

## **Survey of public awareness, understanding, and attitudes toward epilepsy among Chinese in Malaysia**

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### **Abstract**

A survey of public awareness and understanding of and attitudes toward epilepsy among Chinese in Malaysia was made in Petaling Jaya (urban), Karak and Bentong (rural), Malaysia in 1998. In a population sample of 379 adults, 99% had read or heard about epilepsy, 38% knew someone had epilepsy, 62% seen an epileptic attack, indicating a high awareness of epilepsy. Nine percent would object their children associated with persons with epilepsy, 43% would object to their children marrying a person with epilepsy, 87% believed that epileptic persons should be employed in jobs as other persons are, 9% believed that epilepsy is a form of insanity. The attitudes toward epilepsy were more favourable than those detected in similar surveys conducted in Henan, China and Taiwan. The open socio-economic system and greater Western cultural influence in Malaysia might have helped to reduce the discrimination against epilepsy. Although 84% identified convulsion as indicative of an epileptic attack, only 35% identified loss of consciousness, 12% identified transient change of behaviour and 10% identified period of amnesia as indicative of epilepsy. The Malaysian Chinese was thus unfamiliar with nonconvulsive form of epilepsy. Although 80% would recommend an MD; versus only 11% who would recommend a herbal doctor and 2% acupuncture to friends and relatives who have epilepsy, it may not reflect the actual health seeking behaviour of the epilepsy patients with chronic illness. This interview based survey with medical students as interviewers may have biased the answers towards less discrimination and greater preference for modern scientific medicine.

**Key words:** Epilepsy, awareness, attitudes, Chinese, Malaysia

### **INTRODUCTION**

It is believed that misconception and social discrimination may affect the quality of life in epilepsy patients more than the epilepsy itself. Thus, knowing the degree of awareness and attitudes toward epilepsy in a society is important in the goal of striving for better life for the epilepsy patient.

Public awareness and attitude toward epilepsy is variable in different cultures and communities.<sup>1-7</sup> The awareness and attitudes among Chinese have been studied by Lai et al<sup>6</sup> in Henan, China and Chung et al<sup>7</sup> in Taiwan. Lai et al<sup>6</sup> and Chung et al<sup>7</sup> has found that the Chinese in both Henan and Taiwan were aware of epilepsy with understanding comparable to studies in other countries. However, the attitudes towards epilepsy was much more negative in Henan<sup>1</sup>, and less so in Taiwan.<sup>7</sup> Chung et al attributed the difference to greater exposure to Western culture and the different socio-economic system in Taiwan.<sup>7</sup> Chinese constitutes 25% of the Malaysian population. Greater than 80% of the Chinese receives primary education with the

medium of instruction in Chinese. Thus the Malaysian Chinese maintains a strong link to Chinese culture. On the other hand, Malaysia is a multi-racial country with long history of British colonial rule. It is also an open country where external trade constitute an important part of the economy. The strong Western cultural influence is evident in the dominant role of English among the professionals and in big business. There may be thus less negative attitudes towards epilepsy among the Malaysians. However, Menon et al has shown that there existed a large treatment gap of epilepsy particularly among the rural Malaysians attributed mainly to the social-cultural factors suggesting a negative attitude to epilepsy.<sup>8,9</sup> The aims of this study were (a) to determine the public awareness, attitudes and understanding toward epilepsy among a city and rural population among Malaysian Chinese; (b) to correlate the respondents' awareness, attitudes and understanding toward epilepsy with their social background. To facilitate international comparison, the method used in this survey closely mirrored that by Lai et al, Chung et al and others.<sup>1,2</sup>

## MATERIALS AND METHODS

The study consisted of a survey in three areas representing the city and rural populations. The city population surveyed was Petaling Jaya, a suburb west of the capital city of Kuala Lumpur. The rural populations surveyed were Karak and Bentong, which were in the State of Pahang east to Kuala Lumpur. The survey in Petaling Jaya was conducted in streets, shopping malls and markets. The surveys in Karak and Bentong were conducted in streets, market and door-to-door visits.

The survey consisted of 10 questions as shown in Tables 1-5. Both the English and Chinese questionnaires were identical to those used in the previous study in Henan by Lai et al.<sup>6</sup> and Taiwan by Chung et al.<sup>7</sup> The first eight questions originated from the Gallup Poll of public attitudes toward epilepsy<sup>1</sup> and the last two were developed by Lai et al.<sup>6</sup>

The survey was conducted in April and May 1998. The survey team consisted a group of medical students after training by a neurologist. The survey was conducted in one-to-one interview. Languages used in the interview were either Chinese (Mandarin, Cantonese or Hokkien) or English, depending on whichever the language the respondents felt most comfortable. Sometimes, the questions had to be explained when the respondents were unable to understand, but any hint or suggestion was strictly avoided. Persons with epilepsy or epilepsy in their immediate families were excluded. No two respondents were from the same family.

Analysis was done with a common software package. Chi-square tests were used to examine the association and alpha was set at 0.05 to determine the statistical significance. Non committal answers, such as "not familiar with", "not sure", and/or "not applicable" were excluded from the analysis.

## RESULTS

In all, 379 subjects were surveyed, 205 males and 174 females. Among them, 175 were from the urban (Petaling Jaya) and 204 from the rural area (Bentong and Karak). The responses to the survey questions are shown in Tables 1-5. For the purpose of presentation, the survey questions were divided into three categories, i.e. familiarity with epilepsy (questions 1-3), attitudes toward epilepsy (questions 4-7) and understanding of epilepsy (questions 8-10).

### *Familiarity with epilepsy*

The responses to the questions related to familiarity with epilepsy are listed in Table 1. Ninety-nine percent of respondents had read about or heard of epilepsy, 38% knew someone who had epilepsy and 62% had seen someone having a seizure. Older people, married people, those who have more children, lower education level, medical professionals and those who stayed in rural area tended to have a better awareness of epilepsy. Sex did not have a significant association with the familiarity with epilepsy.

### *Attitudes (prejudice) toward epilepsy*

The responses to questions related to attitudes towards epilepsy are listed in Table 2. Nine percentage of the respondents objected to have any of their children associate with epileptic persons in school or at play. This was directly associated with lower education level and housewife. Forty-three percent of respondents objected to their children marrying an epileptic person. This negative attitude was directly associated with older generation, female, married people, those who have more children and those stayed in rural area. Fourteen percent believed that epileptic persons should not be employed in jobs as other persons are. This attitude was directly associated with male, single and lower education level. Nine percent considered epilepsy as a form of insanity and this was associated with young age, male, single, lower education level, labourer and living in rural area.

### *Understanding of epilepsy*

The understanding of epilepsy elucidated were in the area of knowledge of its cause, its clinical presentation, and its treatment. Twenty-six percent of the respondents did not know the cause of epilepsy, 25% believed that epilepsy was a hereditary disease, 24% believed that epilepsy was a birth defect and 12% believed that epilepsy was caused by brain disorder. Eight percent gave a miscellaneous answer. Among the answers were eating goat meat during pregnancy, hot day and fever (Table 3).

As for clinical presentation of epilepsy, 7% did not know what an epileptic attack was like. Eighty-four percent considered convulsions and shaking movements and 35% chose loss of consciousness as the typical manifestation of an epileptic attack. Only 12% considered "transient changes of behaviour" and 10% considered



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

| Results                         | No of Responses | Q 1   |      | Q 2   |      | Q 3   |      |
|---------------------------------|-----------------|-------|------|-------|------|-------|------|
|                                 |                 | Yes % | No % | Yes % | No % | Yes % | No % |
| Total                           | 379             | 99    | 1    | 38    | 62   | 62    | 38   |
| Age of respondent (yr)          |                 |       |      |       |      |       |      |
| 15-29                           | 93              | 99    | 1    | 17    | 83   | 45    | 55   |
| 30-49                           | 154             | 100   | 0    | 41    | 59   | 60    | 40   |
| ≥50                             | 132             | 99    | 1    | 51    | 49   | 78    | 22   |
| Sex of respondent               |                 |       |      |       |      |       |      |
| M                               | 205             | 99    | 1    | 35    | 65   | 64    | 36   |
| F                               | 174             | 99    | 1    | 43    | 57   | 60    | 40   |
| Marital Status                  |                 |       |      |       |      |       |      |
| Never married                   | 123             | 98    | 2    | 28    | 72   | 56    | 44   |
| Married <sup>a</sup>            | 255             | 99    | 1    | 44    | 56   | 65    | 35   |
| No. of offspring                |                 |       |      |       |      |       |      |
| 0                               | 134             | 99    | 1    | 30    | 70   | 57    | 43   |
| 1-2                             | 85              | 99    | 1    | 33    | 67   | 54    | 46   |
| ≥3                              | 160             | 99    | 1    | 48    | 52   | 71    | 29   |
| Education of respondent         |                 |       |      |       |      |       |      |
| Never went to school            | 32              | 100   | 0    | 66    | 34   | 88    | 12   |
| Primary                         | 104             | 99    | 1    | 47    | 53   | 70    | 30   |
| Secondary                       | 159             | 98    | 2    | 34    | 66   | 58    | 42   |
| Tertiary                        | 84              | 100   | 0    | 25    | 75   | 50    | 50   |
| Occupation                      |                 |       |      |       |      |       |      |
| Medical profession <sup>b</sup> | 4               | 100   | 0    | 75    | 25   | 100   | 0    |
| Students <sup>c</sup>           | 41              | 99    | 1    | 10    | 90   | 49    | 51   |
| Labourer                        | 64              | 99    | 1    | 52    | 48   | 75    | 25   |
| Business man                    | 131             | 99    | 1    | 39    | 61   | 60    | 40   |
| Other profession                | 67              | 100   | 0    | 37    | 63   | 60    | 40   |
| Housewife                       | 52              | 100   | 0    | 42    | 58   | 62    | 38   |
| Residence                       |                 |       |      |       |      |       |      |
| Urban                           | 175             | 98    | 2    | 31    | 69   | 54    | 46   |
| Rural                           | 204             | 100   | 0    | 44    | 56   | 70    | 30   |

Three questions were asked. Q1: Have you ever heard of or read about the disease called "epilepsy" or convulsion seizures (fits)? Q2: Did you ever know anyone who had epilepsy? Q3: Have you ever seen anyone having a seizure? The total of "yes" plus "no" plus "not sure" equal 100%.

<sup>a</sup> Married, including a few divorced persons, widows and widowers.

<sup>b</sup> Medical profession, including physicians, nurses, and medical students.

<sup>c</sup> All students except medical students.

"period of amnesia" as manifestations of epilepsy (Table 4).

As for the treatment of epilepsy, 9% did not know what to recommend if their friends or relatives had epilepsy, 80% believed that epilepsy should be treated by a medical doctor. 11% chose herbal medicine, 4% considered epilepsy untreatable and 2% preferred the use of acupuncture (Table 5).

## DISCUSSION

The percentages of respondents who had heard or read about epilepsy, knew someone who have epilepsy, and had seen someone having a seizure in this study were 99, 38 and 62 respectively. The responses to the three questions related to familiarity with epilepsy were generally in the same range as previous studies conducted elsewhere, showing a high awareness of epilepsy

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

| Results                         | No of Responses | Q 4   |      | Q 5   |      | Q 6   |      | Q 7   |      |
|---------------------------------|-----------------|-------|------|-------|------|-------|------|-------|------|
|                                 |                 | Yes % | No % | Yes % | No % | Yes % | No % | Yes % | No % |
| Total                           | 379             | 9     | 85   | 43    | 38   | 82    | 14   | 9     | 79   |
| Age of respondent (yr)          |                 |       |      |       |      |       |      |       |      |
| 15-29                           | 93              | 8     | 81   | 37    | 41   | 79    | 13   | 12    | 84   |
| 30-49                           | 154             | 11    | 79   | 42    | 35   | 80    | 15   | 10    | 77   |
| ≥50                             | 132             | 10    | 84   | 49    | 39   | 81    | 14   | 8     | 77   |
| Sex of respondent               |                 |       |      |       |      |       |      |       |      |
| M                               | 205             | 8     | 85   | 41    | 40   | 80    | 16   | 11    | 78   |
| F                               | 174             | 10    | 85   | 45    | 27   | 82    | 13   | 8     | 79   |
| Marital Status                  |                 |       |      |       |      |       |      |       |      |
| Never married                   | 123             | 11    | 83   | 31    | 42   | 79    | 17   | 11    | 83   |
| Married <sup>a</sup>            | 255             | 8     | 86   | 49    | 36   | 81    | 13   | 9     | 76   |
| No. of offspring                |                 |       |      |       |      |       |      |       |      |
| 0                               | 134             | 9     | 84   | 30    | 43   | 81    | 15   | 10    | 83   |
| 1-2                             | 85              | 9     | 86   | 47    | 34   | 81    | 12   | 2     | 84   |
| ≥3                              | 160             | 9     | 86   | 52    | 35   | 80    | 15   | 13    | 73   |
| Education of respondent         |                 |       |      |       |      |       |      |       |      |
| Never went to school            | 32              | 6     | 84   | 41    | 41   | 72    | 19   | 16    | 60   |
| Primary                         | 104             | 14    | 80   | 48    | 38   | 78    | 15   | 9     | 71   |
| Secondary                       | 159             | 6     | 87   | 45    | 36   | 82    | 14   | 11    | 81   |
| Tertiary                        | 84              | 10    | 87   | 33    | 39   | 83    | 12   | 5     | 89   |
| Occupation                      |                 |       |      |       |      |       |      |       |      |
| Medical profession <sup>b</sup> | 4               | 0     | 100  | 0     | 25   | 75    | 0    | 0     | 100  |
| Students <sup>c</sup>           | 41              | 12    | 85   | 32    | 41   | 83    | 12   | 10    | 90   |
| Labourer                        | 64              | 9     | 83   | 45    | 36   | 81    | 16   | 14    | 66   |
| Business man                    | 131             | 9     | 82   | 41    | 40   | 79    | 15   | 8     | 80   |
| Other profession                | 67              | 6     | 91   | 48    | 39   | 87    | 9    | 6     | 80   |
| Housewife                       | 52              | 12    | 87   | 48    | 38   | 83    | 13   | 10    | 85   |
| Residence                       |                 |       |      |       |      |       |      |       |      |
| Urban                           | 175             | 9     | 87   | 38    | 41   | 81    | 15   | 8     | 86   |
| Rural                           | 204             | 9     | 84   | 47    | 35   | 80    | 13   | 11    | 72   |

Four questions were asked. Q4: Would you object to having any of your children in school or at play associate with persons 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? The total of "yes" plus "no" plus "not sure" equal 100%.

<sup>a</sup> Married, including a few divorced persons, widows and widowers.

<sup>b</sup> Medical profession, including physicians, nurses, and medical students.

<sup>c</sup> All students except medical students.

among Malaysian Chinese. For the question on having heard or read about epilepsy, the range of responses was from 73% in Italy<sup>4</sup> to 97% in Denmark.<sup>5</sup> For the question on knowing someone who have epilepsy, the range of responses was from 49% in Finland<sup>3</sup> to 77% in China.<sup>6</sup> For the question on having seen someone having a seizure, the range of response was from 45% in Finland<sup>3</sup> to 72% in China.<sup>6</sup> Lai et al attributed

the relatively high degree of awareness of epilepsy among the Chinese in Henan to overpopulated condition and close interpersonal relationship.<sup>6</sup> In the present study, there is an association between rural living, lower level of education with knowing someone who have epilepsy. The association could also be due to a more closely knit community in the rural area and those receiving less formal education.

**TABLE 3: Responses to the questions: "What do you think is the cause of epilepsy?"<sup>a</sup>**

| Results                              | %  |
|--------------------------------------|----|
| Don't know                           | 26 |
| Hereditary, inherited disease        | 25 |
| Birth defect                         | 24 |
| Brain disease, disorder, injury      | 12 |
| Mental or emotional stress, disorder | 8  |
| Blood, blood disorder                | 2  |
| Miscellaneous                        | 8  |
| Not familiar with epilepsy           | 12 |

<sup>a</sup>Number of respondents = 379; multiple answers were allowed.

The attitudes toward epilepsy among the Malaysia Chinese was generally more favourable when compared to Henan in China and also to Taiwan. The percentages of respondents who objected to their children playing with, children marrying to, employment and who considered epilepsy a form of insanity were 9, 43, 14 and 9 respectively. The corresponding figures in Henan, China were 57, 87, 53 and 16 and 18, 72, 31 and 7 in Taiwan.<sup>6,7</sup> The favourable attitude could be due to greater openness in the socio-economic system as compared to China, and greater Western cultural influence as compared to China and Taiwan. However, the 43% that objected to their children marrying an epileptic person was still less favourable to the corresponding response of 18% from USA in 1979. Iivanainen et al<sup>3</sup> reported that people tended to answer differently to face-to-face interviews than in self-administered questionnaires. The face-to-face interview tended to produce more socially acceptable answers and could have underestimated the degree of

**TABLE 4: Responses to the questions: "What do you think an epileptic attack is?"<sup>a</sup>**

| Results                        | %  |
|--------------------------------|----|
| Convulsions, shaking           | 84 |
| Loss of consciousness          | 35 |
| Transient changes of behaviour | 12 |
| Period of amnesia              | 10 |
| Don't know                     | 7  |

<sup>a</sup>Number of respondents = 379; multiple answers were allowed.

**TABLE 5: Responses to the question: "If your relatives or friends have epilepsy, what kind of treatment would you suggested?"<sup>a</sup>**

| Results                           | %  |
|-----------------------------------|----|
| Ask for an "M.D."                 | 80 |
| Ask for an herbal medicine doctor | 11 |
| Don't know what to recommend      | 9  |
| Think "epilepsy is untreatable"   | 4  |
| Acupuncture                       | 2  |
| No need to treat                  | 1  |
| Ask for God's help                | 1  |

<sup>a</sup>Number of respondents = 379; multiple answers were allowed.

discrimination against epilepsy. Hassan & Mohd Hussin<sup>10</sup> reported that 20% of the children with epilepsy seen in a teaching hospital in the rural north eastern State of Kelantan, Malaysia did not receive any form of formal schooling although primary school education was free in Malaysia. The report from Hassan & Mohd Hussin suggested that there was significant discrimination against children with epilepsy among the rural Malaysians. The commonly used local Chinese term for epilepsy, 羊癲 "yang-dian", literally translated means "goat-insanity". It tends to reinforce the misconception that epilepsy is a form of mental derangement and thus contribute to the public's negative attitudes towards epilepsy.

As regards to the responses of questions related to the understanding of epilepsy, the results from our study was also more favourable when compared to Henan, China and Taiwan. The percentages of respondents who did not know the cause of epilepsy, did not know what an epileptic attack was and did not know what to recommend were 26, 7 and 9 respectively in this study, as compared to 40, 10 and 17 in China and 34, 13 and 18 in Taiwan.<sup>6,7</sup> For the question on the nature of epileptic attack, although 84% recognised convulsions as a feature, only 35% identified loss of consciousness, 12% identified transient change in behaviour and 10% identified period of amnesia to be features of epileptic attack. This reflected a lag of recognition of nonconvulsive seizure types. Similar findings was also observed in the studies from Henan, China and Taiwan.<sup>6,7</sup>

As for the responses to the question on the kind of treatment to be suggested to friends and relatives with epilepsy, 80% responded with



asking for an "MD", whereas only 11% chose herbal medicine doctor, and 2% chose acupuncture. The preference for modern scientific medicine to traditional treatment may also be biased towards modern medicine in this interview based survey, where the interviewers have identified themselves as medical students. The responses of healthy subjects to survey questions may not reflect the health seeking behaviour of epilepsy patients with chronic illnesses. Tsai from Taiwan reported that although only 6% & 5% of the patients with epilepsy sought the help of Chinese traditional medicine and folk healers after the first seizure, the percentage who sought such treatments increased to 50% and 47% in the chronic course of epilepsy.<sup>11</sup> This indicated a greater use of traditional medicine in chronic illness in Taiwan. Tan & Lim<sup>9</sup> reported the common use of traditional and alternative medicine among the Malaysian Chinese patients with drug-resistant epilepsy. Hassan & Mohd Hussin<sup>10</sup> reported a high rate of defaulters (59.2%) among their paediatric patients with epilepsy in the rural state of Kelantan despite the availability of all common anticonvulsant at heavily subsidised cost. Menon et al<sup>8</sup> reported a high treatment gap of 90% in the rural Malaysia attributed mainly to social-cultural factors. The difference in the health seeking behaviour in acute versus chronic illnesses may partly explain this apparent discordance, with the public opinion survey favouring modern medicine, and clinical data indicating frequent use of traditional treatment. Continuing efforts in public and patient education is necessary in correcting the negative attitudes to epilepsy and improve the treatment compliance.

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