

## ORIGINAL ARTICLES

# Pilot survey of public awareness, attitudes and understanding towards epilepsy in Hong Kong

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### Abstract

**Objective:** To determine the awareness, attitudes, and knowledge towards epilepsy of Chinese in Hong Kong, China and to compare with those conducted for other Chinese and western culture. **Methods:** A street-to-street personal survey was conducted in 233 respondents using a standardized questionnaire on epilepsy for Chinese. **Results:** Concerning awareness, 96% had heard about epilepsy, 27% knew someone with epilepsy, 57% had witnessed a seizure. Concerning attitude, 89% would not object having their children associated with epilepsy, 44% objected having their children marry an epilepsy sufferers, 90% agreed that epileptics should be treated equally in employment, 10% regarded epilepsy as a form of insanity. Concerning understanding towards epilepsy, 15% did not know the cause of epilepsy and 4% did not know what an epileptic attack was. However, the majority suggested seeking medical advice if their relatives or friends had epilepsy.

**Conclusion:** The awareness of epilepsy for Chinese in Hong Kong is comparable to other cultures. The Hong Kong Chinese has a relatively open attitude towards epilepsy when compared to previous studies in China and Taiwan, except in marital issues. Western medicine is the treatment of choice.

### INTRODUCTION

Survey on public awareness, attitude and knowledge towards epilepsy is useful in decreasing discrimination and stigmatization.<sup>1-22</sup>

By identifying misunderstanding and misconception in the population, campaigns can be targeted and cross-cultural comparison can improve management strategy. Previous studies of public awareness, understanding, and attitudes towards epilepsy in Chinese had shown discrimination against epilepsy in China (1988)<sup>13</sup> and Taiwan (1992)<sup>14</sup> as compared to United States (1979).<sup>1,2,7</sup> The discrimination might be an inherent feature of Chinese cultures regardless of their location in Asia. During the First Conference of the World Association of Chinese Epileptologists (WACE) held in Taiwan (1998), the Public Attitudes Study Group was organized under the leadership of Professor CW Lai. The objective was to compare the public attitudes of countries sharing the same Chinese ethnicity, culture and language in Asia (China, Malaysia, Singapore, Taiwan) using the same questionnaire within the same time period (1998-1999). The present study is aimed to address the public attitudes, together with awareness and knowledge

of Chinese in Hong Kong towards epilepsy, to determine whether negative attitude towards epilepsy is an ingrained feature of the Chinese culture.

### METHODS

A public survey was conducted in Hong Kong, a metropolitan city of 6.5 million in south China, in July – September, 1999. Subjects in 3 different regions of Hong Kong (Hong Kong Island, Kowloon and New Territories) were invited to participate in this survey.

The same questionnaire with 10 questions that had been studied in other surveys was used for easy cross-cultural comparison. Questions 1-8 originated from the Gallop Poll of public attitudes toward epilepsy<sup>7</sup> and questions 9 and 10 were from the study in Henan in China.<sup>13</sup> All respondents were Chinese aged more than 15 years old. Those with epilepsy or seizure, or having family members with epilepsy or seizure were excluded. Those who have any family members who had already taken part in the survey was also excluded. The survey was conducted as face-to-face interview. Demographic data including age, sex, education, occupation, marital

status and number of children were collected. This study was approved by the Ethical Committee of the University of Hong Kong.

Statistical analyses were performed with the SAS statistical software Version 6.12 (Cary, NC). Chi-squared tests were used to establish association between demographic data and responses. A p-value of less than 0.05 was taken as statistically significant.

## RESULTS

Altogether, 233 subjects were interviewed, 52 % were males. The mean age was 28 years (standard deviation = 15 years). Thirty five percent were married and 28 % of had more than one child. The majority (>80 percent) had high school education and 23 percent had been to college or above. The occupations were fairly varied.

### Awareness of epilepsy

Concerning the familiarity with epilepsy (Fig. 1), 96% had heard of or read about epilepsy. Twenty seven percent knew someone with epilepsy while 57% had witnessed a seizure.

### Attitude towards epilepsy

Concerning the attitude towards epilepsy (Fig. 1), 89% would not object to having their children associated with persons who had seizure.

However, 44% would object to having their children marrying a person who sometimes had seizures, 90 % agreed that people with epilepsy should be employed in jobs like other people. Ten percent thought that epilepsy was a form of insanity. There was no significant association between the attitudes towards people with epilepsy and demographic factors like age, sex and education.

In Hong Kong, Mandarin-speaking Chinese originated from northern China, whereas Cantonese speaking ones were from southern China. In our study, Mandarin subjects constituted 6.9% (N=15) whereas Cantonese speaking subjects constituted 92.1% (N=216). The proportion who were married in Mandarin or Cantonese speaking subjects were 53% and 32% respectively. The mean age of Mandarin or Cantonese speaking subjects were 33.1 (standard deviation = 15.5) and 27.3 (standard deviation = 14.4) years respectively. Mandarin speaking subjects have a more negative attitude regarding marriage (p=0.001) and employment (p<0.001) towards people with epilepsy as compared to Cantonese speaking subjects. Those who were married also had a more negative attitude regarding marriage towards people with epilepsy (p=0.005). Responders with medically related occupation such as doctors, nurses, pharmacists or medical students were more negative regarding employment of people with epilepsy (p = 0.004).

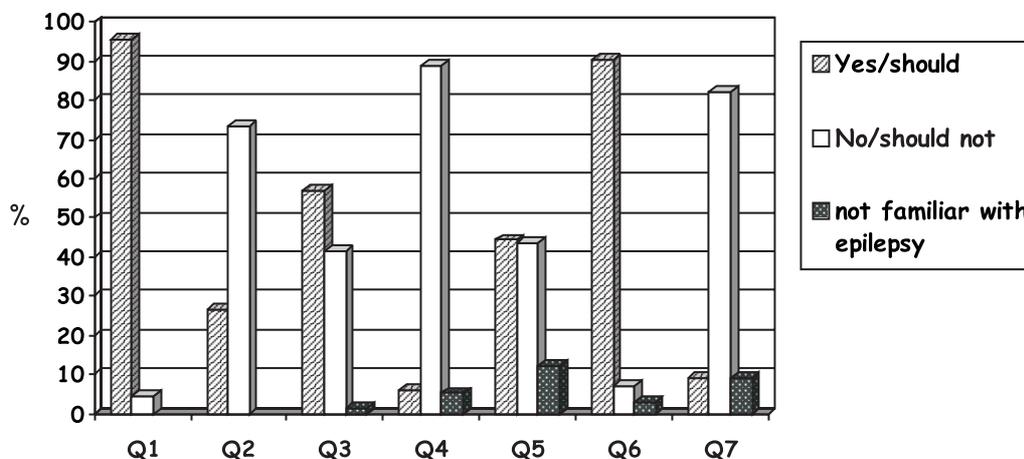


Figure 1: The response to awareness and attitude towards epilepsy. Three questions were asked on awareness. Q1. Have you ever heard of or read about the disease called “epilepsy” or “convulsive seizures” (“fits”)? Q2. Did you know anyone who had epilepsy? Q3. Have you ever seen anyone who was having a seizure? Four questions were asked on attitude. 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 (fits)? 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?

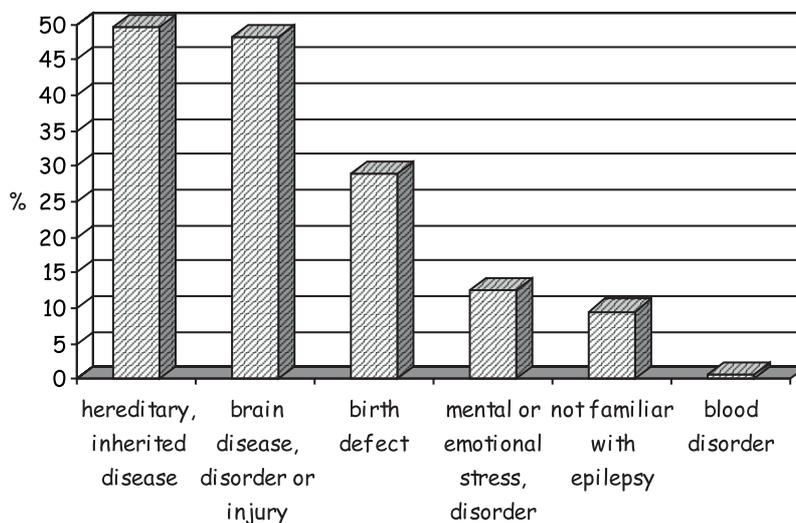


Figure 2: The response to understanding of epilepsy. Three questions were asked on understanding of epilepsy. Q8. What do you think is the cause of epilepsy?

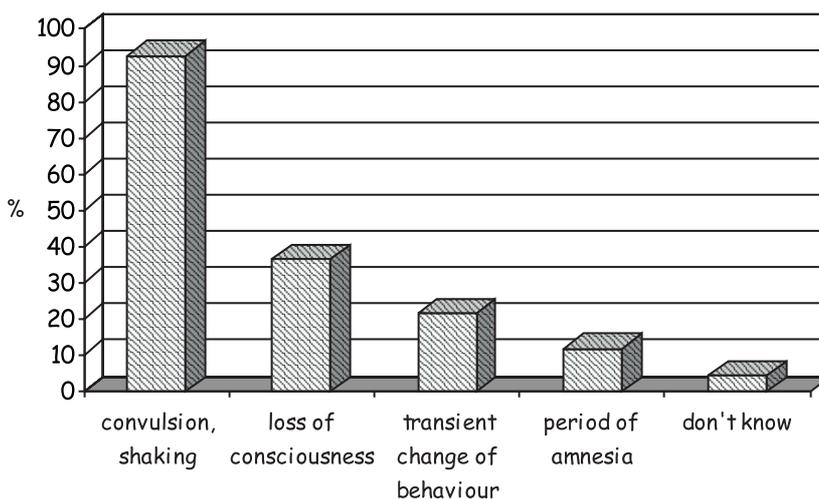


Figure 3: Response to second question on understanding of epilepsy. Q9. What do you think is an epileptic attack?

### *Understanding of epilepsy*

Concerning understanding of epilepsy (Fig. 2,3,4), 15% did not know the cause of epilepsy and 10% claimed that they were not familiar with epilepsy. Forty eight percent thought it was related to brain disorder, disease or injury, 50% thought it was hereditary in nature and 29% thought it was related to birth defect. There was no association between the respondents who objected to their children marrying a person who had seizures, and those who attributed the epilepsy to hereditary disease. Four percent of the subjects did not know what an epileptic attack was. Ninety three

percent knew epileptic attack could be in form of convulsion and shaking but only 36% knew it also involved loss of consciousness. Only 22% and 12% knew that epileptic attack could present as transient behavioral changes and period of amnesia respectively. Most people would seek help from western medical practitioner (97%) when their friends and relatives have epilepsy. Twenty five percent would turn to traditional medicine like herbs and acupuncture. Altogether, four percent of the respondents thought epilepsy was either untreatable, no need to treat or they did not know what to recommend.

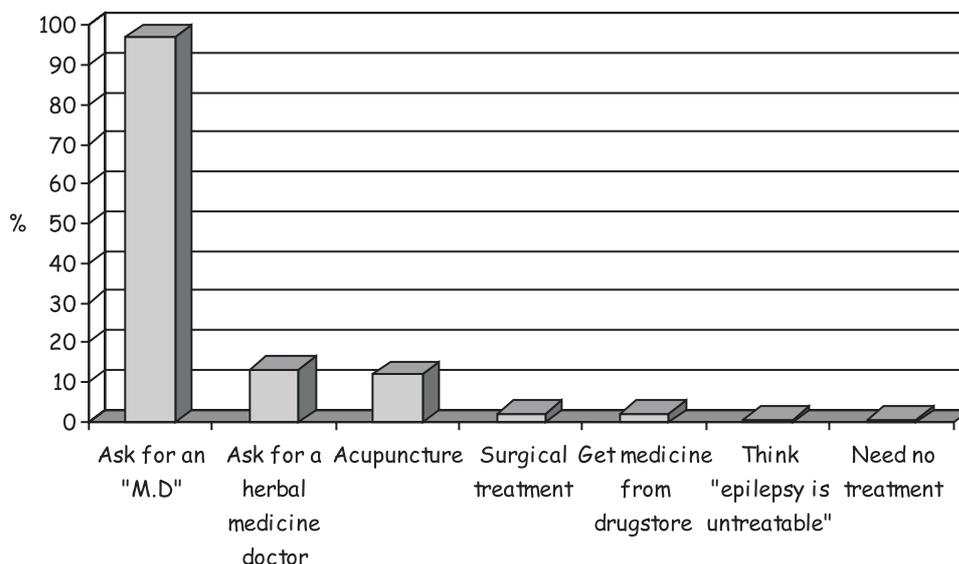


Figure 4: Response to third question on understanding of epilepsy. Q10. If your relatives or friends have epilepsy, what kind of treatment would you suggest?

**DISCUSSION**

Our pilot study is the first multicenter study approved by the Public Attitudes Study Group to study public awareness, attitude and understanding of epilepsy in Hong Kong. Tables 1 and 2 compare the result of this study with similar studies among ethnic Chinese elsewhere in Asia and the general population in the West.

The awareness of epilepsy in Hong Kong was comparable to other countries in Asia and the West. Ninety six percent in Hong Kong had heard of or read about epilepsy and 57 % had witnessed an epileptic attack.

As shown in Table 2, the attitudes toward epilepsy are generally more favorable when compared to Henan in China<sup>13</sup> and Taiwan<sup>14</sup>, comparable to Chinese in Singapore<sup>16</sup> and Malaysia<sup>15</sup>, similar to a previous study in Hong Kong.<sup>17</sup> Only 6 % and 7 % would object to having their children playing with, and employ someone with epilepsy. The corresponding figures are 57% and 53% in Henan in China<sup>13</sup>, and 18% and 31% in Taiwan.<sup>14</sup> This is comparable to figures in United States, of 6 % and 9 % respectively.<sup>7</sup> The more favorable attitude in Hong Kong is probably related to the greater exposure to Western culture in Hong Kong. This shows that the negative attitude to epilepsy is not an ingrained feature of the Chinese culture, but subject to influence from other cultures, and modification from public education.

However, 44% of our respondents objected to their children marrying a person with seizures.

This unfavorable attitude concerning marriage is also seen among Chinese from Henan in China (87%), Taiwan (72%), Malaysia (43%), and Singapore (36%). This is also seen in other parts of Asia: Myanmar (71%)<sup>19</sup>, teachers in Medan, Indonesia (56%)<sup>20</sup>, rural Malays in Malaysia (48%)<sup>21</sup>, and teachers in Thailand (36%).<sup>22</sup> The corresponding figure is 18% from United States.<sup>7</sup> Despite the high proportion of the respondents who attributed the epilepsy to inheritable disease (50%), there was no association with those who objected to their children marrying persons who had seizures.

Our Mandarin-speaking Chinese had more negative attitude in marriage and employment than the Cantonese speakers. However the number of Mandarin speakers in this study was small. Responders in medically related occupation were more resistant in employing an epilepsy sufferer. This probably reflects their heightened awareness of the potential danger of job related accidents in people with epilepsy.

Concerning knowledge in epilepsy, 48% of the subjects responded that it was brain disease or disorder. This compares favorably with the respondents from elsewhere, 30% for Singapore<sup>16</sup>, 25% for China<sup>13</sup>, 20% for Taiwan<sup>14</sup> and 12% for Malaysia.<sup>15</sup> As for the nature of epileptic attack, although 93% recognized convulsion as a feature, less than a quarter of the respondents identified loss of consciousness, transient change of behavior and amnesia to be features of epilepsy. This lack of familiarity with nonconvulsive seizure types

**Table 1: Comparison of the present study on public attitudes, attitude and awareness of epilepsy with similar studies among ethnic Chinese from Asia and the general population in the West.**

<b>Country</b>	<b>Year of study</b>	<b>Population</b>	<b>Type of survey</b>	<b>No of subjects</b>
<b>Hong Kong</b>	1999	Sampling; >15yr	Face-to-face interview	233
<b>Singapore<sup>16</sup></b>	1999	Half-day community health fair	Self-filled questionnaire (English or Chinese version)	214
<b>Malaysia<sup>15</sup></b>	1998	Sampling; >15yr; 1 urban & 2 rural population sites	Face-to-face interview	379
<b>Taiwan<sup>14</sup></b>	1992	Sampling; >15yr; urban & rural population in 2 sites	Face-to-face interview	2610
<b>China<sup>13</sup></b>	1988	Sampling; >15yr; urban & rural population in 2 areas in a central province of China	Face-to-face interview	1278
<b>USA<sup>7</sup></b>	1949, 1954, 1959, 1964, 1969, 1979; 5 yearly trend	American Institute of Public Opinion (The Gallop Poll of public attitudes toward epilepsy); whole population sampling; >18 yr	Face-to-face interview	1539
<b>Finland<sup>9</sup></b>	1978, 1988; 2 yearly trend	Population registry-random sampling; 15-16 yr	Postal enquiry	2272
<b>Denmark<sup>12</sup></b>	1989	Population based-proportional stratified sample	Omnibus survey; face-to-face interview	1500
<b>Italy<sup>10</sup></b>	1983	Population based-randomized proportional stratified sample; >15 yr	Face-to-face interview	1043
<b>Germany<sup>8</sup></b>	1967, 1973, 1978, Trend	Representative sample of adults	Face-to-face interview	2000

	Hong Kong	Singapore <sup>16</sup>	Malaysia <sup>15</sup>	Taiwan <sup>14</sup>	China <sup>13</sup>	USA <sup>7</sup>	Finland <sup>9</sup>	Denmark <sup>12</sup>	Italy <sup>10</sup>	Germany <sup>8</sup>
<b>Q1</b> yes	96	85	99	87	93	95	95	97	73	90
<b>Q2</b> yes	27	36	38	70	77	63	49	60	61	-
<b>Q3</b> yes	57	56	62	56	72	59	45	50	52	-
<b>Q4</b> yes	6	13	9	18	57	6	19	7	8	21
<b>Q5</b> yes	44	36	43	72	87	18	-	-	-	-
<b>Q6</b> should not	7	38	14	31	53	9	-	7	16	18
<b>Q7</b> yes	10	5	9	7	16	3	-	1	3	21
<b>Q8</b> don't know	15	18	26	34	40	39	15	27	16	-
<b>Q9</b> don't know	4	18	7	13	10	-	-	-	-	-
<b>Q10</b> don't know	1	22	9	18	17	-	-	-	-	-
<b>Q10</b> ask for MD	97	60	80	63	55	-	-	-	-	-

Q1. Have you ever heard of or read about the disease called “epilepsy” or “convulsive seizures” (“fits”)? Q2. Did you know anyone who had epilepsy? Q3. Have you ever seen anyone who was having a seizure? 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 (fits)? 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? Q8. What do you think is the cause of epilepsy? Q8. What do you think is the cause of epilepsy? Q10. If your relatives or friends have epilepsy, what kind of treatment would you suggest?

was also observed in the previous Asian studies.<sup>13-16,19-21</sup>

The majority of people (97 %) in Hong Kong studied would seek help from western medical practitioner in treating epilepsy. Traditional Chinese Medicine was the next popular, 13 % would try herbal medicine and 12 % would try acupuncture in Hong Kong. The corresponding responses for China<sup>13</sup> were 15% and 14% respectively, 2 % and 3 % respectively for

Taiwan.<sup>14</sup> The response of healthy subjects to survey questions however, may not reflect the health seeking behavior of epilepsy patients with chronic illnesses.<sup>15</sup>

There are limitations in comparing the present study with the previous studies. The methodology varied in the different studies. (Table 1) For example, the study subjects may respond differently in face-to-face interview and in self-filled questionnaire.<sup>9</sup> There is also difference in

sample size. The Taiwan study and China study involved over 1000 respondents while others including ours involved a few hundreds. The study in USA was 10-20 years earlier than those in Asia, the later mainly in late 1990s. Our study subjects consisted of a larger proportion of younger adults with mean age 28 years. Age has been shown to affect attitude to epilepsy in some previous studies.<sup>13-15,19,21</sup>

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