of yours marrying a person who sometimes had seizures? Q6: Do you think people with epilepsy should or should not be employed in jobs like other people? Q7: Do you think epilepsy is a form of insanity or not?

[a] Married include widow, widowers and divorcees

[b] Include those with no formal education

[c] Urban includes town and perimeter of town

[d] Include other government workers

[e] Include factory workers

**Table 3: Responses to the question: "what do you think is the cause of epilepsy?"**

| Responses | Percentage positive |
|---|---|
| Hereditary | 69 |
| Brain disease or disorder | 30 |
| Mental or emotional disorder | 24 |
| Don't know | 17 |
| Birth defect | 13 |
| Blood disorder | 6 |
| Unsure of answer | 5 |
| Others | 2 |

**Table 4: Responses to the question: "What do you think an epileptic attack is?**

| Responses | Percentage positive |
|---|---|
| Shaking, convulsion | 81 |
| Loss of consciousness | 62 |
| Transient changes of behavior | 18 |
| Loss of memory | 16 |
| Unsure of answer | 7 |

**Table 5: Response to the question: "If your relatives or friends had epilepsy, what kind of treatment would you suggest?"**

| Responses | Percentage positive |
|---|---|
| Ask for a medical doctor | 78 |
| Ask for God's help | 52 |
| Ask for a alternative medicine practitioner | 44 |
| "Dan Fang" and other folk medicine | 16 |
| Acupuncture | 8 |
| No need to treat | 7 |
| Don't know what to recommend | 5 |
| Ask for a witch doctor | 3 |
| Think "epilepsy is untreatable" | 2 |

overpopulated condition and closer interpersonal relationships in Henan.[3]

As for the questions on attitudes towards epilepsy, the responses were less negative than similar studies in China, but more negative than that of previous studies among Chinese in Malaysia. This is particularly so for those who had lower level of education. Twenty percent would object to their children in school or at play associate with a person with seizure, the corresponding figure was 57% in China[3] and 9% among Malaysian Chinese.[7] Fifty-eight percent of the respondents thought that people with epilepsy should not be employed in jobs like others. The corresponding figure was 53% in China[3] but 14% amongst Malaysian Chinese.[7] Forty-eight percent objected to their children marrying a person who sometimes had seizures. The corresponding figure was 87% in China[3] and 43% among the Malaysian Chinese.[7] The objection to marriage was unusual in that it was more evident among those with tertiary education and the urban residence.

Less than a third were able to attribute epilepsy to a disorder or disease of the brain. This is similar to other Asian studies.[3,4,7,8] As in the other Asian studies, there was poor awareness of the non-convulsive form of epilepsy with less than a fifth able to identify "transient changes of behavior" and "loss of memory" as manifestations of epileptic seizure.[3,4,7,8]

The strong emphasis on prayer to supplement

other treatment reflected the highly religious character of the respondents who were predominantly Muslims. In contrast, only 1% of the Malaysian Chinese would invoke the help of God.[7] Forty-four percent of the respondents would recommend alternative medicine practitioner for treatment. This is again higher than the Malaysian Chinese where 11% recommended herbal medicine doctor.[7] Nine percent of the respondents thought that epilepsy was untreatable or there was no need to treat epilepsy. Such a negative attitude to treatment of epilepsy is consistent the previous report of children with epilepsy in Kelantan, where 20% did not receive any form of schooling, although primary schooling is free in Malaysia.[12] In a study on epilepsy awareness among school teachers in Thailand, 47% believed that epilepsy was a chronic incurable disease, and 15% preferred to place all children in a special classroom.[9] Whether the children with epilepsy would continue in school probably depends on the attitude and knowledge of the school teachers as well as the parents. The negative attitude and poor knowledge on epilepsy as shown in this survey is also consistent with the previous report of high treatment gap in the rural part of Malaysia.[2]

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