



# An epidemiological study of epilepsy in Hong Kong SAR, China

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## KEYWORDS

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## Summary

**Background:** Several specialist clinic-based epidemiology studies suggested low prevalence in Hong Kong Special Administrative Region (HKSAR) of China. Population-based epidemiological data for epilepsy is not available. We performed the first population-based epidemiological survey of epilepsy in this locality.

**Method:** We conducted a territory-wide survey. We randomly selected 9547 households from fixed-line telephone directory. We successfully surveyed 17,783 persons of 5178 households by telephone interview. All positive respondents 685 (3.85%) were invited for clinical validation. 127 subjects were validated by board-certified neurologists.

**Results:** Seizure disorders were confirmed in 28 subjects. The crude prevalence of active epilepsy and seizure disorder were estimated to be 3.94/1000 (95% confidence interval (CI): 2.10–6.74/1000) and 8.49/1000 (95% CI: 5.64–12.27/1000), respectively.

**Conclusions:** The prevalence of epilepsy in HKSAR is more common than previously thought. The data retrieved is useful for planning and allocation of health resources for patients with seizure disorders.

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## Introduction

Epilepsy is a common neurological disease in the developed world. It was estimated that 45–100 million people have active epilepsy worldwide.<sup>1</sup> The reported point prevalence for active epilepsy

in developing and developed countries ranged from 4 to 7 per 1000,<sup>2</sup> with limited data available for Chinese populations.<sup>3–5</sup> In this locality, several clinic-based studies were conducted with estimated prevalence figures from 0.5 to 1.5 per 1000<sup>6–9</sup> which are likely to be a gross under-estimation.<sup>10</sup>

Hong Kong Special Administrative Region (HKSAR) is a metropolitan city with a population of over 6.7 million (97% ethnic Chinese). Despite its affluence in economical terms (with gross national income per capita ranked 15th in the World in 2002),<sup>11</sup> population-based health census data for seizure disorders are not available.

A door-to-door approach is a standard community-based epidemiological survey method.<sup>5,12,13</sup> However, because of the existing socioeconomic architecture and cultural reasons, it may be impractical in this locality. Alternative method, such as telephone screening followed by clinical validation, has been tried with success.<sup>14,15</sup> Using a similar

approach, we conducted a population-based epidemiological study for seizure disorders in Hong Kong.

## Methods and materials

A questionnaire with 7 screening questions was designed specifically for the study. An English translated version is reproduced in Table 1. The questionnaire was validated with a cohort of 100 patients with seizure disorders and 100 normal controls.

The actual study was conducted in two stages, namely, a telephone screening phase followed by clinical validation. In addition to the 7 screening questions, demographic data (age, sex, education level, marital status, occupation and location of residence address) was also obtained at the time of telephone interview (Fig. 1). The study was approved by the ethics committee of Institutional

**Table 1** Age and sex distribution of positive respondents

Questions	Age group							Total	Sex		
	0–14	15–24	25–34	35–44	45–54	55–64	>= 65		Male	Female	Total
Q1											
+ve	26	50	34	47	55	49	96	357	166	188	354
%	0.95	1.54	1.39	1.64	1.89	3.03	4.95	2.01	1.92	2.11	2.02
Q2											
+ve	16	21	14	25	30	22	71	199	88	109	197
%	0.58	0.65	0.57	0.87	1.03	1.36	3.66	1.12	1.02	1.22	1.12
Q3											
+ve	10	24	15	14	26	21	64	174	75	98	173
%	0.36	0.74	0.61	0.49	0.90	1.30	3.30	0.98	0.87	1.10	0.99
Q4											
+ve	9	22	9	10	16	11	32	109	52	54	106
%	0.33	0.68	0.37	0.35	0.55	0.68	1.65	0.61	0.60	0.61	0.60
Q5											
+ve	44	50	52	69	69	78	142	504	247	252	499
%	1.60	1.54	2.12	2.40	2.38	4.82	7.32	2.83	2.86	2.83	2.84
Q6											
+ve	72	89	50	22	5	7	9	254	135	118	253
%	2.62	2.74	2.04	0.77	0.17	0.43	0.46	1.43	1.56	1.32	1.44
Q7											
+ve	5	15	10	6	2	7	3	48	27	21	48
%	0.18	0.46	0.41	0.21	0.07	0.43	0.15	0.27	0.31	0.24	0.27

Questions: sensitivity and specificity for seizure disorder – (1) have you or your family members suffered from transient lapses of consciousness or loss of consciousness? (Sensitivity: 54.8%, specificity: 94.9%); (2) have you or your family members ever experienced episodes of sudden involuntary jerky movement affecting limbs, faces or head regions in the day time? (Sensitivity: 19.4%, specificity: 96.0%); (3) have you or your family members experienced sudden drop attacks with tongue biting and/or urinary incontinence? (Sensitivity: 13.3%, specificity: 97.4%); (4) have you or your family members experienced lapse of consciousness with loss of contact with surrounding and staring, not responding to others' call? (Sensitivity: 6.9%, specificity: 97.8%); (5) have you or your family members undergone electroencephalography examination? (Sensitivity: 37.5%, specificity: 93.7%); (6) have you or your family members experienced febrile convulsion before age of 5, i.e., convulsion associated with febrile illness? (sensitivity: 48.6%, specificity: 96.0%); (7) have you or your family members ever been diagnosed to have epilepsy or seizure disorders by doctors? (Sensitivity: 25.0%, specificity: 99.2%).

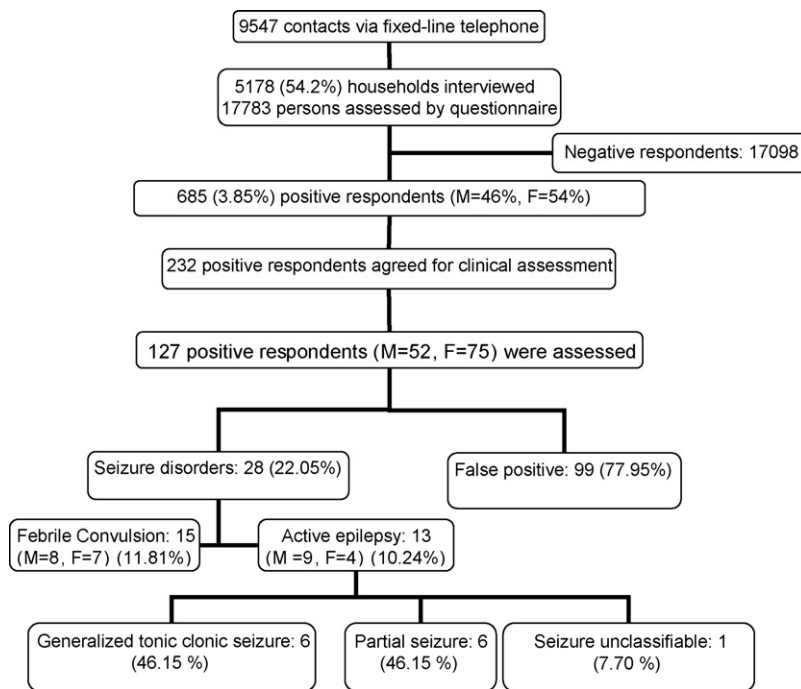


Figure 1 Flow chart of study.

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### Phase I

Professional telephone interview service (Social Science Research Centre of The University of Hong Kong) conducted the telephone interview from July to August 2003. Fixed-line household telephone numbers were randomly selected from their computer database. Adults of 15 years or older were invited to respond (and on behalf of other family members if the respective family member was not available). There was no age limit for individual household members. Considering the averaged household members in HKSAR (at 2001) were 3.23 per household, for practical purposes, the eldest 5 family members were surveyed if the household held more than 5 members. Demographic data from each respondent was obtained. Demographic data would be compared with the general HKSAR population data reported in the 2001 census.

### Phase II

Positive respondents (who responded positive to screening questions) were invited for clinical validation (September to October 2003). At the time of clinical validation, all subjects were seen by board-accredited neurologists to document the presence of seizure disorder and its details (such as age of

onset, seizure semiology, possible aetiology, family history, previous EEGs, neuroimaging results, anti-epileptic drug prescriptions).

Epilepsy was defined as two or more clinically evident afebrile unprovoked seizure. Active epilepsy is defined as a person with epilepsy who experienced at least one seizure in the previous 5 years, regardless of antiepileptic drug treatment. Seizures were classified according to the criteria of the International League Against Epilepsy (ILAE)<sup>16</sup> and with concurring opinion from at least two neurologists. EEG data is optional.

The clinical validation was performed by neurologists from four regional hospitals, namely, Queen Mary Hospital (VW, JF, GCF), Prince of Wales Hospital (AH), Queen Elizabeth Hospital (CL) and United Christian Hospital (PK).

### Sample size and statistical analysis

We aimed to sample 15,000 household members, which would have a margin of error (sampling error) within the range of +0.11% to +0.16% at the 95% level of confidence, assuming that the prevalence of epilepsy in the population was in the range of 0.5–1%. Characteristics between groups were compared using *t*-test and Chi-square test where appropriate. All statistical tests were two-tailed at  $\alpha = 0.05$ . Prevalence rates were calculated in the population studied with the assumption that the number of confirmed cases followed a Poisson

distribution. Statistical calculations were performed using SPSS Version 11.5 for Windows software (Chicago, IL).

## Results

### Phase I

We randomly selected 9547 fixed-line telephone numbers. They were approached and 5178 (54.2%) households responded successfully. The total population was estimated to be 17,783 persons. The demographic data (age, sex, education level, employment and areas of residence) of the respondents were similar to those of the general population as reported in the 2001 census of HKSAR<sup>17</sup> (Table 2).

The questions were answered positively by 357 (2.0%) subjects for question 1 (*episodes of loss of consciousness*), 199 (1.1%) subjects for question 2 (*features suggestive of generalized tonic-clonic convulsion*), by 174 (1.0%) for question 3 (*drop attacks or urinary incontinence or tongue biting*), 109 (0.6%) for question 4 (*features suggestive of complex partial seizures*), 254 (1.4%) for question 6 (*febrile convulsion*).

48 (0.3%) subjects were told to have epilepsy or seizure disorders by their physicians (question 7); and 504 (2.8%) subjects underwent EEG examination in their lifetime (question 5).

Overall, 685 (3.85%, from 614 households) gave positive responses. 232 households with positive respondents agreed to be contacted for clinical validation.

### Phase II

Between September and October 2003, we conducted the clinical validation. All positive respondents agreed for clinical validation were contacted. 127 positive respondents (18.5%, 121 households with 429 members) attended the clinical assessment. Demographic data of the validated positive respondents were similar to those of positive respondents refused to be validated. Demographic data of the families of the validated positive respondents were similar to those families of studied population (Table 2).

Clinical evaluation confirmed 28 patients with seizure disorders (history of febrile convulsion: 15, active epilepsy: 13). Among patients with active epilepsy, 6 had generalized tonic-clonic seizure and 6 had complex partial seizure with or without secondary generalization. The seizure type of a patient, with active epilepsy, could not be classified.

Thirteen patients with active epilepsy were found among the 127 validated positive respondents. Hence, we estimated that 70 cases of active epilepsy should be identified among the 685 positive respondents screened. This gave us an estimated overall prevalence for active epilepsy of 3.94/1000 (95% CI 2.10–6.74/1000).

For febrile convulsion, 15 cases were confirmed from the 127 validated positive respondents. We estimated that 80 subjects with history of febrile convulsion should be found among the 685 positive respondents. Hence, the estimated prevalence for febrile convulsion is 4.55/1000 (95% CI 2.55–7.50/1000).

Overall, the estimated prevalence for seizure disorders is 8.49/1000 (95% CI 5.64–12.27/1000).

Based on the 2001 census in Hong Kong with a total population of 6,708,389,<sup>17</sup> it is estimated that there are 26,447 people with active epilepsy, 30,504 people with history of febrile convulsion, and 56,949 people having seizure disorders in their lifetime in Hong Kong.

## Discussion

Only a few epidemiologic surveys on epilepsy were conducted in Chinese populations.<sup>3,5,18</sup> Li et al. reported a lifetime prevalence of epilepsy of 4.4 per 1000 in urban areas of China.<sup>3</sup> In rural China, it was estimated to be 7/1000 in a recent "demonstration project" of the ILAE/IBE/WHO Global Campaign Against Epilepsy.<sup>5</sup> On the other hand, locally, three specialist-centre based surveys reported a relatively low prevalence rate for epilepsy of 0.45–1.54 in 1000.<sup>6–8</sup> The low estimated prevalence could be due to under-reporting secondary to denial of illness, psychosocial stress and stigmatization associated with epilepsy.<sup>19–21</sup> In addition, centre-based epidemiological studies are prone to under-estimate the true disease burden due to selection bias.<sup>1,2</sup> Hence, we conducted the first population-based study to investigate the epidemiology data for seizure disorder in our society. The information obtained in this study is important for Chinese populations living in a similar metropolitan city.

This study showed a prevalence of active epilepsy of 3.94/1000. The figure was similar to other epidemiological studies conducted in industrialized countries (Table 3). Our rate was intermediate compared with the reported figures from United States and Europe. It was lower among some other Asian countries such as India and Japan.<sup>22–24</sup> Compared with figures worldwide, the prevalence rate of epilepsy at Hong Kong was at the lower end of the

**Table 2** Demographic data of all respondents

Validated patients with	Validated subjects		Total (%)	All respondents (%)	Total <sup>a</sup>
	Seizure disorder				
	Epilepsy	Febrile convulsion			
<b>Age_GP</b>					
0–14	2	2	65 (15)	2754 (15)	2819
15–24	1	5	63 (15)	3249 (18)	3312
25–34	4	3	59 (14)	2450 (14)	2509
35–44	1	3	81 (19)	2870 (16)	2951
45–54	2	0	68 (16)	2903 (16)	2971
55–64	1	1	40 (9)	1618 (9)	1658
>65	2	1	53 (12)	1939 (11)	1992
Total			429 (100)	17783 (100)	18212
<b>Sex</b>					
Male	9	8	222 (52)	8640 (49)	8862
Female	4	7	207 (48)	8908 (51)	9115
Total			429 (100)	17548 (100)	17977
<b>Education</b>					
Uneducated/Kindergarten	1	1	35 (9)	1561 (9)	1596
Primary	4	3	103 (25)	3449 (21)	3552
F1–F3	2	4	79 (19)	2838 (17)	2917
F4–F5	1	5	91 (22)	4773 (29)	4864
F6–F7	0	2	22 (5)	1004 (6)	1026
University: non-Degree	1	1	22 (5)	545 (3)	567
University: Degree	2	1	57 (14)	2274 (14)	2331
Refuse to answer	0	0	0 (0)	123 (1)	123
Total			409 (100)	16567 (100)	16976
<b>Marital</b>					
Single	9	10	183 (43)	7438 (43)	7621
Married	2	5	221 (52)	9036 (52)	9257
Widow	1	0	15 (3)	599 (3)	614
Divorced/separated	0	0	5 (1)	183 (1)	188
Total			424 (100)	17256 (100)	17680
<b>Occupation</b>					
Executives	0	0	13 (3)	607 (4)	620
Professional	0	0	21 (5)	842 (5)	863
Professional assistant	2	2	16 (4)	587 (4)	603
Clerk	0	1	38 (9)	1582 (10)	1620
Machine operation	2	0	27 (7)	1530 (9)	1557
Service/sales	0	0	5 (1)	357 (2)	362
Art or related	1	0	13 (3)	613 (4)	626
Non-technical staff	1	0	23 (6)	893 (5)	916
Farm or unclassified	6	0	7 (2)	155 (1)	162
Other (student, housewife, unemployed, retired, etc.)	0	13	249 (60)	9325 (56)	9574
Refused	0	0	0 (0)	161 (1)	161
Total			412 (100)	16652 (100)	17064
<b>Region</b>					
Hong Kong	9	2	49 (16)	1769 (17)	1818
Kowloon	1	3	79 (25)	3333 (32)	3412
New Territory	2	6	173 (55)	5250 (50)	5423
Island	1	1	12 (4)	117 (1)	129
Total	13	15	313 (100)	10469 (100)	10782

<sup>a</sup> Missing variables exist in different subgroups.

**Table 3** Prevalence of epilepsy in selected countries or regions

Year reported	Country/city	Prevalence (/1000)
1960	Guam <sup>27</sup>	61.8
1961	Carlisle <sup>28</sup>	5.7
1969	Poland <sup>29</sup>	8.9
1973	Norway <sup>30</sup>	3.5
1974	Alabama <sup>31</sup>	9.3
1978	Copiah County <sup>32</sup>	10.7
1983	China <sup>33</sup>	4.5
1985	Bombay <sup>22</sup>	4.9
1993	Iceland <sup>34</sup>	4.8
1994	Bolivia <sup>35</sup>	11.1
1995	Norway <sup>36</sup>	5.1
1997	Estonia <sup>37</sup>	5.3
1998	Madrid <sup>38</sup>	4.12
1999	Istanbul <sup>39</sup>	8.0
2000	Jinshan of Shanghai, China <sup>4</sup>	3.7 (rural); 2.45 (town)
2000	Izmir, Turkey <sup>40</sup>	5.6
2000	Saudi Arabia <sup>41</sup>	6.54
2000	Thailand <sup>42</sup>	7.2
2001	Sicilian <sup>43</sup>	3.3
2004	Hong Kong (present study)	3.94

spectrum, similar to Madrid or Iceland. Comparing to our neighbourhood cities, we are similar to rural area of Jinshan region of Shanghai, but lower than the rest of China or Thailand. The difference in prevalence figures might be due to differences in methodology for case ascertainment. In addition, the result of surveys can be adversely affected by the cultural differences towards patients with epilepsy regarding the willingness of disclosing the information to surveyors.<sup>21</sup>

Door-to-door survey is the gold standard for epidemiological study. However, in a metropolitan city like Hong Kong, it is bound to face significant sampling error, especially for disease with significant social stigmata like seizure disorder.<sup>21</sup> In Hong Kong, it is possible that a household will refuse home visit if there is a member with seizure disorder. It was estimated that 19.3% of general population would conceal their family member with epilepsy if they were being asked.<sup>21</sup> In addition, since the majority of residential buildings in Hong Kong are skyscrapers with security guards to scrutinize visitors at the entrance of the building, interviewers might not be able to enter the building. Sending a letter of intent to arrange an interview may end up seeing a skewed population who wished to be assessed. However, because of the associated social stigmata with the disease, families with seizure disorder could be reluctant to be interviewed during home visit. On the contrary, it may be more psychosocially acceptable over a telephone interview. As the coverage of

fixed telephone lines is extensive and approaches 100% of residential households,<sup>25</sup> it provided a golden opportunity to utilize the network. At the month end of August 2003, when we performed the phase I of the survey, there were 3,811,699 fixed telephone lines installed, among which 2,121,536 were residential.<sup>25</sup> Considering of the above mention factors and with the extensiveness of fixed telephone line coverage, we believe telephone survey and followed by clinical validation is probably the only way of such study can be conducted in a community of this nature. Furthermore, to ensure a high quality data collection at the screening phase, we employed professionally trained staffs with extensive experience of conducting telephone surveys in the local community. The percentage of households completed the telephone screening questionnaire, and the percentage of positive respondents attended for clinical validation in the present study were similar to those of a previous survey on the prevalence of headache using a similar protocol by the same group of staffs.<sup>15</sup>

The overall false positive rate of the screening phase appeared to be high (78%). Most of the false positive answers belong to questions 1, 2 and 4, which were designed to detect subjects with lapses of consciousness, involuntary jerking movement resembling generalized tonic-clonic seizures, and complex partial seizures, respectively. The high false positive rate could be partly due to confusion arisen from Cantonese, the spoken Chinese dialect in Hong Kong. For instance, [Wan4]<sup>26</sup> can refer to "dizziness, vertigo, lapse of consciousness, syncope, or faint" (question 1) or [Cau1 gan1]<sup>26</sup> can refer to "seizure, muscle cramp, or twitching" (question 2). Thus subjects with muscle cramps, vertigo and dizziness were responded positively and were invited for clinical validation. In studies conducted in China where Putunghua is the main dialect,<sup>3-5</sup> such semantic problems shall be less significant as "seizure" and "lapse of consciousness" can be expressed more precisely. In addition, confusion between electroencephalography and electrocardiography (question 5) could also be a source of false-positive answers. Indeed, misunderstanding of questions 1 and 5 was also the likely reasons for the comparatively lower attendance rate for validation in subjects who gave positive answers to these 2 questions. Because of the low sensitivity of these 2 questions, this low attendance rate for validation was unlikely to have led to significant under-estimation of the final prevalence results.

Based on our data, the prevalence of epilepsy in Hong Kong was estimated to be 3.94 per 1000. It was much higher than the earlier figures obtained by



previous clinic-based studies. Our estimation was closer to those reported in Mainland China and elsewhere (Table 2). Because of the high degree of stigmatization and negative attitude of the general public toward patients with epilepsy in the society,<sup>21</sup> it is possible that some patients might have refused to disclose their personal information during the survey causing under-estimation of the "true" prevalence. In addition, only patients with active epilepsy were validated clinically. It was likely due to a bias of who agreed to be examined among those positive respondent. For febrile convulsion, the retrospective nature of the survey also poses problems when assessing the prevalence of febrile convulsion. Failure of recall of a childhood event with no long-term consequence is common. Given these limitations, we believe the measured prevalence is the best estimation of the local figure and approaching the "true" prevalence. While we are waiting long for a door-to-door survey for patients with seizure disorder in this locality, this study can provide baseline data for health care administrators, clinicians and patients, and has implications for the allocation of resources and training of medical manpower.

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