SOCIAL STIGMA IN EPILEPSY, A POPULATION-BASED STUDY IN MALAYSIA

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Abstract (English)

This study aims to determine the magnitude of social stigma in epilepsy as measured by the public attitudes toward epilepsy, in the general as well as in a specific population, in Malaysia. The preliminary study showed that there is a significant impact of epilepsy on the employment in Malaysia, an indirect indicator to a need to study social stigma among Malaysian population. However, the systematic review revealed a need to develop a cross-culturally applicable quantitative scale measuring the public attitudes toward epilepsy, leading to the study on development and validation of a PATE (Public Attitudes Toward Epilepsy) scale, which is developed based on a stigmatization model. Factoring into personal and general domains led to a new concept of classifying the public attitudes toward epilepsy into personal and general attitudes. In order to be applied among Malaysian population, translation of the PATE scale Malay and Chinese languages was performed. Psychometric testing of this translated version showed that the Malay and Chinese translated PATE scales were valid and reliable. The study on students showed that the scale is easily applied among a homogenous group and can be used in a web-based design. In addition, attitudes of students were only better than the general population in the general domain but not in the personal domain, indicating that a significant discrepancy between the personal and general attitudes toward epilepsy. The study on teachers showed significant better attitudes among teachers as compared to the general population with tertiary education, suggesting that attitudes toward epilepsy may be job specific. Population studies showed that there was no significant difference in attitudes toward epilepsy between the Chinese and Malay populations. However, on subcategory analysis, Chinese had better attitudes toward social contact with people with epilepsy, indicating that Chinese patients with epilepsy might have less social restriction as compared with the Malay. In addition, the studies also demonstrated that each ethnic group had a unique urban-rural pattern of attitudes toward

epilepsy, enable us to understand the cultural differences from the sociological perspectives.

(333 words)

Abstract (Malay Language)

Title in Malay: **Stigma social terhadap penyakit sawan, satu pengajian di antara penduduk di Malaysia**

Kajian ini bertujuan untuk menentukan magnitud stigma sosial penyakit sawan seperti yang diukur oleh sikap orang ramai terhadap sawan, di antara penduduk umum serta dalam populasi tertentu di Malaysia. Kajian awal menunjukkan bahawa ada kesan yang ketara bagi epilepsi ke atas pekerjaan di antara pesakit epilepsi di Malaysia, merupakan petunjuk tidak langsung kepada keperluan untuk mengkaji stigma sosial di kalangan penduduk Malaysia. Walau bagaimanapun, kajian yang sistematik mendedahkan keperluan untuk membangunkan skala yang merentas budaya dan kuantitatif dalam mengukur sikap orang ramai terhadap epilepsi. Ini membawa kepada kajian tentang pembangunan dan pengesahan skala PATE (Public Attitudes Toward Epilepsy), yang dibangunkan berdasarkan model stigma. Pemfaktoran kepada domain peribadi dan umum membawa kepada konsep baru mengklasifikasikan sikap orang ramai terhadap sawan kepada sikap peribadi dan umum. Dalam usaha untuk digunakan di kalangan penduduk Malaysia, terjemahan skala PATE bahasa Melayu dan Cina telah dilaksanakan. Ujian psikometrik versi yang diterjemahkan menunjukkan bahawa skala PATE Melayu dan Cina yang diterjemahkan adalah sah dan boleh dipercayai. Kajian ke atas pelajar menunjukkan bahawa skala itu mudah digunakan di kalangan kumpulan seragam dan boleh digunakan dalam reka bentuk yang berasaskan web. Di samping itu, sikap pelajar hanya lebih baik daripada penduduk umum di domain umum tetapi tidak dalam domain peribadi, menunjukkan bahawa ada perbezaan ketara antara sikap peribadi dan umum terhadap epilepsi. Kajian ke atas guru-guru yang menunjukkan sikap yang ketara lebih baik di kalangan guru-guru berbanding dengan penduduk umum yang pendidikan tinggi, menunjukkan bahawa sikap terhadap penyakit sawan mungkin

berasaskan kepada jenis pekerjaan. Kajian Populasi menunjukkan bahawa tidak ada perbezaan yang ketara dalam sikap terhadap penyakit sawan antara penduduk Cina dan Melayu. Walau bagaimanapun, pada analisis subkategori, Cina mempunyai sikap yang lebih baik terhadap hubungan sosial dengan orang-orang dengan epilepsi, menunjukkan bahawa pesakit Cina dengan epilepsi mungkin mempunyai kurang sekatan sosial berbanding dengan Melayu. Di samping itu, kajian juga menunjukkan bahawa setiap kumpulan etnik mempunyai corak bandar dan luar bandar yang unik dalam sikap terhadap sawan membolehkan kita memahami perbezaan budaya dari perspektif sosiologi.

(327 words)

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Most importantly, I would like to express my greatest gratitude to my beloved wife Leh-Hua Hwong and children Yue and Tao, without their understanding and support, this work will not be possibly complete.

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Chapter 1: Introduction

Epilepsy is a disorder of the brain that is characterized by an enduring predisposition to generate seizures and by its neurobiological, cognitive, psychological, and social consequences.[1] A meta-analysis showed that the median lifetime epilepsy prevalence for developed countries was 5.8 per 1,000, as compared to 15.4 per 1,000 for rural and 10.3 for urban studies in developing countries.[2]

However, epilepsy is often an underappreciated health problem especially in Asia.[3] In developing countries, 60% to 90% of people with epilepsy receive no treatment due to inadequacies in health care resources and delivery, and due to social stigma.[4,5]

People with epilepsy are burdened by a multitude of social, psychological and economic consequences of stigmatization which leads to poor quality of life.[6,7] Stigma is precisely described by Boer as follows: children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe.[7] This explains how people with epilepsy are marginalized in the society as a result of negative public attitudes towards epilepsy.

Research questions

This study aims to determine the magnitude of social stigma in epilepsy as measured by the public attitudes toward epilepsy, in the general as well as in a specific population, in Malaysia.

Framework of research

A 3-stage approach was employed, started with (1) a preliminary study and a systematic review to form the basis of the study, which lead to (2) the development and translation of a cross-culturally applicable quantitative scale, and (3) assessment of the public attitudes toward epilepsy using the developed scale in the general and specific populations. Two sub-studies were performed to (a) determine the attitudes variations with how the questions were designed and which social categories were asked, and (b) the correlation between knowledge and attitudes using quantitative scales.

A preliminary study (chapter 2)

In order to determine the consequences of stigmatization as described by Boer, a preliminary study was conducted to determine the impact of epilepsy on employment in Malaysia. 250 adult subjects with epilepsy for more than 1 year and aged 16 years and above were recruited from the Neurology clinic and ward at the University of Malaya Medical Centre, Malaysia, excluding students, full-time housewives, retired subjects, and those with learning disabilities. A further subgroup of 64 subjects who have a sibling with age difference not more than 10 years, were recruited for patient-sibling comparison. This study revealed a significant psychosocial impact of epilepsy on employment in Malaysia with a 20.0% unemployment rate and 42.8% had a monthly income below RM1000 (USD 320). As compared to their age-matched siblings, the patients were more likely to be unemployed (OR 13.1), single, have lower education level and lower monthly income. This is an indirect indicator of a need to study the underlying factors of the psychosocial issues in epilepsy, including social stigma.

A systematic review (chapter 3)

A systematic search using MEDLINE and EMBASE database were performed to identify all studies published before May 2011 that reported public attitudes toward epilepsy. 132 relevant articles from 50 countries including Malaysia were identified for review. There was marked variation of attitudes between Western and non-Western populations, and these attitudes were positively correlated with the standard of living. There was also marked variation in the design of the questionnaires. There were only a few quantitative scales measuring the attitudes toward epilepsy, but these scales are limited by cultural adaptability. Furthermore, most studies were performed in general population but not in a specific population, especially those deemed to have direct influence on the people with epilepsy. There is a need to develop a standardized, quantitative, and yet cross-culturally applicable measure of public attitudes toward epilepsy for cross-sectional and longitudinal comparison, and to be applied in general as well as specific populations.

Development of a quantitative scale (chapter 4)

This leads to the second stage of the research i.e. development of a quantitative scale measuring the public attitudes toward epilepsy. The scale was developed in three phases: (1) formative research and concept development; (2) item development; and (3) data collection, reliability and validity testing. Based on a stigmatization model proposed by Link and Phelan[8], items assessing the separation and disadvantages of people with epilepsy, were selected from the reviewed literatures. These items focused on social restriction of people with epilepsy, specifically related to education, employment, personal and marital relationship, which are less likely to be cultural variable. A 14-item Public Attitudes Toward Epilepsy (PATE) scale was developed, which was factored into two domains, i.e. a general domain (nine items) that requires minimal or no

consideration of respondents' involvement, and a personal domain (five items) that requires a long-term personal commitment or involvement such as marrying a person with epilepsy, working with them or employing them. The PATE scale is a validated scale with good internal consistency (Cronbach's alpha of 0.868 and 0.633, in the general and personal domains respectively).

Scale translation (chapter 5 and 6)

The PATE scale was subsequently translated into Malay and Chinese languages, to be applied among the Malaysian population, of which majority are Malay and Chinese. The translation process of PATE scale was performed in a three-stage cross-cultural adaptation process as developed by the International Quality of Life Assessment project[9], i.e. (1) translation and cultural adaptation of the original scale into the Malay and Chinese languages, and evaluation to ensure conceptual equivalence, (2) formal psychometric testing of the assumptions underlying item scoring and construction of multi-item scales, to ensure that the scoring algorithms can be applied to the population concerned, and (3) validation and norming studies that provide a basis for interpretation. The translated PATE scales were proven to be validated and reliable in measuring the public attitudes toward epilepsy.

Specific populations (chapter 7 and 8)

A web-based survey design was used to study the attitudes toward epilepsy among the students. This was the first web-based survey of public attitudes toward epilepsy in Malaysia, as well as in Asia. Two hundred and seventy five high school and college students were invited to participate in this survey through an email invitation from the research team and 227 (82.5%) responded. The mean score in the general domain was significantly lower than the general population but no difference in the personal domain.

This study indicates that the PATE scale is a validated and reliable scale to measure attitudes toward epilepsy in a homogenous population, and can be delivered as a web-based survey. The scale was also applied among a group of 186 primary and secondary school teachers, which showed that teachers had more positive attitudes toward epilepsy as compared with the general population and the students. When compared to a selected group of general population with tertiary education, teachers had also proven to have more positive attitudes toward epilepsy, indicates that attitude toward epilepsy may differ specific to types of work.

General populations (chapter 9-11)

Three general populations were studied, including 253 Malay and 348 Chinese in Malaysia, and 100 Indonesian in Manado. The rural Chinese had a more positive personal attitudes toward epilepsy than the urban group, but there was no differences between the rural and urban Malay. There was no significant differences between the Chinese and Malay population; whereas the Indonesian in Manado had a significantly poorer attitudes toward epilepsy than the Malaysia Malay and Chinese. This is the first cross-cultural comparison of attitudes toward epilepsy using a quantitative scale.

Sub-studies (chapter 12-13)

Two sub-studies were performed. The first one assessed the variation in attitudes with the types of question and social category. The percentages with negative response to a general item, i.e. “people with epilepsy should not marry” were significantly lower than those to items required personal commitment such as “I would marry someone with epilepsy, even though he/she has epilepsy”. Attitudes toward the social contact was less negative than the employment, followed by the education and marriage. In addition, there was also cultural variation in the pattern of attitudes toward marriage and

employment in epilepsy, between the Malaysian Chinese and Malay, and the Indonesian. The second sub-study assessed the relationship between the knowledge and attitudes toward epilepsy, using the Epilepsy Knowledge Questionnaire (EKQ) and the PATE scale. This study showed that the knowledge toward epilepsy is significantly associated with a better attitudes toward epilepsy. On item analysis, only certain aspects of knowledge in epilepsy affected the attitudes toward epilepsy significantly, supports the need to develop an attitude-specific epilepsy knowledge scale.

Conclusion

It is essential to study the public attitudes toward epilepsy as supported by a significant unemployment rate and lower income among the people with epilepsy. Systematic review revealed a need to develop a cross-culturally applicable quantitative scale in measuring the public attitudes toward epilepsy. The PATE was developed, validated and translated, and applied in various specific and general populations. There were significant differences between the students and the teachers, the teachers and the educated general population, the Malay and Chinese, and the Indonesian and Malaysian.

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Chapter 2: Impact of epilepsy on employment in Malaysia- A preliminary study to support the need for social stigma research in Malaysia.

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Abstract

Introduction: Studies on the impact of epilepsy on employment had been extensively performed in the European and some Asian countries but not in Southeast Asia such as Malaysia, a country with a robust economy, low unemployment rate and minimal social security benefits for the unemployed. This study aims to determine the impact of epilepsy on employment in Malaysia. **Methods:** 250 subjects (52.4% males) with mean age of 35.2 years were recruited from a tertiary neurology clinic in Malaysia. **Results:** 69.6% were employed full-time, 10.4% part-time and 20.0% unemployed. 42.8% had a monthly income below poverty line, i.e. RM1000 (USD 320). Unemployment was associated with female gender, lower education level, younger age of seizure onset, less responsiveness to first antiepileptic drug (AED), higher seizure frequency and less seizure freedom, and higher total score in seizure severity scale. The age of onset (p=0.017), total score in seizure severity scale (p=0.018), and the responsiveness to first AED (p=0.045) were the significant predictors of unemployment. Patients with part-time employment had similar education level as those unemployed, but more likely to be male and married; with intermediate age of seizure onset and seizure severity, but with higher seizure frequency. As compared to their age-matched siblings, the patients were more likely to be unemployed (OR 13.1), single, have lower education level and lower monthly income. **Conclusion:** Epilepsy patients have high unemployment rate in

Malaysia, despite a robust economy and minimal social security. Besides being unemployed, many were in part-time or low-income employment.
(247 words)

Introduction

Epilepsy is one of the common chronic serious neurological diseases present worldwide with an estimated 50 million affected individuals. However, epilepsy is often an underappreciated health problem especially in Asia. People with epilepsy (PWE) suffer from stigmatization and are burdened by a multitude of social, psychological and economic consequences which leads to poor quality of life, Malaysian epileptic patients not being an exception. Understanding and minimizing the socioeconomic and psychological impact of epilepsy is therefore as important as controlling the seizures.

A prospective study on childhood onset epilepsy in UK, followed up from childhood till a mean age of 48, showed that the employment rate was 71% at the mean age of 23 years old, and 59% at the mean age of 48.[1] Comparatively in India and Korea, the unemployment rate of PWE was reported as 31-58%.[2,3] However, a multicentered study in Spain on employment in people with epilepsy showed that the employment rate was 58% and the unemployment rate was only 11%, similar to the general population.[4]

Medical factors play an important role in the employability of PWE. Unemployment was shown to be associated with refractory epilepsy, occurrence of a seizure in the past 12 months, and polytherapy.[4] Antiepileptic drug-related side effects was also part of the reasons for unemployment.[2] Those whose seizures were well controlled or in remission generally did not report problems with employment.[5] The positive predictive factors of

employment were normal intelligence, uninterrupted remission for 5 years, and no history of status epilepticus.[1] Seizure severity, assessed with scales such as the Liverpool Seizure Severity Scale[6], has been shown to affect the quality of life[7-9] and psychological variables, e.g. self-esteem, locus of control, and anxiety[10], but the correlation between seizure severity and the socioeconomic status in epilepsy was not known.

Besides medical factors e.g. seizure frequency and severity, social and cultural factors also limit the employability of people with epilepsy. Malaysia is a newly industrialized country with emerging middle-income economy having a gross domestic product per capita of USD 9,700[11], and good economic growth rate. The unemployment rate is as low as 3%. There are many labor intensive manufacturing industries and a large migrant labor force from neighboring countries. In addition, the disability allowance in Malaysia is only RM150 (USD 47.60) per month[12], significantly lower compared to the West, which should result in increased motivation for people with epilepsy to seek employment . However, social stigma and workplace prejudice, which is prevalent in Asia[13] affected by the cultural misconception of epilepsy, often prevents a person with epilepsy from being employed, although the persons with disabilities act in Malaysia was recently established in 2008, with a subsection stated that persons with disabilities shall have the right to access to employment on equal basis with persons without disabilities.[14] Therefore, our aim is to study the medical as well as social factors affecting positively or negatively the employability of PWE in Malaysia, a country with emerging middle income economy, low unemployment and having a different socio-cultural background from the West.

Comparing PWE to general population may involve too many socioeconomic variables. As we know, there are local factors that might influence the employability of PWE such as the location of the center where the study is performed, the types of patients treated in the specific clinical setting, the urban-rural residency with variation in employment rate and types of employment available, and family background. Taking into account the impact of these local socioeconomic factors, we thought that a direct comparison of the employment status between the patients and their siblings will be more likely to reflect the actual impact of epilepsy on employment. As far as it is known, there has been no previous study comparing the employment status of epilepsy patients with that of their siblings'.

This study aims to determine the impact of epilepsy in general on employment in PWE, as well as investigate their individual socioeconomic background and how it affects their employment status using a paired age-matched patient-sibling comparison.

Methodology

This is a sub-analysis of a cross-sectional, prospective, questionnaire driven, hospital-based psychosocial pilot study, correlating the clinical and social factors with the employment status in PWE.

344 subjects with epilepsy for more than 1 year and aged 16 years and above were recruited from the Neurology clinic and ward at the University of Malaya Medical Centre, Malaysia. Excluding 48 students, 18 full-time housewives, and 28 retired subjects, 250 subjects were included in this sub-analysis. For each subject in the sub-analysis, their demographic profile, socioeconomic background, details of epilepsy and

frequency of seizures over the past one-year were recorded. A further subgroup of 64 subjects who have a sibling with age difference not more than 10 years, were recruited for patient-sibling comparison. The socioeconomic information of their siblings was obtained using the same demographic questionnaire. This study was approved by a local ethics committee (MEC Ref No: 872.5). Informed consent by patient and their caregivers were obtained.

The Liverpool Seizure Severity Scale [6] was used to determine the seizure severity of each seizure type. This scale is a 12-item questionnaire assessing the ictal and post-ictal occurrence, e.g. presence of loss of consciousness, fall, sleepiness, and the length of postictal confusion. It was initially developed to assess outcome of antiepileptic medications in clinical trials, but the scale has now been shown to have strong correlation with quality of life [7-9] and certain psychological variables [10].

Statistical analysis was performed using SPSS version 19.0. The chi-square tests and odds ratios were used to determine the significance and degree of differences in the socioeconomic status between the patients and their siblings. All independent variables were analyzed according to the status of employment, categorized as employed full-time, part-time or unemployed. The chi-square tests were used for univariate analysis of categorical variables. Student's T-tests were used to evaluate these continuous variables: age, age of seizure onset, seizure frequency and seizure severity score. Logistic regression was performed on variables that were significant in univariate analysis. Non-parametric correlation analyses were performed among the social and clinical factors to determine how the variables correlated with others. Spearman's rho > 0.5 was considered to have a strong correlation, 0.3-0.5 as moderate, and <0.3 as weak. A hierarchical cluster analysis of the social factors, i.e. the employment, marital and

education status, was performed to demonstrate their relationship in clusters. The p-value of less than 0.05 was set as significant unless stated otherwise.

Results

250 subjects (52.4% male) were included in this sub-analysis, with a mean age of 35.2 years, range from 16 to 77 years old. The mean age of onset was 19.0 years with standard deviation of 10.8 years. 47.6% were Chinese, 27.2% Malay, 22.8% Indian and 2.4% other races. 56.0% were single and 65.6% had secondary education level or below. 174 (69.6%) of the subjects were employed full-time, 26 (10.4%) employed part-time, and 50 (20.0%) unemployed. 107 subjects (42.8%) had monthly income below the poverty line of RM1000 (USD 320) and 21 were receiving disability allowance.

Demographic and medical profile

As shown in Table 2-1, patients employed full-time were predominantly male, married and more educated, compared to the unemployed. Patients who were unemployed had significantly younger age of seizure onset during their childhood or adolescence, compared to those with full-time employment. They were more likely to be symptomatic in aetiology, and failed at least one antiepileptic drug (AED). In addition, they had higher seizure frequency with less seizure freedom, and higher score in seizure severity scale. (Table 2-2)

Patients with part-time employment had similar education level with those unemployed, but were more likely to be male (*p*, not significant) and married ($p<0.05$). 76.9% had monthly income of RM1000 and below. They had similar clinical profile with the

unemployed patients, except with non-significantly younger age of onset and significantly higher likelihood to respond to first antiepileptic medication ($p<0.01$).

Logistic regression was performed to determine the impact of gender, education level, age of seizure onset, seizure freedom, responsiveness to first AED, and total score of seizure severity scale on the likelihood of being employed full-time, compared to being unemployed. The full model containing all predictors was statistically significant, χ^2 (6, n=224) was 36.42, $p<0.001$. The predictors were responsiveness to first AED (odds ratio, OR 2.19; $p=0.045$), age of onset ($p=0.017$), and the total score in seizure severity scale ($p=0.018$).

Table 2-1: Demographic profile of people with epilepsy, according to the status of employment (n=250)

Demographic profile	Employed full-time (n=174)	Employed part-time (n=26)	Unemployed (n=50)	Total (n=250)
Age, mean±SD	35.9±9.9	35.3±8.5	32.7±11.6	35.2±10.2
Gender: Female, n (%)	76 (43.7)*	12 (46.2)	31 (62.0)	119 (47.6)
Ethnicity: Malay:Chinese:Indian	45:83:41	7:19:2	16:19:14	68:119:57#
Marital status: Single, n (%)	86 (49.4)***	15 (57.7)*	39 (78.0)	140 (56)
Education level: Secondary and below, n (%)	106 (60.9)*	20 (76.9)	38 (76.0)	164 (65.6)
Income: RM1000 and below, n (%)	40 (23.0)***	20 (76.9)*	47 (94.0)	107 (42.8)

*$p<0.05$ and ***$p<0.001$ as compared to those who are unemployed. SD, standard deviation. AED, antiepileptic drug. # Ethnic groups other than Malay, Chinese and Indian were not included.

Table 2-2: Medical profile of people with epilepsy, according to the status of employment (n=250)

Medical profile	Employed full-time (n=174)	Employed part-time (n=26)	Unemployed (n=50)	Total (n=250)
Age of seizure onset, mean±S.D.	20.4±11.0***	18.4±9.7	14.3±9.3	19.0±10.8
Age of seizure onset before 20 years of age, n (%)	92 (52.9)**	18 (69.2)	39 (78.0)	149 (59.6)
Seizure type: Focal, n (%)	121 (69.5)	15 (57.7)	35 (70.0)	171 (74.3)
Aetiology: Symptomatic, n (%)	54 (31.0)*	13 (50.0)	25 (50.0)	92 (40.0)
Seizure frequency per year, mean±SD	1.9±4.3**	6.2±19.4	5.5±14.7	3.1±9.8
Seizure freedom for one year, n (%)	86 (49.4)**	10 (38.5)	12 (24.0)	108 (43.2)
Seizure severity scale (range from 0 to 100 marks)	21.9 ± 25.8***	28.3 ± 28.3	36.7 ± 25.4	25.3±26.1
Failed at least one AED, n (%)	60 (34.5)**	7 (26.9)**	29 (58.0)	96 (38.4)

*p<0.05, **p<0.01 and ***p<0.001 as compared to those who are unemployed. SD, standard deviation; AED, antiepileptic drug.

Correlation analysis

Employment status strongly correlated with monthly income i.e. subjects employed full-time had more income than those employed part-time or were unemployed, and weakly correlated with marital status, seizure freedom for a year, and age of seizure onset, but did not correlate with education level as shown in Table 2-3. Marital status moderately correlated with age of seizure onset, and weakly correlated with employment status.

Table 2-3: Non-parametric correlation analysis among the social and clinical variables (n=250)

Spearman's rho	Education level: Secondary and below	Marital status: Married	Monthly income: RM1000 and below	Seizure freedom for one year	Age of seizure onset: before 20 years old
Employment status: Employed	-.109	.222**	-.517**	.194**	-.187**
Education level: Secondary and below		-.071	.286**	.003	.159*
Marital status: Married			-.278**	-.090	-.387**
Monthly income: RM1000 and below				-.134*	.234**
Seizure freedom for one year					-.138*

*Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the 0.01 level (2-tailed).

Cluster analysis

Hierarchical cluster analysis of the social variables (Table 2-4), i.e. employment, education and marital status, revealed three distinct clusters. Cluster 1, the less educated but employed group, had lower monthly income but similar clinical profile as Cluster 2, the more educated and employed group . Cluster 3, the unemployed group, had lower marital rate, younger age of onset, and more severe clinical profile as compared to Cluster 1.

Table 2-4: Demographic and medical profile of people with epilepsy, according to hierarchical cluster analysis (n=250)

	Cluster		
	1 (n=126)	2 (n=74)	3 (n=50)
Marital status: Married, n (%)	60 (47.6)	39 (52.7)	11 (22.0)**
Education level: secondary and below, n (%)	126 (100.0)	0 (0.0)**	38 (76.0)
Employment status: Employed, n (%) -full-time employment -part-time employment	126 (100.0) -106 -20	74 (100.0) -69 -6	0 (0.0)**
Monthly income: RM1000 and below, n (%)	49 (38.9)	11 (14.9)**	47 (94.0)**
Age of seizure onset: before 20 years old, n (%)	75 (59.5)	35 (47.3)	39 (78.0)**
Seizure frequency per year, mean±S.D.	2.8±9.9	1.9±3.4	5.5±14.7**
Seizure severity scale (range from 0 to 100 marks), mean±S.D.	21.5±25.1	24.2±26.3	36.7±25.4**
Seizure freedom for one year, n (%)	62 (49.2)	34 (45.9)	12 (24.0)**

*p<0.05 and **p<0.01 as compared to cluster 1; SD, standard deviation.

Age-matched patient-sibling comparison

64 pairs of age-matched patient-sibling, consisting of 43.8% Chinese, 25.0% Malay and 31.2% Indian and, were included in this subgroup analysis. There was no statistically significant difference in the mean age between the patients and their siblings (36.5±11.1 vs. 37.5±12.2 years, p >0.05). As shown in Table 2-5, the patients were more likely to be unemployed (OR 13.1), have education at secondary level or lower (OR 2.5), and single (OR 3.0), compared to their siblings. The percentage of patients with monthly income of RM1000 and below was significantly higher than their siblings (OR 5.5).

Table 2-5: Comparison of the socioeconomic status of the patients and their siblings, (n=64 pairs)

	Patient (n=64)	Sibling (n=64)	Odds ratio
Age, mean±SD	36.5±11.1	37.5±12.2	
Gender: Female, n (%)	27 (42.2)	36 (56.3)	
Marital status: Single, n (%)	40 (62.5)**	23 (35.9)	3.0
Education level: Secondary and below, n (%)	49 (76.6)*	36 (56.2)	2.5
Employment status: Unemployed, n (%)	19 (29.7)***	2 (3.1)	13.1
Employment status: part-time, n (%)	2 (3.1)	1 (1.6)	
Monthly income: RM1000 and below, n (%)	29/64 (45.3)***	6/46 (13.0)[#]	5.5

*p<0.05, **p<0.01 and ***p<0.001 as compared to their siblings. SD, standard deviation. [#]Full-time and part-time students were excluded from analysis.

Discussion

The unemployment rate of our studied population, calculated as a percentage of the number of unemployed population of the labor force i.e. the total number of people employed plus unemployed as defined by International Labour Organisation [15], was 20.7%. This is comparable to other published data [5,16] but significantly higher compared to the 3.0% unemployment rate in Malaysia reported in June 2011.[17] The unemployment rate of their siblings at 3.1% as shown in Table 2-3 was more consistent with the general rate of unemployment in Malaysia. We believe that the unemployment rate of epilepsy patients of greater than 13 times their siblings' unemployment rate is particularly significant, as the result has taken into account the many social and economic factors that may influence the employment rate locally. It should also be noted that such a high unemployment rate occurs in the context of a society with robust economy, low unemployment overall, and minimal social security and support for the unemployed. Moreover, it is unusual for Malaysians to take on part-time employment. The 10.4% of part-time employment among the epilepsy patients, with three quarter of these patients having income below the poverty line (Table 2-1), demonstrate further the difficulties of finding paid work in Malaysia.

Our data also showed that 42.8% of our patients had a monthly income below the poverty line, i.e. RM1000 (USD 320), significantly higher than the 7.3% Malaysian with RM1000 or less monthly household income in 2009 [18] and 13% of their siblings. They consisted of those who were unemployed, employed part-time as well as those in low wage employment as shown in the cluster analysis. This indicates that people with epilepsy in Malaysia are facing significant socioeconomic challenges.

The comparison between epilepsy patients and their siblings also showed that significantly higher proportion of the patients remained single (62.5% vs 35.9%), and had lower level of education (Table 2-4). It is likely that the lower level of education contributed to unemployment, and the unemployment affected the marriage rate.

Review on employment in epilepsy showed that there were higher rates of unemployment in individuals with more frequent seizures. [19] However, there were also studies with contradictory results, reporting no correlation between seizure frequency and employment status. [19] Adding a subgroup of part-time employment, this study showed that those with more frequent seizure could still be employed but they were mostly employed in a part-time position. In addition, the cluster analysis revealed a subgroup of patients, with lower education level, employed full-time but yet with low monthly income, who might be unemployed in countries with good unemployment or disability benefits. Work serves as a purposeful activity and employment is known as an important factor for psychological health. [20] Studies have repeatedly demonstrated that the levels of depression and other forms of impaired mental health are significantly higher among unemployed people. [21] Present study supports that patient with uncontrolled epilepsy can still be employed especially in part-time position, and thus provides a basis for establishing more part-time employment in the society for people with epilepsy, which will increase their employment rate with consequent improvement in the psychological health. In view of the increase in the percentage of part-time employment over the years [22], it is recommended that a subcategory of part-time or low-income employment be included in future study on employment in people with epilepsy, especially in Asia.

The total score of Liverpool Seizure Severity Scale is lowest in those with full-time employment, followed by part-time employment, and unemployment, as seen in Table 2-1. Logistic regression showed that seizure severity was a significant predictor of employment status; whereas seizure frequency was not. This is consistent with Bautista's study which found that seizure severity is associated with quality of life independent of seizure frequency. [9] Similarly in a study on psychological variables, the importance of including seizure severity in the study is again demonstrated, in which seizure severity, but not seizure frequency, was proven to be the most significant predictor of psychological variables. [10]

Age of seizure onset is another significant factor affecting the employment status of people with epilepsy. The majority (78%) of unemployed patients had an age of seizure onset prior to adulthood, significantly more than those with full-time employment. Study has shown that children with seizure disorders have distinctive temperament and character patterns, modulated by seizures, with higher harm avoidance, less persistence, self-directedness, and cooperativeness than normal control. [23] In addition, adolescent onset of epilepsy was also shown to influence the development of adult personality trait. [24] These studies thus support the hypothesis that patients with younger seizure onset have higher tendency to adopt an avoidant coping strategy and less adult personality trait, which prevent them from being employed or continue in employment.

Limitations and future studies

Socio-cultural factors might play a more important role than the clinical factors in determining the employability especially in Asia, but were not assessed in this study. These include the negative public attitudes against employment in epilepsy especially in

Asia [13], misconceptions such as work aggravates seizures, and an overprotective or isolation approach to children with epilepsy. Exploration of the impact of these socio-cultural factors on employment in epilepsy either qualitatively or quantitatively is needed especially in the Asian population.

Psychological factors in related to employability were also not assessed in this study. Previous study demonstrated that low self-esteem, passive coping style, and low self-efficacy predicted unemployment.[25] Perceived stigma and fear of discrimination at work are also predictors of epilepsy patients not seeking for a job.[2,26,27] Based on our finding correlating younger age of seizure onset with unemployment, identifying and providing counseling to patients with younger onset of epilepsy with coping difficulties might reduce the rate of unemployment in epilepsy patients. In addition, a better understanding of the impact of these psychological factors on the employability of people with epilepsy may be achieved using patient-sibling comparison model, which minimizing the influence of local socioeconomic factors.

Employment is associated with the belief in the importance of work, which is culturally variable.[26] In Varma's study, patients who were unemployed have listed poor motivation as one of the main reasons for not seeking a job.[2] According to Maslow's need hierarchy theory, human is motivated by a hierarchy of needs: the physiological needs, the safety needs, the love needs, the esteem needs and the need of self-actualization.[28] Previous study has shown that the majority of patients with epilepsy who were employed believed that work was important for their personal growth and financial needs.[26] Therefore, in future study, the kind of needs that would motivate epilepsy patients to seek employment should be examined.

This study was performed in a tertiary center, in which the patients recruited are generally having more severe epilepsy with less seizure freedom (43.2%), as compared to 75% reported in a community study.[29] Therefore, the socioeconomic status of our cohort is expected to be poorer than the general epilepsy population. However, the heterogeneity of our cohort allows comparison between groups with different medico-demographic profile.

Conclusion

The employment issue in epilepsy is not only affected by the clinical, but also the social factors as shown in this study on the Malaysian population. Besides being unemployed, many Malaysian epilepsy patients were in part-time or low-income employment in Malaysia.

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Chapter 3: Attitudes toward epilepsy, a systematic review.

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Abstract

Surveys about attitudes towards those with epilepsy have been performed since 1949, in order to understand the social stigma toward epilepsy. This review aims to demonstrate the variation in public attitudes towards epilepsy and its associated factors, with a critical review of the methodology used to examine attitudes towards epilepsy. There was marked variation of attitudes between Western and non-Western populations, and these attitudes were positively correlated with the standard of living. Besides the general public, studies were also performed within specific groups, particularly teachers and students. However absence of a standardized questionnaire makes direct comparison difficult. A few quantitative methods were developed but these were limited by cultural variations and thus lack of global acceptance. Short-term intervention studies demonstrate an improvement of attitude with knowledge. Nonetheless, the cultural and social reasons underlying the attitudes, and how this affects the life of people with epilepsy, are understudied. Therefore, surveys on attitudes should continue to be carried out, particularly in populations prone to have negative attitudes with emphasis on underlying reasons, and such progress should be monitored longitudinally. Attitudes of people such as parents, teachers, school counselors, health care professionals, and employers, which have a direct impact on people with epilepsy, should be more extensively studied.

Introduction

Epilepsy is a disorder of the brain that is characterized by an enduring predisposition to generate seizures and by its neurobiological, cognitive, psychological, and social consequences.[1] A meta-analysis showed that the median lifetime epilepsy prevalence for developed countries was 5.8 per 1,000, as compared to 15.4 per 1,000 for rural and 10.3 for urban studies in developing countries.[2]

However, epilepsy is often an underappreciated health problem especially in Asia.[3] In developing countries, 60% to 90% of people with epilepsy receive no treatment due to inadequacies in health care resources and delivery, and due to social stigma.[4,5]

People with epilepsy are burdened by a multitude of social, psychological and economic consequences of stigmatization which leads to poor quality of life.[6,7] Stigma is precisely described by Boer as follows: children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe.[7] This explains how people with epilepsy are marginalized in the society as a result of negative public attitudes towards epilepsy.

The earliest research in social stigma was to examine public attitudes towards epilepsy by Caveness in the United States in 1949.[8] This was a population-based study, which was subsequently repeated at 5-year intervals, until 1979.[9-14] Since then, similar studies were repeated in various countries and regions, in selected populations (e.g., teachers, health care providers), and in various languages.

In this review, we aim to determine the variability of public attitudes towards epilepsy among different populations, across time, and between different study populations as well as the challenges in comparing results obtained from studies using differing methodology. The pros and cons of various study methods will then be analyzed and discussed, aiming to guide future research in attitudes towards epilepsy.

Methods

Search strategy and selection

MEDLINE and EMBASE database were systematically searched by the first and second author to identify all studies published before May 2011 that reported public attitudes toward epilepsy. The Boolean search using "(attitude*[Title] OR stigma[Title]) AND epilepsy" were performed. Additional search using specific MeSH subheading "health knowledge, attitudes, practice" was used to widen the scope of the search strategy.

Inclusion and exclusion criteria

A study was included if it reported the public or patients' attitudes towards epilepsy, regardless of its targeted respondents. Studies using qualitative methodology were not excluded. Papers written in languages other than English were excluded in the search. Case reports, review articles, meeting abstracts, brief communications, and non-journal articles were excluded.

Study selection

All abstracts were independently reviewed by the two reviewers to determine if they met eligibility criteria. Any study identified by either reviewer was included. The full text articles of eligible abstracts were then reviewed independently by both reviewers to determine final eligibility for data abstraction. Disagreements were resolved by discussions between the reviewers. Additional papers were identified and gathered manually by searching the reference lists of all included articles.

Data extraction and analysis

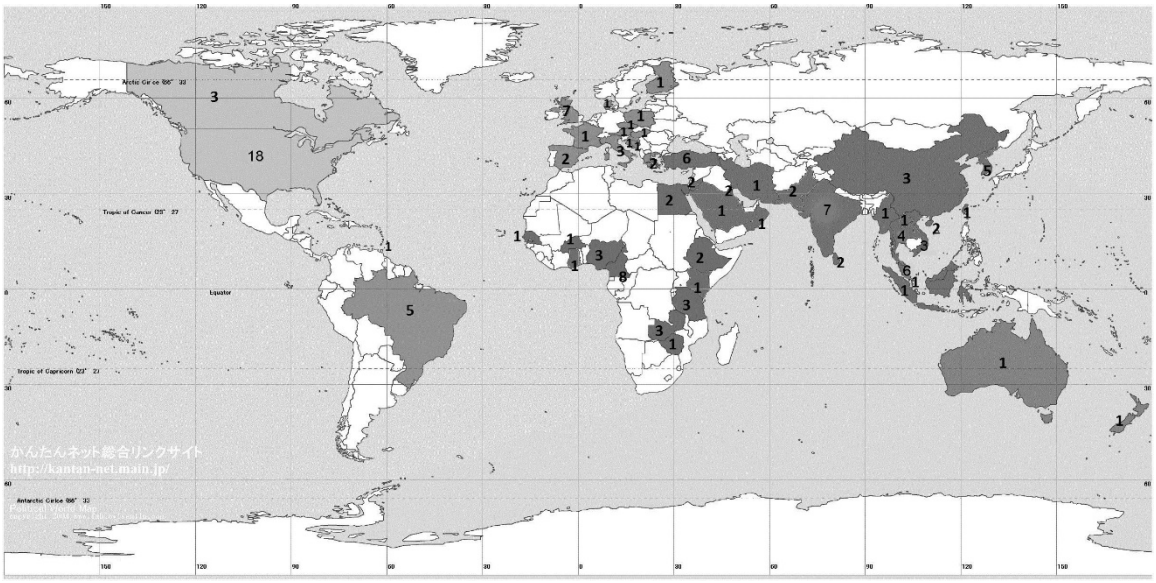
The data for all eligible articles were then independently abstracted by both reviewers using a standardized form including variables such as the sample size, target respondents, year of publication, country, and continent. Additional variables including the percentage of negative attitudes toward marriage, employment and social contact were screened and tabulated. Descriptive statistics including frequency and percentage were used in analysis. The association between public attitudes towards epilepsy and the standard of living in a country was examined. Gross domestic product (GDP) per capita is a good indicator of standard of living in a country. GDP per capita for the year 2010 was thus used in this comparison, and obtained from World Economic Outlook Database-April 2011, International Monetary Fund.

Results

Three hundred and thirty one abstracts were identified from the initial search with 129 full text articles meeting all eligibility criteria. These included 119 full text papers and

10 abstracts without full text papers from regional journals, e.g. Ethiopia Medical Journal and West Africa Journal of Medicine, all of which were selected for data abstraction. Three additional papers were identified from the reference lists and included. In total, 132 relevant articles from 50 countries were identified, as demonstrated in Figure 3-1.

Figure 3-1. Countries with publications on public attitudes toward epilepsy (n=50). The numbers represent the number of papers published in each country.



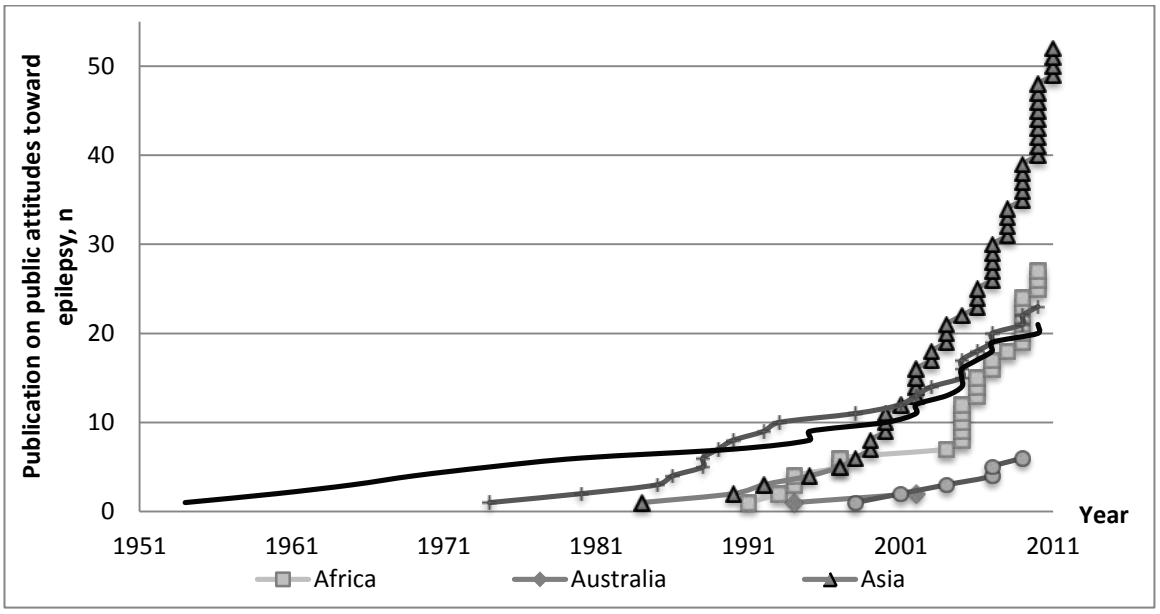
History

The first questionnaire on public attitudes towards epilepsy was designed by Caveness in 1949 using a Gallup poll in the US, and consisted of 10 questions on the knowledge, attitude and practice in epilepsy.[8] Four questions were asked regarding attitudes toward epilepsy, including social contact (e.g., "Would you object to having any children in school or at play associate with persons who sometimes had seizures (fits)?"), employment (e.g., "Do you think people with epilepsy should or should not be employed in jobs like other people?"), marriage (e.g., "Would you object to having a

son or daughter of yours marrying a person who sometimes had seizures?"), and perception (e.g., "Do you think epilepsy is a form of insanity or not?").

The study by Caveness on public attitudes towards epilepsy was subsequently repeated, modified, and quantified in various countries across the 6 continents, as in Figure 3-1 and 3-2, and carried out in various languages including Malay[15], Thai[16], Vietnamese[17-19], Chinese[18,20-22], French[23], Turkish[24], Spanish[25], Lao language[26], Malayalam language[27,28], Swahili language[29], and Urdu language.[30]

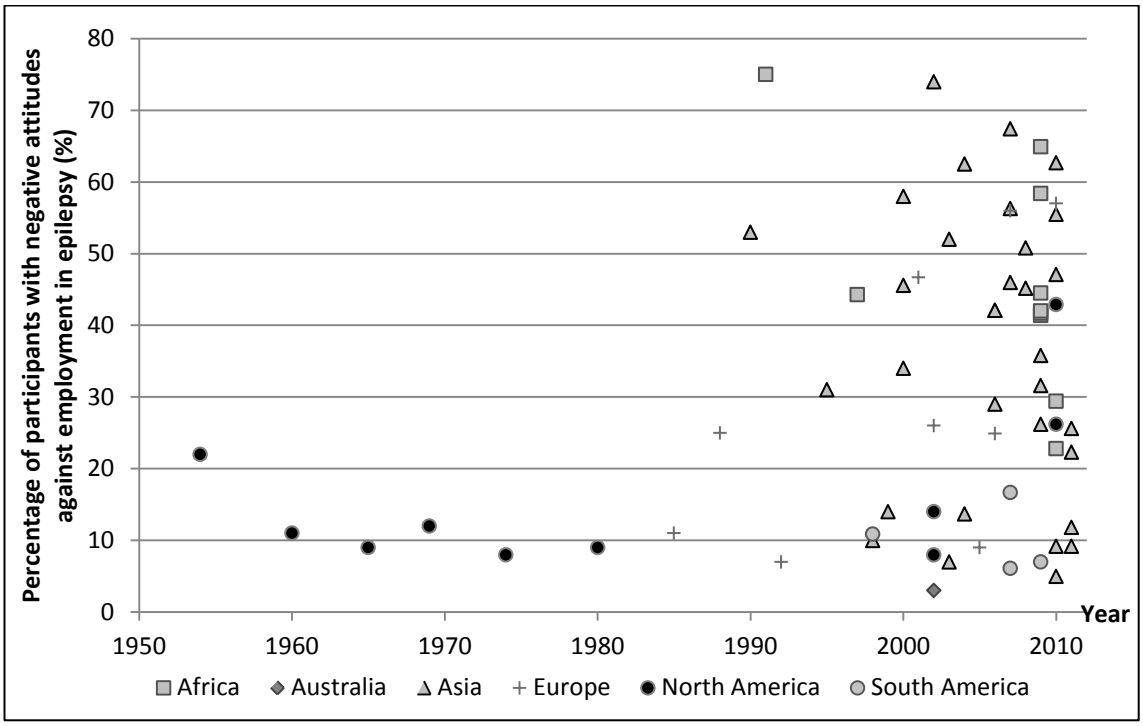
Figure 3-2. Publications on public attitudes towards epilepsy (n=132 papers)



The first paper in Europe was published in 1974[31], followed by Asia in 1984, Africa in 1991[32], Australia in 1994[33] and South America in 1998.[34] There was an exponential increasing trend in the number of publications after 1990, especially in Asia and Africa, resulting in the highest number of publications in Asia (46/120, 38.7%), followed by Africa and Europe (21.7% and 19.2%, respectively).

Taking attitudes towards employment in epilepsy as a mean for comparison, public attitudes towards epilepsy was compared. Across time, Caveness demonstrated that attitudes in the United States improved over 30 years (1949-1979), as shown by the black dots in Figure 3 before 1970.[8-14] Hicks also reported a similar positive trend in employment in United State of America (USA) over 30 years (1958-1988).[35] However, there were no studies demonstrating a similar trend in attitudes in other continents, with Asia and Africa showing a significantly worse trend instead, as shown in Figure 3-3.

Figure 3-3. Negative attitudes against employment in epilepsy, according to geographical distribution and year (n=66 papers)



Attitudes towards epilepsy and the associated factors

Factors associated with negative attitudes towards epilepsy

Attitudes towards epilepsy can be influenced by the individual's socioeconomic background, knowledge, and the illness perceptions of epilepsy. People from rural areas with lower educational level and socioeconomic status have been found to have more negative attitudes towards epilepsy.[15,16,20,22,32,34,36-39] Other factors include old age[19,47,48,50], male gender[22,36,37], female gender[38], being single[22], and Hindu ethnicity.[40]

Knowledge about epilepsy is an important factor in reducing the degree of discrimination and negative attitudes toward epilepsy. Studies show that people with less knowledge about epilepsy, or without personal contact with someone with epilepsy, have poorer attitudes.[15,16,20,34,36-39] The magnitude of the negative attitudes seems to be aggravated by the presence of misconception of epilepsy, which include the perception of epilepsy as a form of insanity[16,37,20], being untreatable[36,41], contagious[30], hereditary[41], or a form of mental retardation.[20]

Attitudes toward epilepsy across continents

The studies in Northern America, in general, demonstrate more positive attitudes towards epilepsy, as shown in Figure 3-3. However, direct comparison and statistical analysis could not be performed as these papers utilized different questions and target populations. Interestingly, Chung studied the attitudes of Chinese and Vietnamese adults in the United States, and found a higher percentage of negative attitudes against

employment in epilepsy as compared to the earlier studies by Caveness (43% vs. 8-22%).[9-14,18]

Asia and Africa are the two continents with the worst attitudes against employment in epilepsy, where 50.0% (16/32) and 80.0% (8/10) of the published papers respectively reported more than 40% of participants with negative attitudes, as compared to none in North and South America, and Australia, except the study by Chung on Asian migrants in the United States.[19] Studies in South America were however only limited to Brazil and Trinidad & Tobago.

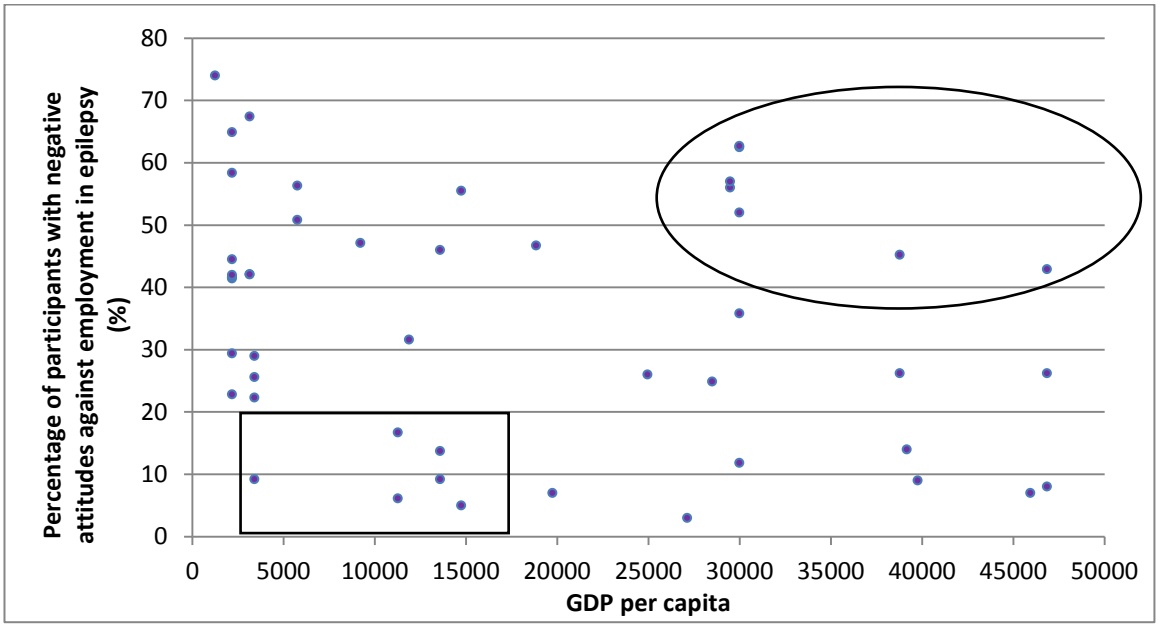
Publications in Europe showed mixed results where two papers in Italy and one in Hungary reported high percentage of participants with a negative attitude towards employment in epilepsy (56%, 57% and 47%, respectively).[38,42,43]

Attitudes towards epilepsy and standard of living

Figure 3-4 shows that in general, the magnitude of negative attitudes towards epilepsy is inversely proportional to the GDP per capita, except in Italy and Kuwait[38,42,44], countries with a high GDP per capita and a high percentage of negative attitudes towards epilepsy (circled in Figure 3-4), and in Turkey, Brazil, India and the Chinese in Malaysia[20,34,45-49] ,countries with a low GDP per capita and a low percentage of negative attitudes towards epilepsy (squared in Figure 3-4).

Figure 3-4. Negative attitudes against employment in epilepsy, according to gross domestic product per capita, based on papers published in 2001-2011 (n=47

papers). Countries with high GDP per capita with poor attitude are circled, and the opposite are squared.



Study design

Variability in the questions

Some questions have been phrased in the form of a general statement (as shown in Table 3-1 and 3-2), whereas some questions required personal consideration, for example a marriage involving the participants or their children.

Table 3-1: Examples of questions on attitudes towards marriage in epilepsy

General Statement
• Do you think it is appropriate for a person with epilepsy to get married?[45]
• Should people with epilepsy get married?[18]
• Would you agree to people with epilepsy getting married?[75]
• People with epilepsy should not marry.[56]
• I believe people with epilepsy should not marry.[64]
• Do you think that epilepsy is an important impediment for marriage[42]
• How much does epilepsy limit marriage?[38]

Personal consideration of marriage involving the participants themselves

- Would you be willing personally to marry someone with epilepsy?[76]
- Would you marry a person with epilepsy?[45,47]
- Would you agree to marry (yourself or your children) with him/her provided this person is otherwise acceptable?[20,62,68]

Personal consideration of marriage involving the participants' children

- Would you object to having a son or daughter of yours marrying a person who sometimes had seizures (fits)? [9,11,14,19,22,37,50-55,77]
- Do you allow your son to marry a girl with epilepsy?[57-60]
- Do you allow your daughter to marry a man with epilepsy?[57-60]
- Would you object to a person with epilepsy marrying a close relative of yours (brother, sister, or child)?[78,79]
- Would you object to your child getting married to a person with epilepsy?[18]
- Would you object to your son or daughter marrying a person with epilepsy?[44]
- Would you allow your children to marry people with epilepsy?[41,61,75]
- My child can marry a people with epilepsy.[23]
- Would you agree to marry (yourself or your children) with him/her provided this person is otherwise acceptable?[20,62,68]
- Would you approve if your son/daughter married a person with epilepsy?[45]
- I would object to the marriage of my child with someone who has epilepsy.[46]

Table 3-2: Examples of questions on attitudes towards employment in epilepsy

General statement

- Equal employment opportunities should be available to individuals with epilepsy.[63]
- Do you think people with epilepsy should or should not be employed in jobs like other people?"[9,11,14,19,22,37,50-55,77]
- Do you think that, in general, persons with epilepsy should be employed at the same jobs as other people?[53,78,79]
- Do you think that epilepsy patients can be employed?[28]
- Do you think that epilepsy is an important impediment for a job[42]

Personal consideration as an employer

- I would object to hiring someone who has epilepsy.[46]
- Would you employ someone with epilepsy?[47]
- Would you employ an epileptic?[32]
- Are you going to hire a person with epilepsy if you are an employer?[41]
- If you were an employer, would you hire people with epilepsy?[44,75]
- If you are an employer, do you allow a patient with epilepsy to be your employee?[57]
- If you were an employer, would you knowingly hire someone with epilepsy?[18]
- As an employer, would you hire a person who is subject to epileptic seizures?[80]
- Would you hire him/her in your own business provided he-she had the skills or qualifications for it?[62,68]
- Assuming you had a business of your own, would you hire an epileptic in your own business, if he/she has the skills or qualifications for it? [20]
- If you were an employer, would you terminate the employment of persons with epilepsy, if a seizure occurred during work because of unreported epilepsy?[18]

Personal consideration in relation to a specific job (with a choice of jobs including teacher, nurse, doctor etc.)

- Would you be willing personally to employ someone with epilepsy in a clerical job?[76]
- What jobs do you think epileptics should not be employed in?[20,57]
- Which, if any, of the following jobs do you think people with epilepsy should not be employed in?[39]

Most of the questions were phrased negatively, e.g. using the words "object"[14,19,37,50-55] and "should not"[56]. Some phrased the statement in a neutral tone, while others positively (e.g., "can"[23] and "allow"[57-60]).

Some questions asked in greater detail, for example, it was specified as "marry a girl" or "marry a man" in questions on attitudes against marriage[57-60], and in regards to employment participants were requested to consider the types of occupation.[20,39]

Terminology used also varied, in which the term "epilepsy" was most commonly used, though the words "seizures or fits"[9] used by Caveness were subsequently used in many other studies.[18,46,52-58]

Variability in study populations

Half (52.5%) of the studies were carried out within the general population, followed by 13.3% amongst teachers and students respectively. Ten papers reported the attitudes of health care providers, mostly general practitioners, but also included physicians, nurses, and psychiatrists; two studies were carried out amongst caregivers, and one amongst employers, clerics and police.

Some of the countries performed the studies within the general population as well as within a specific group, allowing indirect comparisons to be made. Using the percentage of participants with negative attitudes towards social contact in epilepsy as a mean of comparison, Table 3-3 shows that students had better attitudes towards epilepsy in most countries, except Turkey. Teachers had better attitudes in Thailand and Turkey[18,45], but conversely in India.[61]

Table 3-3: Comparison of the attitudes against social contact between the community, students and teachers, according to country

Country	Percentage of participants with negative attitudes against social contact in epilepsy*		
	Community (%)	Students (%)	Teachers (%)
Cameroon	15.9-51.4 [54,81-83]	14.6-37.9 [84-86]	
India	5.0-10.8 [28,49]	13.0-15.6 [27,87]	38.4 [61]
Korea	18.1-50 [36,41,62]		32.1 [75]
Kuwait	27.6 [44]	12.5 [76]	
Tanzania	51.0 [29]	46.0 [88]	
Thailand	17.3 [16]		2.8 [89]
Turkey	28.0 [51]	53.2 [24]	6.3 [45]

*Questions on attitudes against social contact, e.g. "Would you object to your children associating with people who sometimes had seizures?" were asked in the included studies. The percentages quoted were the percentage of the participants who gave a negative response to these questions.

Attitudes towards epilepsy when compared between people with epilepsy and their family members[78] showed that there were no significant differences in attitudes between the two groups. When compared to general populations[62], people with epilepsy had better attitudes toward epilepsy.

Quantitative and qualitative approaches

Questionnaires using a scale enabled the measurement of the attitudes towards epilepsy in a quantitative manner. Ten studies used either Likert's scale or a scoring system to measure attitudes towards epilepsy.[15,46,62-69] The scales, that had been developed or adapted from previous scales, included the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale[70], the Attitudes Toward Persons with Epilepsy (ATPE)[63,71], the Epilepsy Attitude Scale[46], and the Elementary School Epilepsy Survey (ESES)[67] for elementary school children. Although there were significant overlaps between the scales, there were also differences in questions, subscales, number of items, and scoring system.

One study in Africa used a qualitative approach (n=200) and provided new insight into some of the aspects of attitudes that would otherwise remain undetected using structured questionnaires, including attitudes such as tolerance, kindness, and sympathy towards people with epilepsy.[72]

Intervention studies

Five intervention studies using educational programs, personal contact, or educational material about epilepsy showed that besides an improvement in the knowledge about epilepsy, there was also significant improvement in the attitudes towards epilepsy.[24,36,47,73,74]

Discussion

Attitudes towards epilepsy and the associated factors

This study describes the prevalence and variability of public attitudes toward epilepsy. The variation of attitudes across geographical regions are likely multifactorial. In medical anthropology, the Western Civilization is viewed as depending mostly on a naturalistic explanation of illness. This probably minimizes the misconception and stigma in epilepsy, which may lead to better attitudes. In contrast, geographical regions with strong cultural perception of disease that rely on non-scientific explanation, e.g. Asia and Africa have poorer attitudes towards epilepsy. In addition, Western philosophy with emphasis on basic human rights could be another explanation for better attitudes in Western countries. Even though non-scientific influence on disease perception is still

predominant in Asia and Africa as evidenced by the misconception of epilepsy as spiritual, contagious and a form of insanity, modern scientific education and political emphasis on basic human rights might have a positive impact on these misconceptions. However we have yet no historical data to prove the above.

The inversely proportional relationship between the magnitude of negative attitudes towards epilepsy and the GDP per capita (Figure 3-4) might be indirectly related to modern education and emphasis on human rights, or directly related to economic status. As evidenced in many studies demonstrating better attitudes in urban population compared to rural population in the same region, economic status has a direct impact on attitude towards epilepsy. However, there are exceptions as shown in Figure 4, where the economic status is not the only variable explaining the variation in public attitudes.

Factors associated with negative attitudes towards epilepsy have been extensively examined. These include socioeconomic status, knowledge and education level, perception and misconceptions. However, we are uncertain about the actual reasons behind such negative attitudes. For example, a community that emphasizes a family's honor may be more likely to object to marriage with people with epilepsy as compared to a community that emphasizes freedom of choice in marriage. Therefore, the cultural values molding the attitudes should be explored qualitatively. The study by Chung, which reported a higher percentage of negative attitudes against employment in epilepsy in the Chinese and Vietnamese adults in United States as compared to American adults (43% vs. 8-22%)[9-14,18], suggested that cultural influence on public attitudes towards epilepsy might not be easily changed merely through geographical migration.

Study design

Questionnaires varied depending on the population studied, and the local cultural context and personal preferences, creating great difficulty in directly comparing published study results. A general statement tended to produce more positive results, giving a false impression. Questions which required personal consideration, either a marriage involving the participants or their children, were more reflective of the actual stigmatization, and this tended to skew the results negatively. In general, negatively phrased statements encouraged negative attitude as disagreeing with a negatively phrased statement is cognitively a complex task. Furthermore, statements which emphasized parental authority, e.g. “Would you object to having a son or daughter of yours marrying a person who sometimes had seizures (fits)?” may not be appropriate in a society that emphasizes freedom of choice; whereas statements using the word “can” assessed purely the personal perception of one’s suitability to work or marry, without taking the parental authority into account. Questions asked in greater detail, such as questions related to specific occupation, though providing the understanding of the discriminating factors like gender and types of occupation, might have excessively prolonged the survey.

Surveys on epilepsy patients allow us to determine the discrepancy between patients and the general population in knowledge and perception towards epilepsy. The degree of discrepancy will indirectly indicate the magnitude of social stigma in the studied population. Therefore, direct comparison of attitudes towards epilepsy between epilepsy patients and the public should be encouraged.

Previous studies had provided a way to measure public attitudes, either through a questionnaire or a scale, but lack of standardization of the study design made direct comparison among various studied populations difficult. A quantitative scale is essential and practical to provide an overall picture of attitudes in a selected study population, and allows for comparison among different populations. Furthermore, this approach allows monitoring of changes over time, as well as measuring the outcome of an intervention. However, none of the scales were widely accepted as a gold standard. Thus we should aim to develop a standardized, quantitative, and cross-cultural measure of public attitudes toward epilepsy for cross-sectional and longitudinal comparison.

Although there are specific questions dealing with a specific issue (e.g., employment), the results might not reflect the actual concerns of the community and employers, and the challenges faced by people with epilepsy. Therefore, qualitative assessment of the concerns and challenges should be encouraged.

Interventional studies have shown that education on epilepsy could improve attitudes in a studied group. These results reinforced the importance of public education in reducing the stigma of epilepsy. Furthermore, this interventional design might be effective in determining the usefulness of epilepsy awareness campaign in changing public attitudes. However, we are uncertain of whether improvement in socioeconomic status and education level of the population will translate into an improvement in public perception and attitudes towards epilepsy. Longitudinal studies in multiple regions are required to answer this uncertainty.

Most studies on attitudes are designed from a human rights perspective, to determine whether the patients are being discriminated against. Other attitudes such as

overprotection, empathy and tolerance, are equally important. For example, overprotection of children with epilepsy may affect their personality development. Therefore, future studies should also aim at greater understanding of these attitudes.

It is a methodological challenge to study how public attitudes might impact life of people with epilepsy. However, if we are unable to determine this relationship, we will face a bottleneck in research of public attitudes toward epilepsy.

Thus, studies on attitudes should be conducted continuously, particularly in populations prone to have negative attitudes with emphasis on underlying reasons, and progress should be monitored longitudinally. Attitudes of people such as parents, teachers, school counselors, health care professionals, and employers, which have direct impact on people with epilepsy, should be more extensively studied.

Limitations of the study

This review only included studies presented in English, as it is limited by the inaccessibility of journals written in other languages and the inability to interpret the results without translation. Nonetheless, as shown in Figure 1, the information about public attitudes towards epilepsy was available in most countries in each continent, except Africa and South America.

Conclusion

Since 1949, public attitudes towards epilepsy had been extensively studied with an exponential increase in publications in the past twenty years. However, the increase in

number of published studies did not lead to improved quality of care for people with epilepsy. This review presents the background, development and progression of research on public attitudes toward epilepsy, focusing on the status of attitudes across time and geographical regions, its associated factors, as well as the study design, aiming to provide a guide for future study.

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Chapter 4: Development and validation of the Public Attitudes Toward Epilepsy (PATE) scale

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Abstract

Introduction: A quantitative scale of public attitudes towards epilepsy is essential to determine the magnitude of social stigma against epilepsy. This study aims to develop and validate a cross-culturally applicable scale of public attitudes toward epilepsy. **Methods**: A set of questions was selected from questionnaires identified from a literature review, followed by a panel review performed to determine the final version, consisting of 18 items. A 1-5 Likert scale was used for scoring. Additional questions, related to perception of the productivity of people with epilepsy and a modified epilepsy stigma scale, were added as part of construct validation. One hundred and thirty heterogeneous respondents were collected, consisting of various age groups, ethnicity and occupation status levels. **Results:** After item and factor analysis, the final version consisted of 14 items. Psychometric properties of the scale were first determined using factor analysis, which revealed a general and a personal domain, with good internal consistency (Cronbach's coefficient 0.868 and 0.633, respectively). Construct validation was demonstrated. The mean score for the personal domain was higher than the general domain (2.72$\pm$0.56 and 2.09$\pm$0.59 respectively). The mean scores of those with tertiary education were significantly lower for the general domain but not the personal domain. Age was positively correlated with the mean scores in the personal domain but not the

general domain. **Conclusion:** This scale is a reliable and valid scale to assess public attitudes toward epilepsy, in both the general and personal domains.

Key words: Epilepsy, attitudes, stigma, social stigma, scale

Introduction

Stigma against epilepsy has been accepted as one of the key factors influencing quality of life for people with epilepsy. [1-4] Stigma against epilepsy is generally based on stereotypical and uninformed impressions or characterizations of epilepsy. People with epilepsy tend to be related to an epileptic identity, which is passively accepted as undesired difference. [5] They are commonly negatively stereotyped as having a socially discredited personality. [6]

Socioeconomically, the stigmatized person experiences discrimination in the working place, school, and community. Psychologically, those who perceive themselves to be members of a stigmatized group, whether or not it is acknowledged by others, often experience psychological distress and many view themselves contemptuously.[7] Stigma often acts as a self-fulfilling prophecy in that those who are stereotyped often start to act in ways perceived as expected by the stereotyping perceiver. This psychological process is not limited to change in behaviour, but may also shape emotions and beliefs. In turn, these stereotypic beliefs become reinforced and further perpetuated by disabilities and dysfunctional behaviours caused through self-fulfilling prophesy.

A systematic review was performed to understand the scope and extent of studies of public attitudes towards epilepsy. [8] These studies of public attitudes towards epilepsy

typically were conducted both in general populations and in specific groups (e.g. teachers and students), as well as among epileptic populations, of various ethnicities and geographical regions. The initial study, done by Caveness in 1949, focused on questions related to the rights of people with epilepsy to marry, be employed and socially contacted, and has been widely applied thereafter. However, these studies mostly used a 'yes' or 'no' format and only direct comparison among groups was possible.

Quantitative study design using a scale allows us to measure the degree of social stigma, so facilitating the design of interventional strategies to break the stigma cycle of epilepsy. Up until 2011, ten studies using either Likert's scale or a scoring system to measure attitudes towards epilepsy were identified. [9-18] The scales included the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale [19], the Attitudes Toward Persons with Epilepsy (ATPE) scale [9,20] the Epilepsy Attitude Scale [15], and the Elementary School Epilepsy Survey (ESES) [14] for elementary school children.

These scales were factored into negative stereotypes, risk and safety concerns, fear and social avoidance, and behavioural optimism, as well as social integration. [9,19,20] However, statements on factors like negative stereotypes (for example, "People with epilepsy are possessed by a supernatural spirit.") may not prevail in some cultures. Thus, disagreement with these statements by the majority of the studied population does not necessarily imply more positive attitudes towards epilepsy in this population. As a result, these scales may not be suitable for some cultural groups.

Link and Phelan [21] proposed a four-component stigmatization model, inclusive of (1) Differentiation and labelling: Individuals differentiate and label human variations; (2) Linking to stereotypes: Prevailing cultural beliefs tie those labelled to adverse attributes;

(3) Separation between us and them: Labelled individuals are placed in distinctive groups that serve to establish a sense of disconnection between "us" and "them"; and (4) Disadvantage: Labelled individuals experience "status loss and discrimination" that leads to unequal circumstances. Of these four components, differentiation and labelling, and stereotyping may vary among different cultures. The third and fourth components, i.e. separation between us and them, and disadvantage, picture the consequences of stigmatization, irrespective of the types of differentiation and labelling. Therefore, statements developed based on these first two components of the stigmatization model, i.e. differentiation and labelling, and stereotyping, may not be suitable to be applied universally; whereas statements related to the third and fourth components will do otherwise.

Most studies on attitudes towards epilepsy included a knowledge component, which is a broad category including the participant's exposure to seizures and people with epilepsy and their perceptions of its causes, manifestations, timeline and consequences. However, correlation analyses have usually been performed on knowledge as a whole rather than on individual subcategories. Furthermore, there are marked cultural variations, e.g. some cultures may consider epilepsy as contagious but others not. However, this knowledge might change over time e.g. the concept of hereditary following an exponential development in genetics.

The initial questions on public attitudes towards epilepsy focused on questions requiring the participants to make a personal judgement. For example, "I would get divorced if my spouse was diagnosed with epilepsy." [10] There is a lack of questions enquiring about general opinions on the right of people with epilepsy to be socially contacted, employed,

and educated. This variation in question design is expected to enable us to understand a broader spectrum of stigmatization, from a general as well as personal perspective.

The Epilepsy Attitude Scale [15] factored the scale according to positive and negative attitudes. In general, negatively phrased statements tend to encourage negative attitude expression as disagreeing with a negatively phrased statement is cognitively a complex task. Thus, including both positive and negatively phrased statements in the same scale will allow us to capture a broader range of response. However, instead of factoring the scale into two separate components, it would be more appropriate to combine both positively and negatively phrased items using a reverse scoring for one component because of its similar context of measurement.

In this study, we aimed to develop a scale measuring public attitudes towards epilepsy, which can be applied cross-culturally as characterized by: (1) including statements related to separation and disadvantages in Link's stigmatization model [21], (2) excluding questions testing the participants' knowledge and perception of epilepsy, (3) including statements of general opinions about epilepsy as well as statements requiring personal judgement, and (4) including both positively and negatively phrased statements.

Methodology

1. Scale Development

The scale was developed in three phases: (1) formative research and concept development; (2) item development; (3) data collection, reliability and validity testing. Phase one included a review of literature on attitudes towards epilepsy published before

May 2011. [8] In phase 2, a set of 52 items, assessing the separation and disadvantages of people with epilepsy, were selected from the reviewed literature. These items focused on social restriction of people with epilepsy, specifically related to education, employment, personal and marital relationship. These items were reviewed by a panel of neurologists, leading to a set of 18 items that were judged unambiguous, non-redundant and that elicited relatively extreme responses.

These items were conceptualized into two components. The first component consisted of items requiring long term or higher level of commitment, e.g. marrying with or employing someone with epilepsy. The second component assessed respondents' opinions which required lower level of personal commitment, e.g. social contact with PWE or general opinions regarding the human rights of PWE. Conceptualization of the items into two components was expected to provide an understanding of public attitudes towards epilepsy from two different perspectives. The first perspective is the understanding of actual stigmatization using items requiring consideration of higher personal commitment but the response will tend to be skewed; whereas it was expected that items requiring a general opinion would elicit a less skewed response.

These items were then randomly arranged and a 5-point Likert scale was added with 1 being strongly disagree and 5 being strongly agree, chosen because scales with five to seven options are more valid than those with fewer options. [22] In addition, a scale with a middle point, indicating neutral in opinion, was chosen to ensure the accuracy of information collected and to prevent social desirable effect, though certain respondents might tend to be neutral in most items. To prevent this, the respondents are encourage to make a stand in as many items as possible. The score for all positively stated items, e.g. "People with epilepsy have the same rights as all people." were reversed, so that the

weighted sums of the items provide a measure of the respondent's attitudes towards epilepsy, with a higher score indicating a more negative attitude.

2. Sample recruitment

Selective (diversity) sampling of 130 respondents was performed in Petaling Jaya and Kuala Lumpur in Malaysia after approval from the ethics committees at the University Malaya Medical Center (MEC Ref No: 878.10). Petaling Jaya and Kuala Lumpur were selected because they are two of the urban cities with highest population density, rural-to-urban migration, and highest number of foreigners. Diversity sampling in these cities allowed data collection from different age groups, ethnicities, and socio-economic status levels, including a subset of foreigners. Written consents were obtained. All questionnaires were administered anonymously.

3. Measures

Demographic data were also collected on the respondent's gender, age, ethnicity, marital status, education and employment status, current monthly income, and presence of family member(s) with epilepsy or seizures. The instructions emphasized that the scale was not a test, but rather an opinion questionnaire.

Three questions related to perception of the unproductivity of people with epilepsy were added, as part of testing for construct validity. (Appendix 1) A 5-point Likert scale was added to these questions with 1 representing 'strongly disagree' and 5 'strongly agree'. A higher score indicated a stronger perception of people with epilepsy being unproductive.

The epilepsy stigma scale is a 3-item scale assessing the patient's perception of stigma [23], using a 5-point Likert scale. It is a validated scale to determine the perceived stigma against people with epilepsy. The statements were mirrored to be answered by someone without epilepsy. (Appendix 1) This mirror version was established to provide a measure of social stigma, for testing construct validity. A higher score indicated a higher level of social stigma towards people with epilepsy.

4. Statistical analysis

This study employed the Statistical Package for Social Sciences version 19 (SPSS 19.0) for data analyses. All demographic data was analyzed descriptively and presented as frequencies as well as percentages. For continuous data, independent t-tests were used for group comparison.

Psychometric properties of the scale

Exploratory factor analysis

Exploratory factor analysis was conducted to determine how well the factor structure revealed fitted with the original concepts identified as potential components of an attitude towards epilepsy. [24] First, a scree test was used to determine how many components should be formed. Correlation matrices were then used to understand the relationships between items. Variance accounted for by each of the items within these measures was assessed using extraction communalities, and any items with extraction communalities below 0.2 at this stage were dropped from further analysis. Factor

extraction provided loading values to indicate the degree of involvement of items in each factor pattern. Following initial factor extraction, an oblimin rotation with Kaiser Normalization was used to transform the original matrices for easier interpretation. The post-rotation factor loadings measure the importance of an item within each factor and therefore were used to determine the items contributing to each factor. Items were considered acceptable and retained if the loading coefficient was 0.4 or greater and differences of at least 0.2 existed between the loadings on the two factors. Items loading on more than one factor were ascribed to the factor for which the loading coefficient was highest. Correlation matrices were examined to look for correlations ≥ 0.9, which indicates item redundancy. Observation of the high loading items enabled interpretation and naming of the final components of the scale.

Reliability

Item analysis, by calculating the Cronbach's α value, was used to assess the internal consistency of the overall scale and its components. Cronbach's α values of 0.7 to 0.9 are considered acceptable [25]; whereas values of 0.6 to 0.7 are considered satisfactory. Test-retest reliability was not included as a measure of reliability, as it may underestimate the degree of reliability of measurements over time by interpreting true change as measurement instability. [26] Mean inter-item correlation was used if α values were below 0.7, and a range of 0.2 to 0.4 was taken to indicate that items were measuring the same construct. [27]

Validity

Construct validity was assessed, given that there is no "gold standard" for the measurement of public attitudes towards epilepsy. Three a priori predictions were made based on hypothesized theory that, if upheld, would offer support of construct validity: (1) subjects who perceived people with epilepsy as being less productive would have overall more negative attitudes towards epilepsy; (2) subjects who had a higher stigma score using the modified Jacoby's stigma scale would have more negative attitudes towards epilepsy, and (3) subjects who had a lower education level would have more negative attitudes towards epilepsy. Pearson correlation was used to test the first two predictions and coefficients of 0.5 to 1.0 were accepted as supportive of construct validity. [28] Convergent validity was assessed by testing the correlation between the score on each component and the total score.

Results

Demographic characteristics of the sample

A total of 130 respondents were recruited from the public, caregivers of persons with epilepsy, and medical personnel. The mean age of the respondents was 41.4 $\pm$ 14.6 years, ranging from 19 to 74 years. The respondents were almost equally distributed in gender, with slightly higher proportions of Malay and Chinese compared to other ethnic groups. More than half were married (56.9%), with a tertiary education level (54.7%), and had fulltime employment (58.5%). Approximately 9.2% of the respondents had family member(s) with epilepsy or seizures (See Table 4-1).

Table 4-1: Demographic characteristics of the respondents (n=130)

		Number (%)
Gender	Male	66 (50.8)
	Female	64 (49.2)
Race	Malay	43 (33.1)
	Chinese	46 (35.4)
	Indian	30 (23.1)
	Others (including non-Malaysian)	11 (8.5)
Marital status	Married	74 (56.9)
	Single	50 (38.5)
	Widowed	4 (3.1)
	Divorced	2 (1.5)
Education level	No formal education	0
	Primary	0
	Secondary	22 (16.9)
	A level	37 (28.5)
	Degree	50 (38.5)
	Post graduate	21 (16.2)
Employment status	Fulltime student	17 (13.1)
	Fulltime house duties	9 (6.9)
	Employed part time	8 (6.2)
	Employed full time	76 (58.5)
	Unemployed	2 (1.5)
	Retired	16 (12.3)
	Others	2 (1.5)
Individual monthly income (Ringgit Malaysia)	None	22 (16.9)
	1000 and below	8 (6.2)
	1001-2000	24 (18.5)
	2001 and above	76 (58.5)
Family member with epilepsy/seizures	Yes	12 (9.2)

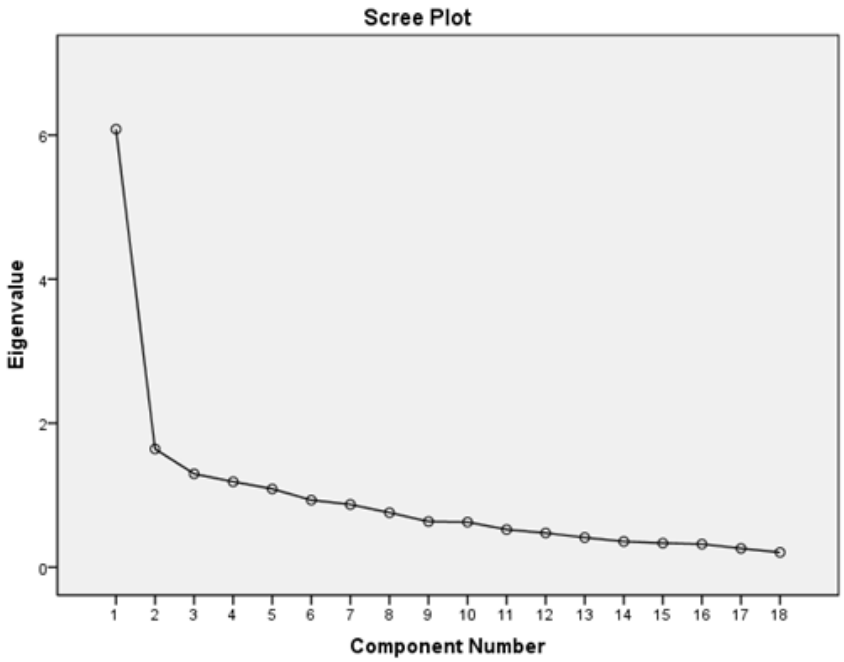
Psychometric properties of the scale

Exploratory factor analysis

Bartlett's test of sphericity was significant, indicating a rejection of the null hypothesis that there is no relationship among items (χ^2= 863, df=153, p<0.001). A scree plot was used to study the overall structure of the questionnaire (Figure 4-1). The elbow point on the scree plot revealed a two-component structure. The Kaiser-Meyer-Olkin test (KMO),

a measure of sampling adequacy that tests the strength of partial correlations among variables when the linear effects of items have been removed, showed a KMO estimate of 0.841, exceeding the criterion of ≥0.7.

Figure 4-1: Scree plot of the items related to attitudes towards epilepsy.



No items were excluded because of low extraction communalities (below 0.2). Using an oblimin rotation with Kaiser Normalization for a two-factor model, these items were loaded into two domains with nine and five items respectively, as shown in Table 4-2 with the factor loadings of each item. Items 2, 5, 10 and 18 were excluded because they failed to reach the 0.4 cut-off in the rotated factor matrix. Correlation matrices showed none of the correlations was beyond the 0.9 range that would have indicated item redundancy.

Table 4-2: Rotated factor matrix for attitudes towards epilepsy

Item		Mean (SD)	Factor	
			1	2
15	People with epilepsy should not study in college or university.	1.82 (0.70)	0.868	
11	People with epilepsy have the same rights as all people.	2.05 (0.91)	0.805	
12	People with epilepsy should be isolated from others.	1.94 (0.84)	0.773	
14	People with epilepsy should not participate in social activities.	2.00 (0.78)	0.681	
6	I will not mind being seen in company with someone known to have epilepsy.	2.06 (0.77)	0.657	
13	People with epilepsy should not marry.	2.06 (0.78)	0.634	
8	I would stay away from a friend if I knew she/he had epilepsy.	2.08 (0.92)	0.620	
16	People with epilepsy should study in a special school.	2.43 (0.97)	0.603	
17	Schools should not place children with epilepsy in regular classrooms.	2.35 (0.90)	0.499	
7	I would date someone even though he/she has epilepsy.	2.78 (0.84)		0.822
4	I would marry someone with epilepsy, even though he/she had epilepsy.	3.03 (0.85)		0.686
1	I would feel uncomfortable working with someone who has epilepsy.	2.42 (0.87)		0.601
3	I would advise my family members against marrying someone with epilepsy.	2.95 (0.91)		0.561
9	If I were an employer, I would give equal employment opportunities to someone with epilepsy.	2.41 (0.96)		0.456

Note: Items 2 (I think people with epilepsy should be employed in jobs like other people), 5 (I will not change the way I treat someone after knowing that he/she has epilepsy), 10 (It is important for someone with epilepsy to find a job) and 18 (The onset of epileptic seizures in a spouse is sufficient reason for divorce) were dropped because they loaded <0.40.

The nine items loading on the first domain assess the general opinions on the rights of PWE to study, participate in social activities, and marry, as well as the ways in which the respondents would treat someone with epilepsy. This domain required minimal or no consideration of respondents' personal involvement, and thus was named the "general domain". The second domain with five items loaded is about marrying a person with epilepsy, working with them or employing them. This domain concerned a

long-term personal commitment or involvement, and thus was named as the "personal domain".

Reliability

Cronbach's α for the general domain was 0.868 (within acceptable range of 0.7-0.9), with mean inter-item correlations of 0.433, and corrected item-to-total correlations ranging from 0.544 to 0.764, as shown in Table 4-3. Whereas for the personal domain, Cronbach's α was 0.633 (satisfactory) with mean inter-item correlations of 0.263, and corrected item-to-total correlations ranging from 0.266 to 0.556 (Table 4-3).

Table 4-3: Internal reliability and convergent validity of each domain

Domain (number of items)	Mean (SD)	Reliability (Cronbach's α)	Mean inter-item correlation	Convergent Validity (correlation with total score)
General domain (9)	2.24 (0.48)	0.868	.433	0.933*
Personal domain (5)	2.70 (0.55)	0.633	.263	0.736*

*significant at $p<0.001$

Validity

Three a priori predictions were made to assess construct validity of the attitudes scale. First, we expected subjects who perceived that PWE were less productive would have a more negative attitude or overall higher total score. This prediction was supported by strongly significant correlation between the mean score for perception of unproductivity in PWE and the total attitudes score, of 0.736 ($p<0.001$). Second, the mean stigma score using the modified Jacoby's stigma scale was moderately correlated with the total

attitude score with a Pearson correlation coefficient of 0.589 (p<0.001), supporting the second prediction. Third, those with education level less than tertiary level had a higher mean total attitude score, as compared to those with tertiary education level and above (2.42 $\pm$ 0.40 vs. 2.22 $\pm$ 0.56 respectively, p-value < 0.05), supporting the third prediction.

Convergent validity was demonstrated, as evidenced by strong and significant correlations between the individual domains and the total attitudes score (r=0.933 and 0.736, p<0.001, for the general and personal domains respectively, as shown in table 4-3).

Factor scores by domains and demographic characteristics

Mean scores were calculated for each domain, with a possible range from 1 to 5. Higher scores indicated more negative attitudes. The mean and standard deviation of the total score was 2.31 $\pm$ 0.50. The mean score for the personal domain was higher than for the general domain (2.72$\pm$0.56 and 2.09$\pm$0.59 respectively).

The mean scores for the general domain were shown by t-test to be significantly lower in those with tertiary education (p<0.001), but did not differ by age, gender, marital status, employment status, monthly income or family history. For the personal domain, age significantly predicted mean scores. Persons with single marital status had lower mean scores in the personal domain ($p<0.05$) but no significant difference was observed for the general domain. (Table 4-4)

Table 4-4: Mean scores by domains and demographic characteristics (n=130)

Variable	Group (n)	General domain	Personal domain
Age[1]		-0.062	0.175*
		Mean score (SD)	Mean score (SD)
Gender	Male (66) Female (64)	2.10 (0.58) 2.07 (0.60)	2.75 (0.56) 2.68 (0.58)
Marital status	Single (50) Others (80)	2.14 (0.65) 2.05 (0.55)	2.58 (0.62) 2.81 (0.51)*
Education level	Tertiary (71) Others (59)	1.96 (0.62) 2.24 (0.51)**	2.68 (0.65) 2.76 (0.43)
Employment status	Employed full time (76) Others (54)	2.09 (0.61) 2.09 (0.57)	2.71 (0.55) 2.73 (0.59)
Monthly income in Ringgit Malaysia	2000 and above (76) Others (54)	2.03 (0.59) 2.17 (0.59)	2.74 (0.59) 2.68 (0.53)
Family member with epilepsy/seizures	Yes (12) No (118)	2.08 (0.54) 2.09 (0.60)	2.80 (0.61) 2.71 (0.56)

[1]Based on Pearson correlations
*p-value is < 0.05 **p-value is <0.001

Discussion

The PATE scale was developed in response to a need for a brief, quantitative, easy-to-use, and psychometrically sound tool to measure public attitudes towards epilepsy, which can be employed in various cultural groups. Findings from the analysis confirmed that the attitude scale has good item properties, and is valid and reliable.

After item and factor analysis, four items were omitted. The final version consisted of 14 items. Factor analysis revealed two spectrums of stigmatization, a "general domain" with minimal personal commitment and a "personal domain" which requires long-term commitment. Factor loadings were high on each dominant factor and low on the nondominant factor. Statistical tests indicated the data was factorable based on sufficient sample size relative to the number of items on our scale. [29] None of the interitem correlations within each factor had correlation coefficients above 0.8, supportive of the claim that there is no significant redundancy. Each subscale

demonstrated acceptable internal consistency, with Cronbach's α of the general domain within an acceptable range of 0.7 to 0.9, and Cronbach's α of the personal domain within a satisfactory range of 0.6 to 0.7.

Factor scores differed by domains. In previous studies without a general and personal dichotomy, people from rural areas with lower educational level and socioeconomic status have been found to have more negative attitudes towards epilepsy. [18,30-38] Other factors include old age [34-36,39], male gender [32,33,37], female gender [35], being single [37], and Hindu ethnicity. [40] In the current study, attitudes towards epilepsy in each demographic group differed by domain assessed. Age was found to be positively correlated with attitude scores in the personal domain, but not in the general domain. That is to say, older participants gave higher scores indicating a less favourable attitude when relating to epilepsy in a personal context. In the general context however, there seemed to be no difference in attitude relating to age. In addition, participants with higher education displayed better attitudes towards epilepsy in the general domain but this difference in attitude was not observed in the personal domain.

Increased levels of stigma expressed by the older participants in the current study may be explained by Socioemotional Selectivity Theory [41], which posits differences in selecting social network composition and social preferences based on increasing chronological age. With advancing age, perception of the limitation on time leads to psychological and emotional needs to optimize one's social network units. Pruning of the compositional units in one's social network may occur resulting in a smaller social circle with increased emotional bonding. Older participants may be more stigmatized towards those with epilepsy in context of their personal association but not in general perception, due to this selection process.

With respects to the relationship found between increased education and better general attitudes towards epilepsy patients, the current results seem to support previous stigma research conducted in the area of chronic illnesses such as HIV/AIDS [42], whereby effectiveness in reducing stigma is achieved to various degrees through increased education in forms of information and exposure.

It is of note however, that while this positive correlation was observed, it was confined to the general domain and no such relationship was found in the personal domain. This seems to suggest an isolation of generalized knowledge-based attitude from an interpersonal emotion-based attitude in the perception of sufferers of epilepsy. A plausible explanation of this finding may lie in Evolutionary Psychology and its conceptualization of stigma. Past research has proposed through the notion of natural selection, the unique function of the formation of stigmas in achieving optimum genetic material for the survival of future progeny [43]. Therefore in contexts of personal contact and socialization, increased education had no effect on personal attitude.

Limitations of the study

This study may be biased by only being performed in an urban city in Malaysia. However, a selective sampling was performed with the aim to include a broad category in each demographic variable to overcome selection bias. From the demographic data, about 40% of the respondents had an education level below tertiary and an income less than RM2000 a month, which can categorize them into the lower socio-economic group.

Further studies using the scale to assess attitudes to people with epilepsy using an adequate sample of a known population are requied to provide further validation.

A second limitation was that the scale requires English fluency, reading comprehension, and functional capacity, which may have excluded non-English-speaking population, and adults with limited education. Malaysia is a multi-ethnic country, using various languages in daily life. There might be cultural differences between groups using different languages. Further research could investigate this

Two validity measures, i.e. perception of the productivity of people with epilepsy and a modified epilepsy stigma scale, were initially used in this study to determine the construct validity. However, on retrospective review, these two measures, though measuring different aspects of social stigma, were not ideal because of their similarities in content with the attitude scale. A high correlation may reflect shared biases. Thus, a third hypothesis, i.e. subjects who had a lower education level would have more negative attitudes towards epilepsy, was added to strengthen the construct validity.

Study implications

In order to overcome the shadow of stigmatization, we need an effective tool to measure the degree of social stigma cross-sectionally as well as longitudinally. Using Link's stigmatization model as a guide, items with least cultural influence were selected, so that the scale can be applied cross-culturally and allows comparison between various populations. With its convenient size of only 14 items, together with its reliability and validity, the usefulness of the scale in measuring the attitudes towards epilepsy quantitatively is fully supported.

Variation in attitude scores between the personal and general domains has not been reported before. This might explain the variation in results from previous studies on public attitudes towards epilepsy, when different questions were used. In addition, this finding provides a reason to study the underlying social and psychological factors affecting social stigma not only from the general perspective, but also from an individual perspective.

Knowledge about epilepsy has been shown to be an important factor in reducing the degree of discrimination and negative attitudes toward epilepsy. [18,31-36,39] Intervention studies using educational programs about epilepsy have found significant improvement in attitudes towards epilepsy among the educated. However, as people with higher education were found to have better attitudes towards epilepsy in the general domain but not in the personal domain, the improvement in the attitudes with educational programs might have been limited to attitudes in the general domain. This question requires further research.

Conclusion

A scale assessing public attitudes towards epilepsy was developed using criteria that allow it to be applied in various cultural groups. This study has demonstrated that it is a psychometrically valid and reliable tool for measuring public attitudes towards epilepsy in both the general and personal perspectives.

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Appendix 1: Public Attitudes Toward Epilepsy (PATE) Scale and scoring manual

This scale aims to understand the view of general public related to seizures and epilepsy. Answering these questions will indicate that you have consented to participate in this study.

Instructions: Answer the following questions as spontaneously as possible. There is no right or wrong answer. Each question can have one of 5 possible answers, as followed. Circle the answer closest to your view.	**Strongly disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
1. People with epilepsy should not study in college or university.	**1**	**2**	**3**	**4**	**5**
2. People with epilepsy have the same rights as all people.*	**1**	**2**	**3**	**4**	**5**
3. People with epilepsy should be isolated from others.	**1**	**2**	**3**	**4**	**5**
4. People with epilepsy should not participate in social activities.	**1**	**2**	**3**	**4**	**5**
5. I will not mind being seen in the company with someone known to have epilepsy.*	**1**	**2**	**3**	**4**	**5**
6. People with epilepsy should not marry.	**1**	**2**	**3**	**4**	**5**
7. I would stay away from a friend if I knew she/he had epilepsy.	**1**	**2**	**3**	**4**	**5**
8. People with epilepsy should study in a special school.	**1**	**2**	**3**	**4**	**5**
9. Schools should not place children with epilepsy in regular classrooms.	**1**	**2**	**3**	**4**	**5**
10. I would date someone even though he/she has epilepsy.*	**1**	**2**	**3**	**4**	**5**
11. I would marry someone with epilepsy, even though he/she has epilepsy.*	**1**	**2**	**3**	**4**	**5**
12. I feel uncomfortable working with someone who has epilepsy.	**1**	**2**	**3**	**4**	**5**
13. I will advise my family members against marrying someone with epilepsy.	**1**	**2**	**3**	**4**	**5**
14. If I am an employer, I would give equal employment opportunities to someone with epilepsy.*	**1**	**2**	**3**	**4**	**5**

*Reverse scoring is required for these items.

The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy (Lim, 2012)[1]. A 1-5 Likert scale was used for scoring with 1 being strongly disagree and 5 being strongly agree. Some items were reverse

scored so that a higher score would indicate a more negative attitude. This scale was performed in a general population and factored into two domains, i.e. a general domain (items 1-9) that required minimal or no consideration of respondents' involvement, and a personal domain (items 10-14) that required a long-term personal commitment or involvement. This is a validated scale with good internal consistency (Cronbach's alpha of 0.868 and 0.633, in the general and personal domains respectively).

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Appendix 2: Additional questions for construct validity.

Modified epilepsy stigma scale

1. I think people with epilepsy are inferior.
2. I am uncomfortable with people with epilepsy.
3. I would prefer to avoid people with epilepsy.

Perceptions of people with epilepsy being unproductive

1. People with epilepsy usually fail to reach the required standards of society.
2. People with epilepsy have low productivity.
3. People with epilepsy are not able to assume responsibility.

Chapter 5: Malay Public Attitudes Toward Epilepsy (PATE) scale: translation and psychometric evaluation

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Abstract

Introduction: None of the quantitative scale for public attitudes toward epilepsy was translated to Malay language. This study aimed to translate and test the validity and reliability of a Malay version of the Public Attitudes Toward Epilepsy (PATE) scale. **Method:** The translation was performed according to standard principles and tested in 140 Malay-speaking adults aged more than 18 years for psychometric validation. **Results:** The items in each domain had similar standard deviations (equal item variance), ranged from 0.90-1.00 in personal domain and 0.87-1.23 in general domain. The correlation between an item and its domain was 0.4 and above for all, and higher than the correlation with the other domain. Multitrait analysis showed the Malay PATE had a similar variance, floor and ceiling effects, and relative relationship between the domains, as the original PATE. The Malay PATE scale showed a similar correlation with almost all demographic variable except age. Item means were generally clustered in the factor analysis as hypothesized, except item 1 and 2. The Cronbach's α values was within acceptable range (0.757 and 0.716 for the general and personal domains, respectively). **Conclusion:** The Malay PATE scale is a validated and reliable translated version in measuring the public attitudes toward epilepsy.

Keywords: Malay, PATE scale, attitudes, epilepsy, public

Introduction

People with epilepsy are burdened by a multitude of social, psychological and economic consequences of stigmatization which leads to poor quality of life.[1,2] There are great variations in social stigma among various countries, ethnicities and cultural groups, affected by various socio-economic and cultural factors. Assessment of the public attitudes toward epilepsy is therefore best conducted in local languages.

Majority of the Malaysian population is Malay (50.4%) and most Malaysians speak the Malay language, which is the national language. Surveys on public attitudes toward epilepsy in Malaysians in Malay language had been performed previously.[3,4] However, a standard and quantitative scale was not used in these studies, resulting in difficulty in comparing the results.[5]

There were a few quantitative assessment tools for public attitudes toward epilepsy, such as the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale[6], the Attitudes Toward Persons with Epilepsy (ATPE)[7,8], the Epilepsy Attitude Scale[9], and the Elementary School Epilepsy Survey (ESES)[10] for elementary school children, but not all can be applied cross-culturally as limited by items related to local perception of epilepsy and none was translated into Malay language. The Public Attitudes Toward Epilepsy (PATE) scale was designed to be applied cross-culturally, as characterized by the following: (1) including statements related to separation and disadvantages in Link's stigmatization model[11], which are universally applicable, and (2) excluding questions

testing the participants' knowledge and perception of epilepsy, which are culturally dependent.

The aim of this study was to test the validity and reliability of a Malay version of the Public Attitudes Toward Epilepsy (PATE) scale.

Methodology

The Public Attitudes Toward Epilepsy (PATE) scale (Lim et. al. 2012) is a two-dimensional 14-item scale measuring public attitudes towards epilepsy.[5] The two dimensions which the scale measures are (1) personal dimension/domain, includes items that require participants to consider personal involvement and commitment with sufferers of Epilepsy and (2) general domain, in which a general opinion of patients of Epilepsy. Each item on the PATE is scored using a 5-point Likert scale with 1 being "strongly disagree" and 5 being "strongly agree". A higher total score reflects more negative attitudes towards epilepsy. PATE scale is a valid and reliable test instrument, demonstrating appropriate content and construct validity. Cronbach's coefficient was reported to be 0.633 and 0.868 for each respective dimension.

The translation process of PATE scale was performed using a three-stage cross-cultural adaptation process as developed by the International Quality of Life Assessment project[12], i.e. (1) translation and cultural adaptation of the original scale into the Malay language, and evaluation to ensure conceptual equivalence, (2) formal psychometric testing of the assumptions underlying item scoring and construction of multi-item scales, to ensure that the scoring algorithms can be applied to the population concerned, and (3) validation and norming studies that provide a basis for interpretation.

Participants

Ten Malay-speaking adults from various socioeconomic backgrounds were included in the translation and cultural adaptation process. For psychometric validation, a convenience sampling of 140 Malay-speaking adults aged more than 18 years, from a wide range of age and socioeconomic background. Samples were recruited from Petaling Jaya and Kuala Lumpur, the two most populous and culturally diverse cities in Malaysia. All questionnaires were self-reported and administered anonymously. Consent was obtained whence participants responded to the questionnaire. Demographic information on age, gender, education level, and social strata by occupation were also obtained. This study was approved by the ethics committees of the institutional review board (MEC Ref No: 878.10).

Translation and cultural adaptation

The Malay translation of the PATE scale was performed according to the Principles of Good Practice Translation and Cultural Adaptation of Patient Reported Outcomes Measures[13], which include preparation, forward translation and reconciliation, backward translation, harmonization, cognitive debriefing, and finalization. With these principles, the aim was to develop a culturally sensitive version of the scale that was equivalent to the original in the following aspects: item, semantic, operational and measurement equivalence.

Translation: The PATE scale was first transferred to an Excel file for translation. Forward translation was performed by two independent translators and the two translations was reconciled into a single form. The reconciled form was back translated

into English by two independent translators, and combined into one back translation. The back translation was compared with the original version. Differences was highlighted and discussed by a panel consisted of two neurologists, a psychologist and a statistician, and changes were made accordingly to ensure consistency in the concepts between the original and the translations. This resulted in the Malay translated versions of PATE.

Cognitive debriefing: To pretest the questionnaire, semi-structured interviews were conducted with 10 Malay speaking participants. The interviews explored questions' relevancy and understandability besides identifying potential difficulties in responding.

Finalization: An expert panel meeting was organized to evaluate the content and face validity of the translated versions, the results of the pretesting, and the equivalence with the original i.e. conceptual, semantic and normative equivalence for each item.

Statistical analysis

All data analyses were performed using Statistical Package for Social Sciences version 19 (SPSS 19.0). All demographic data were analyzed descriptively and presented as frequencies and percentages. For continuous data with normal distribution, independent t-tests were used for group comparison.

Psychometric and validation testing

Validity: Multitrait analysis and principal-axis factoring were used to evaluate the validity of the translation based on the following assumptions:

1. Equal item variance: Items measuring the same concept should have approximately equal variances (standard deviations).
2. Convergent validity: Items in a given scale should contain approximately the same proportion of information about a concept, with roughly equal item-total correlation.
3. Discriminant validity: An item should correlate higher with its hypothesized scale than with scales measuring other concepts, tested with correlation analysis.
4. Construct validity: The construct of the translated version as assessed by principal-axis factor analysis should be similar to the initial study. In addition, it was hypothesized that (a) the scale means and standard deviations, and floor and ceiling effects of this translation, and (b) the relative relationship between the personal and general domain, were comparable to the initial results of PATE scale in Malaysian population.[5] Correlation between the mean score of each domain and the demographic variables were also assessed with a hypothesis that the current study should have similar correlation patterns as reported previously.[5]

Reliability: Item analysis was performed to assess the internal consistency of the overall scale and its components. Cronbach's α values of 0.7 to 0.9 were considered acceptable[14]; whereas values of 0.6 to 0.7 are considered satisfactory. Mean inter-item correlation was used if α values are below 0.7, and a range of 0.2 to 0.4 are used to ensure that items are measuring the same construct.[15] Item-total correlation of 0.3 and above was used to indicate that the item correlated well with the scale overall.[16]

Results

One hundred and forty Malay-speaking adults with mean age of 36.4 years (SD 13.4 and range 16-78) were recruited. There were slightly more females in the sample. The

samples were predominantly of Malay ethnicity and married. Approximately two-thirds of the participants had tertiary education level and with full-time employment. About 5.7% of the participants had family history of epilepsy. (Table 5-1)

Table 5-1: Demographic characteristics of the respondents (n=140)

Characteristics	Frequency (%)
Age	36.4 (13.4)*
Gender	
Male	65 (46.4)
Female	75 (53.6)
Race	
Malay	117 (83.6)
Chinese	2 (1.4)
Indian	17 (12.1)
Others	4 (2.9)
Marital status	92 (65.7)
Married	42 (30.0)
Single	4 (2.9)
Widowed	2 (1.4)
Divorced	
Education level	
None or primary education	2 (1.4)
Secondary	54 (38.6)
Pre-University	42 (30.0)
Degree	37 (26.4)
Post graduate	5 (3.6)
Employment status	17 (12.1)
Fulltime student	11 (7.9)
Housewife	7 (5.0)
Employed part time	84 (60.0)
Employed full time	6 (4.3)
Unemployed	11 (7.9)
Retired	4 (2.9)
Others	
Individual monthly income (Ringgit Malaysia)	
1000 and below	33 (23.9)
1001-2000	46 (32.9)
2001 and above	61 (43.6)
Family member with epilepsy/seizures	8 (5.7)

* reported as mean (standard deviation)

Translation equivalence and acceptability

The back-translation of the Malay PATE was equivalent to the original PATE for all the questions and responses, except item 5. For item 5, the equivalent Malay translation for dating is “kencan” which is not commonly used terminology among Malaysian. A more commonly used terminology is “*temujanji*” which can be interpreted as “dating” or “making an appointment”. A phrase “(date) with someone” was thus added to the verb to make the meaning more explicit. All 10 participants involved in the cognitive debriefing indicated that the items were relevant, easy to understand, and had no difficulty in answering the questions. No change was made in the final expert panel meeting to the reconciled Malay translation of the scale.

Psychometric and validation testing

1. Equal item variance

The mean score and standard deviation (SD), floor and ceiling effects of each item in the Malay PATE were shown in Table 5-2, according to the domain and were compared to the results performed in the initial study.[5] The items in each domain had similar standard deviations (equal item variance), ranged from 0.90-1.00 in personal domain and 0.87-1.23 in general domain. (Table 5-2)

Table 5-2: Mean score, SD, floor and ceiling effects of the Malay PATE, as compared with the results of the initial study performed in Malaysian population[5]

ID	Item	Mean (SD)		Floor/Ceiling effects (%)	
		Malay PATE (n=140)	General populations (n=130)	Malay PATE (n=140)	General populations (n=130)
	Personal domain	2.37 (0.64) ***	2.72 (0.56)		
1	I feel uncomfortable working with someone who has epilepsy.	2.06 (0.90) **	2.42 (0.87)	25.0/2.1	10.8/1.5
2	I will advise my family members against marrying someone with epilepsy.	2.51 (1.00) ***	2.95 (0.91)	15.7/2.1	6.9/2.3
3	I would marry someone with epilepsy, even though he/she has epilepsy.[#]	2.76 (0.91) *	3.03 (0.85)	7.9/3.6	2.3/3.8
5	I would date someone even though he/she has epilepsy.[#]	2.62 (0.92)	2.78 (0.84)	8.6/2.9	3.1/3.1
7	If I am an employer, I would give equal employment opportunities to someone with epilepsy.[#]	1.89 (0.93) ***	2.41 (0.96)	37.1/2.1	10.8/4.6
	General domain	2.09 (0.59)	2.09 (0.59)		
4	I will not mind being seen in the company with someone known to have epilepsy. [#]	1.99 (1.01)	2.06 (0.77)	32.1/5.0	16.9/1.5
6	I would stay away from a friend if I knew she/he had epilepsy.	1.74 (0.91) **	2.08 (0.92)	45.7/2.9	21.5/3.8
8	People with epilepsy have the same rights as all people. [#]	1.82 (1.01)	2.05 (0.91)	42.9/5.0	26.2/2.3
9	People with epilepsy should be isolated from others.	1.84 (0.87)	1.94 (0.84)	39.3/0.7	32.3/0.8
10	People with epilepsy should not marry.	1.91 (0.87)	2.06 (0.78)	35.7/0.7	22.3/0.8
11	People with epilepsy should not participate in social activities.	1.97 (0.98)	2.00 (0.78)	38.6/10.0	22.3/0.8
12	People with epilepsy should not study in college or university.	2.05 (1.00) *	1.82 (0.70)	30.7/3.6	32.3/0.8
13	People with epilepsy should study in a special school.	2.76 (1.23) *	2.43 (0.97)	17.1/9.3	16.9/1.5
14	Schools should not place children with epilepsy in regular classrooms.	2.74 (1.13) **	2.35 (0.90)	14.3/5.0	13.8/2.3

[#]These items were reversely scored. Significant at *p <0.05, ** p <0.01 and *** p <0.001, as compared to the results of the initial study performed among Malaysian population.

2. Convergent and discriminant validity

The correlation between an item and its domain was 0.4 and above for all, and higher than the correlation with the other domain, as highlighted in bold in Table 5-3.

Table 5-3: Item-domain and corrected item-total correlations.

ID	Correlation	Personal domain	General domain	Corrected Item-total correlation
1	I feel uncomfortable working with someone who has epilepsy.	**.636****	.587**	.440
2	I will advise my family members against marrying someone with epilepsy.	**.653****	.390**	.439
3	I would marry someone with epilepsy, even though he/she has epilepsy.#	**.755****	.380**	.610
5	I would date someone even though he/she has epilepsy.#	**.737****	.213*	.526
7	If I am an employer, I would give equal employment opportunities to someone with epilepsy.#	**.632****	.343**	.371
4	I will not mind being seen in the company with someone known to have epilepsy. #	.366**	**.567****	.295
6	I would stay away from a friend if I knew she/he had epilepsy.	.413**	**.614****	.458
8	People with epilepsy have the same rights as all people. #	.316**	**.539****	.336
9	People with epilepsy should be isolated from others.	.396**	**.696****	.637
10	People with epilepsy should not marry.	.435**	**.547****	.450
11	People with epilepsy should not participate in social activities.	.292**	**.607****	.467
12	People with epilepsy should not study in college or university.	.377**	**.674****	.506
13	People with epilepsy should study in a special school.	.318**	**.618****	.435
14	Schools should not place children with epilepsy in regular classrooms.	.156	**.561****	.399

Significant at *p <0.05, ** p <0.001. Number in bold indicated that the correlation of item is higher with its hypothesized scale than with scales measuring other concepts.

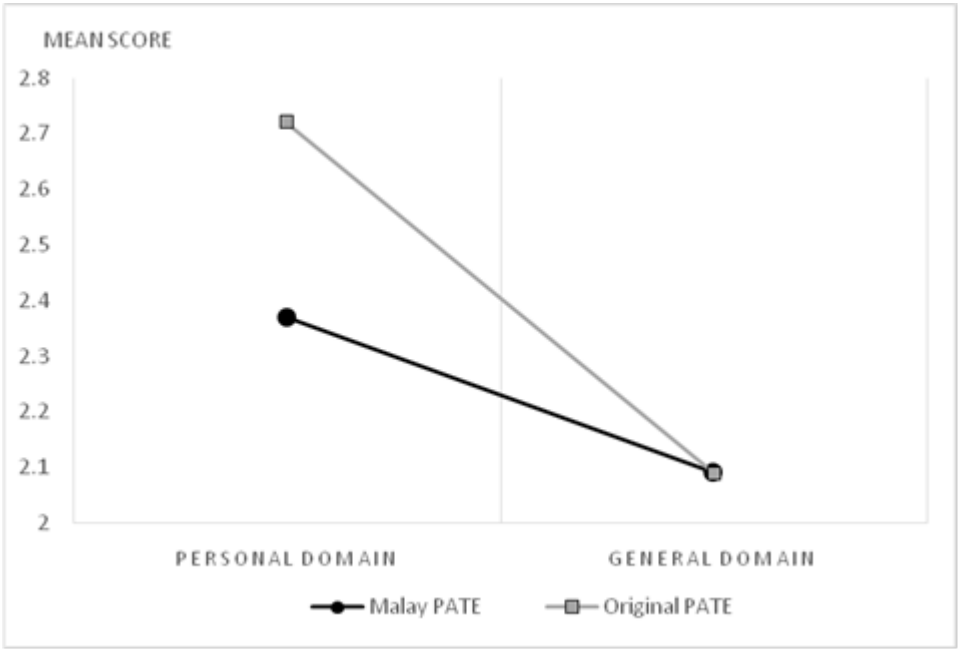
3. Construct validity

a) Compatibility with previous study

The scale means and standard deviations, the floor and ceiling effects of the Malay PATE were compared with the initial results in Malaysian general population in Table 5-2. The means of 4 items (1, 2, 3 and 7) in the personal domain were significantly lower, and the means of 3 items (12, 13 and 14) in the general domain were significantly higher, than the original PATE. The standard deviations were slightly higher but comparable between the two groups. The floor and ceiling effects followed the same pattern as initial study, in which the floor effect was greater than the ceiling effect in all items. In addition, the floor effect in all items in the Malay PATE was greater than the original study.

As shown in Figure 5-1, the mean score in the personal domain of Malay PATE was significantly lower than the initial study ($p<0.001$). The relative relationship between the personal and general domains was similar between the Malay and initial PATE.

Figure 5-1: The relative relationship between the mean scores of the personal and general domain, in current (Malay) and initial PATE studies.



b) Correlation of mean scores with demographic characteristics

The mean scores in general domain were significantly lower in female, those with tertiary education and those with monthly income RM2000 and above ($p<0.05$), but no correlation with marital status, employment status and family history. For personal domain, there were no significant correlation between the mean scores and all demographic factors. (Table 5-4)

Table 5-4: Mean scores by domains and demographic characteristics (n=140)

Variable	Group (n)	General domain	Personal domain	Total
Age[1]		0.110	0.105	0.106
		Mean score (SD)	Mean score (SD)	Mean score (SD)
Gender	Male (65) Female (75)	2.25 (0.53) 1.95 (0.60)**	2.44 (0.58) 2.31 (0.68)	2.32 (0.48) 2.08 (0.57)**
Marital status	Single (42) Others (98)	2.14 (0.58) 2.07 (0.59)	2.46 (0.53) 2.33 (0.68)	2.25 (0.49) 2.16 (0.56)
Education level	Tertiary (84) Others (56)	1.99 (0.58) 2.23 (0.57)*[#]	2.34 (0.67) 2.42 (0.59)	2.12 (0.55) 2.30 (0.50)
Employment status	Employed full time (84) Others (56)	2.10 (0.57) 2.08 (0.61)	2.34 (0.59) 2.41 (0.71)	2.18 (0.52) 2.20 (0.58)
Monthly income in Ringgit Malaysia	2000 and above (61) Others (79)	1.96 (0.54) 2.19 (0.60)*	2.36 (0.70) 2.38 (0.59)	2.10 (0.53) 2.26 (0.54)
Family member with epilepsy/ seizures	Yes (8) No (132)	1.99 (0.38) 2.10 (0.60)	2.30 (0.39) 2.37 (0.65)	2.10 (0.29) 2.20 (0.55)

[1]Based on Pearson correlation, Significant at *$p < 0.05$. [#]This difference was comparable to the initial PATE study.

c) Correlation between the items and rotated principal components

Table 5-5 showed the factor loadings of the items using a principal axis factor analysis and their correlation with the hypothesized domain. The results fit the hypothesized personal and general domains, except items 1 and 2 which had a higher loading on the general domain than the hypothesized with a difference of more than 0.2 (0.563 and 0.237 respectively).

Table 5-5: Correlation between the hypothesized domain and rotated principal components

ID	Item	Hypothesized Domain	Factor	
			General	Personal
9	People with epilepsy should be isolated from others.	General	.699	.045
12	People with epilepsy should not study in college or university.	General	.603	-.009
14	Schools should not place children with epilepsy in regular classrooms.	General	.560	-.211
6	I would stay away from a friend if I knew she/he has epilepsy.	General	.556	.034
11	People with epilepsy should not participate in social activities.	General	.551	-.006
10	People with epilepsy should not marry.	General	.512	.137
13	People with epilepsy should study in a special school.	General	.499	-.026
8	People with epilepsy have the same rights as all people.	General	.344	.043
4	I will not mind to be seen in the company with someone known to have epilepsy.	General	.312	.039
1	I feel uncomfortable working with someone who has epilepsy.	Personal	.661	.098
2	I will advise my family members against marrying someone with epilepsy.	Personal	.430	.193
5	I would date someone even though he/she has epilepsy.	Personal	-.087	.813
3	I would marry someone with epilepsy, even though he/she has epilepsy.	Personal	.179	.657
7	If I am an employer, I would give equal employment opportunities to someone with epilepsy.	Personal	.151	.442

Extraction Method: Principal Axis Factoring. Rotation Method: Oblimin with Kaiser Normalization.

Reliability

The Cronbach's α values of both domains was within acceptable range (0.7 to 0.9). The mean inter-item correlations for both general and personal domains were within the range of 0.2 to 0.4. The mean scores of both general and personal domain had a strong correlation with the total mean score, as shown in Table 5-6. Corrected item-total

correlation of all items were 0.3 and above, except item 4 with a correlation coefficient of 0.295 (Table 5-3).

Table 5-6: Internal reliability and convergent validity of each domain

Domain (number of items)	Mean (SD)	Reliability (Cronbach's α)	Mean inter-item correlation	Convergent Validity (correlation with total score)
General domain (9)	2.09 (0.59)	0.757	0.265	0.919*
Personal domain (5)	2.37 (0.64)	0.716	0.338	0.782*

*significant at $p<0.001$

Discussion

This study showed that the Malay PATE scale is content and construct validated, and reliable translated version, which was translated according to standard principles[13], and tested with multitrait analysis and principal-axis factor analysis, with an acceptable internal consistency with acceptable Cronbach's α values for the general and personal domains.

Though a convenient sampling was employed in this study, an attempt to recruit participants with a wide-range of age (16-78 years) and socio-economic status was made, with equal gender representation and the mean age of this cohort was compatible to the initial cohort[5] (36.4 vs. 41.4 years respectively). This will ease the generalisation of the results to the general Malay population from the same region.

A modification to item 5 was made because of the Malay translation for "dating" in the Malaysia context can be interpreted as either dating or making an appointment. The

mean score and standard deviation of this item were compatible with other items within the same domain and the original study, indicating that the modified item is measuring the same concept. The translated version had fulfilled the criteria for equal item variance, convergent and discriminant validity

Multitrait analysis showed the Malay PATE had a similar variance, floor and ceiling effects (Table 5-2), relative relationship between the domains (Figure 5-1), as the original PATE. All items in the Malay PATE had greater floor effects, is likely because the attitudes toward epilepsy among Malay-speaking population were better than the general population. All items in the translated version had greater floor than ceiling effects, compatible to the original PATE study.

The Malay PATE scale showed a similar correlation with almost all demographic variable, as the original study, except gender and monthly income. In this study, the female and those with higher monthly income had significantly more positive attitudes toward epilepsy, in related to the items in the general domain, which was not found in the original study.

The deviation of items 1 and 2 from the hypothesized domain with a difference of more than 0.2 as compared the factor loading in the other domain. (Table 5-5) resulted in a re-examination of the concepts of these two items. Item 1 (I feel uncomfortable working with someone who has epilepsy) had almost similar correlation with both personal and general domains (0.636 and 0.587 respectively, as shown in Table 5-3). Conceptually, item 1 can be included into either domain depends on how close the relationship among the co-workers. For example, if a person is working in a big company, having a co-worker who has epilepsy has not much impact on his life and thus item 1 may not

necessary be categorized as personal. Item 2 (I will advise my family members against marrying someone with epilepsy) had a strong item-domain correlation (Table 5-3). The panel also viewed that for local Malay population, which formed the majority (83.6%) in this study, this item is consistent with the concept in the personal domain. However, personal opinion against a family member marrying a person with epilepsy can be overridden by the paternal authority in the family among the Malay population. However, in order to maintain the consistency of comparison among various translated versions of PATE, no change in the factoring of these two items was made but a note was added to this translated version, stating that factoring of these two items can be culturally dependent.

The reliability of the Malay PATE was confirmed by a Cronbach's α value that was within acceptable range. In addition, the mean inter-item correlations were within the acceptable range and all corrected item-total correlation were above 0.3, indicating that this translated version is a reliable tool in measuring the public attitudes toward epilepsy.

Limitations and future implications

This Malay translated version of the PATE scale was tested among a multi-ethnic group of Malay speaking Malaysian population in the urban region, with predominant Malay. Malay language was the second language in those who are not Malay. However, it was an advantage to have multiple ethnic group involvement in the translation adaptation process, to ensure the cross-cultural validity of this translated version. In Malaysia and some of the South-East Asian countries e.g. Indonesia, Malay language is a common second language including the indigenous groups. The Malay translated PATE scale

will enable us to understand the public attitudes toward epilepsy among this group of population.

Conclusion

The Malay PATE scale is a validated and reliable translated version in measuring the public attitudes toward epilepsy.

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Appendix 3: Malay translated version of PATE scale

Arahan: Jawab soalan-soalan berikut dengan secara spontan yang mungkin. Tidak ada jawapan yang betul atau salah. Setiap soalan mempunyai lima jawapan yang mungkin. Bulatkan jawapan yang paling dekat dengan pandangan anda.	**Sangat Tidak Bersetuju**	**Tidak Bersetuju**	**Tidak Pasti**	**Bersetuju**	**Sangat Bersetuju**
1. Penghidap epilepsi tidak wajar belajar di kolej atau universiti.	**1**	**2**	**3**	**4**	**5**
2. Penghidap epilepsi mempunyai hak yang sama seperti semua orang.	**1**	**2**	**3**	**4**	**5**
3. Penghidap epilepsi harus diasingkan daripada orang lain.	**1**	**2**	**3**	**4**	**5**
4. Penghidap epilepsi tidak harus mengambil bahagian dalam aktiviti sosial.	**1**	**2**	**3**	**4**	**5**
5. Saya tidak kisah dilihat bersama dengan seseorang yang diketahui menghidapi epilepsi.	**1**	**2**	**3**	**4**	**5**
6. Penghidap epilepsi tidak harus berkahwin.	**1**	**2**	**3**	**4**	**5**
7. Saya akan menjauhkan diri dari seorang kawan jika saya mengetahui dia menghidapi epilepsi.	**1**	**2**	**3**	**4**	**5**
8. Penghidap epilepsi harus belajar di sekolah khas.	**1**	**2**	**3**	**4**	**5**
9. Sekolah tidak harus menempatkan kanak-kanak yang menghidapi epilepsi ke dalam bilik darjah biasa.	**1**	**2**	**3**	**4**	**5**
10. Saya akan bertemujanji (dating) dengan seorang lelaki/perempuan walaupun dia menghidapi epilepsi.	**1**	**2**	**3**	**4**	**5**
11. Saya akan berkhawin dengan seseorang walaupun dia menghidapi epilepsi.	**1**	**2**	**3**	**4**	**5**
12. Saya rasa tidak selesa bekerja dengan seseorang yang menghidapi epilepsi.	**1**	**2**	**3**	**4**	**5**
13. Saya akan menasihati ahli keluarga saya untuk tidak berkahwin dengan seseorang yang menghidapi epilepsi.	**1**	**2**	**3**	**4**	**5**
14. Jika saya seorang majikan, saya akan memberi peluang pekerjaan yang sama adil kepada seseorang yang menghidapi epilepsi	**1**	**2**	**3**	**4**	**5**

Chapter 6: Chinese Public Attitudes Toward Epilepsy (PATE) scale: translation and psychometric evaluation

(Published as *Lim KS, Choo WY, Wu C, Hills MD, Tan CT. Chinese Public Attitudes Toward Epilepsy (PATE) scale: translation and psychometric evaluation. Neurology Asia 2013; 18 (3):261-270.*)

Abstract

Introduction: None of the quantitative scale for public attitudes toward epilepsy was translated to Chinese language. This study aimed to translate and test the validity and reliability of a Chinese version of the Public Attitudes Toward Epilepsy (PATE) scale. **Method:** The translation was performed according to standard principles and tested in 140 Chinese-speaking adults aged more than 18 years for psychometric validation. **Results:** The items in each domain had similar standard deviations (equal item variance), ranged from 0.85-0.95 in personal domain and 0.75-1.04 in general domain. The correlation between an item and its domain was 0.4 and above for all, and higher than the correlation with the other domain. Multitrait analysis showed the Chinese PATE had a similar variance, floor and ceiling effects, and relative relationship between the domains, as the original PATE. The Chinese PATE scale showed a similar correlation with almost all demographic variable except age. Item means were generally clustered in the factor analysis as hypothesized. The Cronbach's α values was within acceptable range (0.773) in the personal domain and satisfactory range (0.693) in the general domain. **Conclusion:** The Chinese PATE scale is a validated and reliable translated version in measuring the public attitudes toward epilepsy.

Keywords: Chinese, PATE scale, attitudes, epilepsy, public

Introduction

People with epilepsy are burdened by a multitude of social, psychological and economic consequences of stigmatization which leads to poor quality of life.[1,2] There are great variation in social stigma among various countries, ethnicities and cultural groups, affected by various socio-economic and cultural factors. Assessment of the public attitudes toward epilepsy is therefore best conducted in local languages.

Public surveys on attitudes toward epilepsy had been conducted in many countries in local languages.[3] However, a standard and quantitative scale was not used in most studies, resulting in difficulty in comparing the results.

There were a few quantitative assessment tools for public attitudes toward epilepsy, such as the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale[4], the Attitudes Toward Persons with Epilepsy (ATPE)[5,6], the Epilepsy Attitude Scale[7], and the Elementary School Epilepsy Survey (ESES)[8] for elementary school children, but not all can be applied cross-culturally as limited by items related to local perception of epilepsy and none was translated into Chinese language. The Public Attitudes Toward Epilepsy (PATE) scale was designed to be applied cross-culturally, as characterized by the following: (1) including statements related to separation and disadvantages in Link's stigmatization model[9], which are universally applicable, and (2) excluding questions testing the participants' knowledge and perception of epilepsy, which are culturally dependent.

The aim of this study was to test the validity and reliability of a Chinese version of the Public Attitudes Toward Epilepsy (PATE) scale.

Methodology

The Public Attitudes Toward Epilepsy (PATE) scale (Lim et. al. 2012) is a two-dimensional 14-item scale measuring public attitudes towards epilepsy.[10] The two dimensions which the scale measures are (1) personal dimension/domain, include items that require participants to consider personal involvement and commitment with sufferers of Epilepsy and (2) general domain, in which a general opinion of patients of Epilepsy is gauged by each item. Each item on the PATE is scored using a 5-point Likert's Scale with 1 being "strongly disagree" and 5 being "strongly agree". A higher total score reflects more negative attitudes towards epilepsy. PATE scale is a valid and reliable test instrument, demonstrating appropriate content and construct validity, and Cronbach's coefficient of 0.633 and 0.868.

The translation process of PATE scale was performed in a three-stage cross-cultural adaptation process as developed by the International Quality of Life Assessment project[11], i.e. (1) translation and cultural adaptation of the original scale into the Chinese language, and evaluation to ensure conceptual equivalence, (2) formal psychometric testing of the assumptions underlying item scoring and construction of multi-item scales, to ensure that the scoring algorithms can be applied to the population concerned, and (3) validation and norming studies that provide a basis for interpretation.

Participants

Ten Chinese-speaking adults from various socioeconomic backgrounds were included in the translation and cultural adaptation process. For psychometric validation, a convenience sampling of 140 Chinese-speaking adults aged more than 18 years, from a wide range of age and socioeconomic background, were recruited from Petaling Jaya and Kuala Lumpur in Malaysia. Answering the questionnaire was regarded as having given consent. All questionnaires were administered anonymously. Demographic information on age, gender, education level, and social strata by occupation were also obtained. This study was approved by the ethics committees at the University Malaya Medical Center, Malaysia (MEC Ref No: 878.10).

Translation and cultural adaptation

The Chinese translations of the PATE scale was performed according to the Principles of Good Practice Translation and Cultural Adaptation of Patient Reported Outcomes Measures[12], which include preparation, forward translation and reconciliation, backward translation, harmonization, cognitive debriefing, and finalization. With these principles, the aim was to develop a culturally sensitive version of the scale that was equivalent to the original in the following aspects: item, semantic, operational and measurement equivalence.

Translation: The PATE scale was first transferred to an Excel file for translation. Forward translation was performed by two independent translators and the two translations was reconciled into a single form. The reconciled form was back translated into English by two independent translators, and combined into one back translation.

The back translation was compared with the original version. Differences was highlighted and discussed by a panel consisted of two neurologists, a psychologist and a statistician, and changes were made accordingly to ensure consistency in the concepts between the original and the translations. This resulted in the Chinese translated versions of PATE.

Cognitive debriefing: Ten adults knowledgeable in the Chinese language were pretested using semistructured interviews to explore whether questions are relevant and understandable, as well as to identify potential difficulties in answering.

Finalization: An expert panel meeting was organized to evaluate the content and face validity of the translated versions, the results of the pretesting, and the equivalence with the original i.e. conceptual, semantic and normative equivalence for each item.

Statistical analysis

This study employed Statistical Package for Social Sciences version 19 (SPSS 19.0) for data analyses. All demographic data were analyzed descriptively and presented as frequencies as well as percentages. For continuous data, independent t-tests were used for group comparison.

Psychometric and validation testing

Validity: Multitrait analysis and principal-axis factoring were used to evaluate the validity of the translation based on the following assumptions:

5. Equal item variance: Items measuring the same concept should have approximately equal variances (standard deviations).
6. Convergent validity: Items in a given scale should contain approximately the same proportion of information about a concept, with roughly equal item-total correlation.
7. Discriminant validity: An item should correlate higher with its hypothesized scale than with scales measuring other concepts, tested with correlation analysis.
8. Construct validity: The construct of the translated version as assessed by principal-axis factor analysis should be similar to the initial study. In addition, it was hypothesized that (a) the scale means and standard deviations, and floor and ceiling effects of this translation, and (b) the relative relationship between the personal and general domain, were comparable to the initial results of PATE scale in Malaysian population.[10] Correlation between the mean score of each domain and the demographic variables were also assessed with a hypothesis that the current study should have similar correlation patterns as reported previously.[10]

Reliability: Item analysis was performed to assess the internal consistency of the overall scale and its components. Cronbach's α values of 0.7 to 0.9 were considered acceptable[13]; whereas values of 0.6 to 0.7 are considered satisfactory. Mean inter-item correlation was used if α values are below 0.7, and a range of 0.2 to 0.4 are used to ensure that items are measuring the same construct.[14] Item-total correlation of 0.3 and above was used to indicate that the item correlated well with the scale overall.[15]

Results

One hundred and forty Chines-speaking adults with mean age of 41.8 years (standard deviation, SD, 15.2 and range, 18-76) were recruited. There were 43.6% male, 62.9%

married, 55.7% with tertiary education level, 49.3% with full-time employment, and 5.7% with family history of epilepsy. (Table 6-1)

Table 6-1: Demographic characteristics of the respondents (n=130)

		Number (%)
Gender	Male	61 (43.6)
	Female	79 (56.4)
Race	Chinese	140 (100.0)
Marital status	Married	88 (62.9)
	Single	51 (36.4)
	Divorced	1 (0.7)
Education level	No formal education	1 (0.7)
	Primary	16 (11.4)
	Secondary	45 (32.1)
	Pre-University	39 (27.9)
	Degree	30 (21.4)
	Post graduate	9 (6.4)
Employment status	Fulltime student	15 (10.7)
	Housewife	25 (17.9)
	Employed part time	6 (4.3)
	Employed full time	69 (49.3)
	Unemployed	5 (3.6)
	Retired	19 (13.6)
	Others	1 (0.7)
Individual monthly income (Ringgit Malaysia)	None	42 (30.0)
	1000 and below	12 (8.6)
	1001-2000	27 (19.3)
	2001 and above	59 (42.1)
Family member with epilepsy/seizures	Yes	8 (5.7)

Translation equivalence and acceptability

The back-translation of the Chinese PATE was equivalent to the original PATE for all the questions and responses. All ten participants involved in the cognitive debriefing indicated that the items were relevant, easy to understand, and had no difficulty in answering the questions. No change was made in the final expert panel meeting to the reconciled Chinese translation of the scale.

4. Equal item variance

The mean score and standard deviation (SD), floor and ceiling effects of each item in the Chinese PATE were shown in table 6-2, according to the domain and were compared to the results performed in the initial study.[10] The items in each domain had similar standard deviations (equal item variance), ranged from 0.85-0.95 in personal domain and 0.75-1.04 in general domain. (Table 6-2)

Table 6-2: Mean score, SD, floor and ceiling effects of the Chinese PATE, as compared with the initial results in Malaysian population[10]

ID	Item	Mean (SD)		Floor/Ceiling effects (%)	
		Chinese PATE (n=140)	General populations (n=130)	Chinese PATE (n=140)	General populations (n=130)
	Personal domain	2.41 (0.66)	2.72 (0.56)***		
1	I feel uncomfortable working with someone who has epilepsy.	2.00 (0.87)	2.42 (0.87)***	26.4/1.4	10.8/1.5
2	I will advise my family members against marrying someone with epilepsy.	2.38 (0.95)	2.95 (0.91)***	17.1/1.4	6.9/2.3
3	I would marry someone with epilepsy, even though he/she has epilepsy.#	2.91 (0.94)	3.03 (0.85)	5.7/7.1	2.3/3.8
5	I would date someone even though he/she has epilepsy.#	2.54 (0.93)	2.78 (0.84)*	8.6/3.6	3.1/3.1
7	If I am an employer, I would give equal employment opportunities to someone with epilepsy.#	2.24 (0.85)	2.41 (0.96)	16.4/0.7	10.8/4.6
	General domain	2.08 (0.49)	2.09 (0.59)		
4	I will not mind being seen in the company with someone known to have epilepsy. #	1.94 (0.94)	2.06 (0.77)	31.4/3.6	16.9/1.5
6	I would stay away from a friend if I knew she/he had epilepsy.	1.71 (0.84)	2.08 (0.92)**	42.9/2.9	21.5/3.8
8	People with epilepsy have the same rights as all people. #	1.90 (0.93)	2.05 (0.91)	35.0/2.1	26.2/2.3
9	People with epilepsy should be isolated from others.	1.70 (0.75)	1.94 (0.84)*	42.1/0.7	32.3/0.8
10	People with epilepsy should not marry.	2.26 (0.92)	2.06 (0.78)	19.3/1.4	22.3/0.8
11	People with epilepsy should not participate in social activities.	1.86 (0.85)	2.00 (0.78)	34.3/1.4	22.3/0.8
12	People with epilepsy should not study in college or university.	1.95 (0.89)	1.82 (0.70)	30.0/2.1	32.3/0.8
13	People with epilepsy should study in a special school.	2.81 (1.04)	2.43 (0.97)**	9.3/3.6	16.9/1.5
14	Schools should not place children with epilepsy in regular classrooms.	2.59 (1.03)	2.35 (0.90)*	10.0/5.7	13.8/2.3

#These items were reversely scored. *p-value is <0.05, ** p-value is <0.01 and *** p-value is <0.001, as compared to current study.

5. Convergent and discriminant validity

The correlation between an item and its domain was 0.4 and above for all, and higher than the correlation with the other domain, as highlighted in bold in table 6-3.

Table 6-3: Item-domain and corrected item-total correlations.

ID	Correlation	Personal domain	General domain	Corrected Item-total correlation
1	I feel uncomfortable working with someone who has epilepsy.	**.594****	.522**	.420
2	I will advise my family members against marrying someone with epilepsy.	**.749****	.421**	.596
3	I would marry someone with epilepsy, even though he/she has epilepsy.#	**.844****	.369**	.785
5	I would date someone even though he/she has epilepsy.#	**.722****	.225**	.597
7	If I am an employer, I would give equal employment opportunities to someone with epilepsy.#	**.568****	.265**	.346
4	I will not mind being seen in the company with someone known to have epilepsy.#	.258**	**.563****	.247
6	I would stay away from a friend if I knew she/he had epilepsy.	.303**	**.503****	.227
8	People with epilepsy have the same rights as all people.#	.400**	**.587****	.341
9	People with epilepsy should be isolated from others.	.295**	**.669****	.546
10	People with epilepsy should not marry.	.474**	**.542****	.375
11	People with epilepsy should not participate in social activities.	.209*	**.640****	.462
12	People with epilepsy should not study in college or university.	.276**	**.565****	.403
13	People with epilepsy should study in a special school.	.384**	**.644****	.476
14	Schools should not place children with epilepsy in regular classrooms.	.179*	**.493****	.277

*p-value is <0.05, and ** p-value is <0.01. Number in bold indicated that the correlation of item is higher with its hypothesized scale than with scales measuring other concepts.

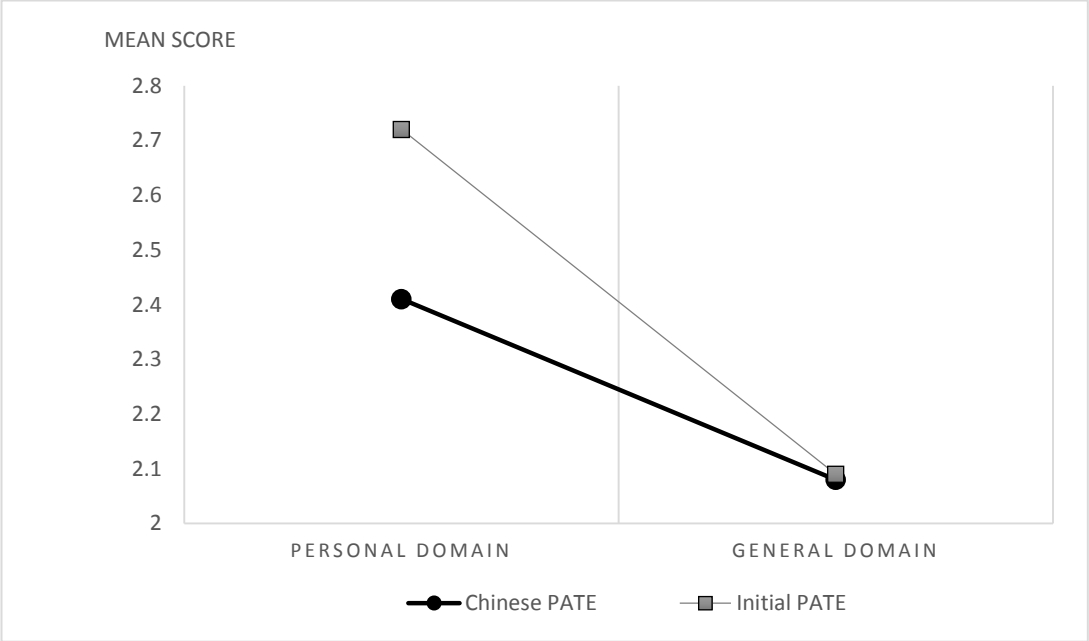
6. Construct validity

d) Compatibility with previous study

The scale means and standard deviations, the floor and ceiling effects of the Chinese PATE were compared with the initial results in Malaysian general population in Table 6-2. The means of items 1, 2, 5, 6 and 9 were significantly lower, except items 13 and 14 with higher mean, than the initial PATE. The standard deviations were comparable between the two groups. The floor and ceiling effects followed the same pattern as initial study, in which the floor effect was greater than the ceiling effect in all items. However, in four items (1, 4, 6 and 11) the floor effect of the Chinese PATE was greater (more than 25%) when there was a smaller floor effect (<25%) noted in the initial study.

As shown in figure 1, the mean score in the personal domain of Chinese PATE was significantly lower than the initial study ($p<0.001$). The relative relationship between the personal and general domains were similar between the Chinese and initial PATE.

Figure 6-1: The relative relationship between the mean scores of the personal and general domain, in current (Chinese) and initial PATE studies.



e) Correlation of mean scores with demographic characteristics

The mean scores in general domain were significantly lower in those with tertiary education (p<0.05), comparable with the result in the initial PATE study. There was also positive correlation between the mean scores in general domain and age (p<0.05), but no correlation with gender, marital status, employment status, monthly income and family history. For personal domain, there were no significant correlation between the mean scores and all demographic factors. (Table 6-4)

Table 6-4: Mean scores by domains and demographic characteristics (n=140)

Variable	Group (n)	Personal domain	General domain	Total
Age[1]		0.111	0.176*	0.189*
		Mean score (SD)	Mean score (SD)	Mean score (SD)
Gender	Male (61) Female (79)	2.48 (0.66) 2.36 (0.66)	2.15 (0.49) 2.03 (0.49)	2.27 (0.47) 2.15 (0.48)
Marital status	Single (51) Others (89)	2.37 (0.51) 2.44 (0.73)	2.06 (0.48) 2.09 (0.50)	2.17 (0.44) 2.21 (0.50)
Education level	Tertiary (78) Others (62)	2.35 (0.63) 2.48 (0.69)	1.99 (0.49) 2.20 (0.47)*[#]	2.12 (0.45) 2.30 (0.49)*
Employment status	Employed full time (69) Others (71)	2.39 (0.66) 2.43 (0.66)	2.04 (0.56) 2.12 (0.42)	2.16 (0.52) 2.23 (0.44)
Monthly income in Ringgit Malaysia	2000 and above (59) Others (81)	2.40 (0.75) 2.42 (0.58)	2.01 (0.51) 2.13 (0.47)	2.15 (0.49) 2.24 (0.46)
Family member with epilepsy/seizures	Yes (8) No (132)	2.30 (0.73) 2.42 (0.66)	2.08 (0.59) 2.08 (0.49)	2.16 (0.62) 2.20 (0.47)

[1]Based on Pearson correlation. **p*-value (two-tailed) is < 0.05. [#]This difference was comparable to the initial PATE study.

f) Correlation between the items and rotated principal components

Table 6-5 showed the factor loadings of the items using a principal axis factor analysis and their correlation with the hypothesized domain. The results fit the hypothesized personal and general domains, although items 10 and 13 had a slightly higher loading on the personal domain than the hypothesized.

Table 6-5: Correlation between the hypothesized domain and rotated principal components

ID	Item	Hypothesized Domain	Factor	
			Personal	General
3	I would marry someone with epilepsy, even though he/she has epilepsy.	Personal	1.028	-.189
2	I will advise my family members against marrying someone with epilepsy.	Personal	.701	.050
5	I would date someone even though he/she has epilepsy.	Personal	.675	-.074
1	I feel uncomfortable working with someone who has epilepsy.	Personal	.412	.236
7	If I am an employer, I would give equal employment opportunities to someone with epilepsy.	Personal	.367	.071
13	People with epilepsy should study in a special school.	General	.339	.327
10	People with epilepsy should not marry.	General	.335	.300
9	People with epilepsy should be isolated from others.	General	-.137	.831
11	People with epilepsy should not participate in social activities.	General	-.179	.760
12	People with epilepsy should not study in college or university.	General	.053	.415
8	People with epilepsy have the same rights as all people.	General	.219	.359
6	I would stay away from a friend if I knew she/he has epilepsy.	General	.034	.265
4	I will not mind to be seen in the company with someone known to have epilepsy.	General	.026	.250
14	Schools should not place children with epilepsy in regular classrooms.	General	.123	.212

Extraction Method: Principal Axis Factoring. Rotation Method: Oblimin with Kaiser Normalization.

Reliability

The Cronbach's α values of the personal domain was within acceptable range (0.7 to 0.9) and of the general domain was satisfactory (between 0.6 and 0.7). The mean inter-item correlations for both general and personal domains were within the range of 0.2 to 0.4. The mean scores of both general and personal domain had a strong correlation with the

total mean score, as shown in Table 6-6. Corrected item-total correlation of all items were 0.3 and above except items 4, 6 and 14 (Table 6-3).

Table 6-6: Internal reliability and convergent validity of each domain

Domain (number of items)	Mean (SD)	Reliability (Cronbach's α)	Mean inter-item correlation	Convergent Validity (correlation with total score)
General domain (9)	2.08 (0.49)	0.693	0.206	0.899*
Personal domain (5)	2.41 (0.66)	0.773	0.399	0.785*

*significant at $p<0.001$

Discussion

This study showed that the Chinese PATE scale is a validated and reliable translated version, which was translated according to standard principles[12], and tested with multitrait analysis and principal-axis factor analysis, with an acceptable internal consistency with a Cronbach's α values of 0.693 and 0.773 for the general and personal domains.

Though a convenient sampling was employed in this study, an attempt to recruit participants with a wide-range of age (18-72 years) and socio-economic status was made, with equal gender representation and the mean age of this cohort was compatible to the initial cohort[10] (41.8 vs. 41.4 years respectively). This will ease the generalisation of the results to the general Chinese population from the same region.

The translated version had fulfilled the criteria for equal item variance, convergent and discriminant validity, based on the results shown in table 6-2 and 6-3.

Multitrait analysis showed the Chinse PATE had a similar variance, floor and ceiling effects (Table 6-2), relative relationship between the domains (Figure 6-1), as the original PATE. Though some items in the Chinese PATE had greater floor effects, probably related to better attitudes toward epilepsy among Chinese-speaking population as compared with the general population, all items in the translated version had greater floor than ceiling effects, compatible to the original PATE study.

The Chinese PATE scale showed a similar correlation with almost all demographic variable except age. In this study, there was a positive correlation between the mean scores in general domain and age (r, 0.176) as compared with a positive correlation between the mean scores in personal domain and age (r, 0.175) in the original study. However, the correlation coefficient, r, were low and close to each other in both studies.

The deviation of items 10 and 13 from the hypothesized domain (Table 6-5) resulted in a re-examination of the concepts of these two items. The factor loading in the hypothesized domain of these items were lower than the other domain, but the differences were small (0.035 and 0.012 respectively). Though items 10 and 13 are general statement without involving personal commitment, they measures aspects of life (i.e. education and marriage) which are likely personal for some Chinese-speaking population. Therefore, it is not surprising that the loading is higher with the personal domain. However, the panel decided that conceptually these two items are more consistent with the general domain and thus no change was made to the factoring of these two items.

The reliability of the Chinese PATE was confirmed by a Cronbach's α value that was within acceptable range in the personal domain and satisfactory range in the general domain. In addition, the mean inter-item correlations were within the acceptable range. Though there were three items with corrected item-total correlation below 0.3, they were nonetheless all above 0.2. Corrected item-total correlation above 0.2 was viewed as acceptable by some authors[16], and was decided by the panel that these items should not be removed from the scale.

Conclusion

The Chinese PATE scale is a validated and reliable translated version in measuring the public attitudes toward epilepsy.

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Appendix 4: Chinese translated version of PATE scale

说明：尽可能自发地回答以下问题。答案并无对和错。每个问题有如下五种选择。请圈出最靠接近你的想法的答案。	非常不认同	不认同	不肯定	认同	非常认同
1. 有癫痫症的人不应该在学院或大学读书。	**1**	**2**	**3**	**4**	**5**
2. 有癫痫症的人拥有和全部人同等的权利。	**1**	**2**	**3**	**4**	**5**
3. 有癫痫症的人应该和其他人隔绝。	**1**	**2**	**3**	**4**	**5**
4. 有癫痫症的人不应该参加社会活动。	**1**	**2**	**3**	**4**	**5**
5. 我不介意被人看见和一位有癫痫症的人在一起。	**1**	**2**	**3**	**4**	**5**
6. 有癫痫症的人不应该结婚。	**1**	**2**	**3**	**4**	**5**
7. 我会远离一个朋友，如果我知道她/他有癫痫症。	**1**	**2**	**3**	**4**	**5**
8. 有癫痫症的人应在特殊学校学习。	**1**	**2**	**3**	**4**	**5**
9. 学校不应该把有癫痫病的儿童纳入普通课室。	**1**	**2**	**3**	**4**	**5**
10. 我会和男/女生约会，就算他/她有癫痫症。	**1**	**2**	**3**	**4**	**5**
11. 我会和有癫痫症的人结婚，就算他有癫痫症。	**1**	**2**	**3**	**4**	**5**
12. 和有癫痫症的人一起工作，我会觉得不舒服。	**1**	**2**	**3**	**4**	**5**
13. 我会劝告我的家人不要和有癫痫症的人结婚。	**1**	**2**	**3**	**4**	**5**
14. 如果我是雇主，我会给有癫痫症的人同等的就业机会。	**1**	**2**	**3**	**4**	**5**

Chapter 7: A web-based survey of attitudes toward epilepsy in secondary and tertiary students in Malaysia, using the Public Attitudes Toward Epilepsy (PATE) scale.

(Published as *Lim KS, Hills MD, Choo WY, Wong MH, Wu C, Tan CT. A web-based survey of attitudes toward epilepsy in secondary and tertiary students in Malaysia, using the Public Attitudes Toward Epilepsy (PATE) scale. Epilepsy & Behavior 2013;26:158-61.*)

Abstract

Background: Students' attitudes toward epilepsy have been studied in few countries but none of the studies used a quantitative scale. We aimed to determine the validity and reliability of the Public Attitudes Toward Epilepsy (PATE) scale in a homogenous population consisting of secondary and tertiary students in Malaysia, and to quantify their attitudes toward epilepsy, using a web-based survey. **Results:** A total of 227 respondents with a mean age of 19.6±2.07 years, predominantly Chinese (85%), female (62%) and in a pre-university education level (71%) completed the web-based survey. Psychometric testing showed that the PATE is a valid and reliable scale to be applied in a homogenous population. The mean score in the personal domain was significantly higher than that in the general domain (2.73±0.61 vs. 2.12±0.60 respectively, $p<0.001$). Compared with a study previously performed on a general population (Lim et al., 2012), the mean score in the general domain was significantly lower ($p<0.01$); whereas there was no significant difference between the mean scores in the personal domain. The mean scores for the general domain were significantly lower for those with tertiary education ($p<0.001$), but did not correlate with gender and ethnicity. **Conclusion:** The

attitudes of secondary and tertiary students are better than those of the general population in the general domain, but not in the personal domain.

(217 words)

Key words: Epilepsy, students, attitudes, stigma, scale

Introduction

Public attitudes in secondary or tertiary students have been studied in Cameroon [1-3], India [4,5], Kuwait [6], Tanzania [7], and Turkey [8], and showed better attitudes toward epilepsy amongst students than in the general community in most countries, except Turkey. A systematic review by the first author [9] had concluded that the questions used in these studies were not standardized, making direct comparison between these countries difficult. In addition, only yes-no questions were used in these studies, making quantification of the attitudes toward epilepsy impossible.

The Public Attitudes Toward Epilepsy (PATE) scale was performed in a general population and factored into two domains, i.e. a general domain that required minimal or no consideration of respondents' involvement, and a personal domain that required a long-term personal commitment or involvement. [10] As reported in the previous study, the mean scores of those with tertiary education were significantly lower for the general domain but not the personal domain and age was positively correlated with the mean scores in the personal domain but not the general domain. [10] Therefore, it is postulated that the secondary and tertiary students will score lower in the general domain but not the personal domain. However, in order to apply the scale for future comparison, it is essential to test the reliability and validity of this scale in a homogenous group.

Web-based survey or online survey is becoming more popular in research, accounted for 20% of global-data-collection expenditure in 2006. [11] There are several advantages to using a web-based survey, including faster and simpler data collection, cheaper cost, applicability of restriction to avoid missing data, and more importantly minimal social desirability effects as a result of being less intrusive [12].

This study therefore aimed to test the reliability and validity of this scale in a homogenous group and quantify the attitudes toward epilepsy in secondary and tertiary students in Malaysia, using a web-based design with a quantitative scale (PATE). A comparison with the previous study in general population will also be performed.

Methodology

1. Sample recruitment

This was the first web-based survey of public attitudes toward epilepsy in Malaysia, as well as in Asia, and was performed after approval from the ethics committees at the University Malaya Medical Center (MEC Ref No: 878.10). Two hundred and seventy five high school and college students from Petaling Jaya and Kuala Lumpur in Malaysia were selected through convenient sampling and invited to participate in this survey through an email invitation from the research team and 227 (82.5%) responded. Responding to the email invitation was regarded as giving consent. All questionnaires were administered anonymously.

2. Measures

The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy [10]. A 5-point Likert scale was used for scoring with 1 being strongly disagree and 5 being strongly agree. Positively stated items were reverse scored so that a higher score would indicate a more negative attitude. This scale was performed in a general population and factored into two domains, i.e. a general domain (nine items) that required minimal or no consideration of respondents' involvement, and a personal domain (five items) that required a long-term personal commitment or involvement such as marrying a person with epilepsy, working with them or employing them. This is a validated scale with good internal consistency (Cronbach's alpha of 0.868 and 0.633, in the general and personal domains respectively).

A form comprising the 14-item in PATE scale was designed in the SurveyMonkey website, which allowed the researchers to send out email invitations. Responding to a link in the email allowed the respondents to enter their answers, which were saved automatically into a database. Every item had to be answered before the respondents were allowed to proceed to the next item, to avoid missing data. The instructions emphasized that the scale was not a test, but rather an opinion questionnaire.

Demographic data were also collected on the subject's gender, age, ethnicity, highest education level, and the presence of family member(s) with epilepsy or seizures.

3. Statistical analysis

This study employed the Statistical Package for Social Sciences version 19 (SPSS 19.0) for data analysis. All demographic data was analyzed descriptively, with nominal data presented as frequencies as well as percentages, while continuous data were presented as means and standard variations. For continuous data, independent t-tests were used for group comparison.

Psychometric properties of the PATE in a specific population

The psychometric testing was based on the following assumptions:

1. Items measuring the same concept should have approximately equal variances (standard deviations); a test of equal item variance.
2. Items should be internally consistent, assessed as having item-total correlations of 0.4 and above.
3. Items in a given scale should contain approximately the same proportion of information about a concept, with roughly equal item-total correlations.
4. An item should correlate more highly with its hypothesized scale than with scales measuring other concepts (item discriminant validity), tested with correlation analysis. Pearson correlation coefficients of 0.5 to 1.0 were accepted as indicators of strong correlation.[13]
5. Scale scores should be reproducible (assessed by Cronbach's α coefficient) and interpretable (i.e. the correlation between scales should be less than their internal reliability coefficients if each scale measures a unique concept). Cronbach's α values of 0.7 to 0.9 were considered acceptable [14]; whereas values of 0.6 to 0.7 were considered satisfactory. Mean inter-item correlation was used if α values were

below 0.7, and a range of 0.2 to 0.4 was used to ensure that items were measuring the same construct. [15]

Comparison between the scores in personal and general domains

The difference between the mean scores in the personal and general domain was tested with a paired samples t-test. In order to test whether the score on the personal domain in the PATE scale was influenced by the score on the general domain, regression analysis was performed.

Comparison with previous study

Independent t-tests were calculated using OpenEpi [16], an open software, to determine the significance of differences in the mean scores between the current and the previous studies.

Results

Demographic characteristics of the sample

A total of 227 respondents completed the web-survey. The mean age of the respondents was 19.6 ± 2.07 years (ranging from 17 to 28 years). The respondents were predominantly female (62.1%) and Chinese (85.5%). 12.8% of the respondents were at secondary level, 71.4% at pre-university level and 15.9% at tertiary level. 2.6% of the respondents had family member(s) with epilepsy or seizures.

As a test of equal item variance, the standard variations of the items in the personal and general domains were measured. Within the personal domain, the standard variations of all items were approximately equal, ranging from 0.88 to 1.12. The standard variations of items within the general domain were also approximately equal (ranging from 0.80-1.08), as shown in Table 7-1.

Table 7-1: The means and standard deviations of the items and their correlations with the total score in each domain (n=227)

ID	Item	Mean (SD)	Item-total correlation[#]	
			General domain	Personal domain
1	I feel uncomfortable working with someone who has epilepsy.	2.62 (0.93)	.344	**.629**
2	I will advise my family members against marrying someone with epilepsy.	2.73 (0.92)	.250	**.658**
3	I would marry someone with epilepsy, even though he/she has epilepsy.*	3.01 (0.88)	.284	**.657**
5	I would date someone even though he/she has epilepsy.*	2.85 (0.94)	.428	**.716**
7	If I am an employer, I would give equal employment opportunities to someone with epilepsy.*	2.42 (1.12)	.296	**.524**
4	I will not mind being seen in the company with someone known to have epilepsy.*	2.14 (0.86)	**.619**	.373
6	I would stay away from a friend if I knew she/he had epilepsy.	1.96 (0.86)	**.602**	.307
8	People with epilepsy have the same rights as all people.*	1.96 (1.04)	**.511**	.230
9	People with epilepsy should be isolated from others.	2.02 (0.97)	**.706**	.349
10	People with epilepsy should not marry.	2.01 (0.92)	**.645**	.353
11	People with epilepsy should not participate in social activities.	2.00 (0.90)	**.725**	.373
12	People with epilepsy should not study in college or university.	1.78 (0.80)	**.794**	.426
13	People with epilepsy should study in a special school.	2.69 (1.08)	**.574**	.239
14	Schools should not place children with epilepsy in regular classrooms.	2.44 (1.03)	**.620**	.306

*These items were reversely scored. [#]Based on Pearson's correlations, with *p*-value as <0.001 unless stated otherwise.

The items were internally consistent within each domain, with item-total correlations from 0.524 to 0.716 in the personal domain, and 0.511 to 0.794 in the general domain, which are within the acceptable range of 0.4 and above. The items correlated more highly with their hypothesized domain than with the other domain. (Table 7-1)

Cronbach's α for the general domain was 0.816 (within the acceptable range of 0.7-0.9), with a mean inter-item correlation of 0.343, as shown in Table 7-2. Whereas for the personal domain, Cronbach's α was 0.620 (satisfactory) with a mean inter-item correlation of 0.259.

Table 7-2: Means and standard deviations and internal reliability of each domain in the current (n=227) and previous studies[10] (n=130)

Domain (number of items)	Study	Mean (SD)	Reliability (Cronbach's α)	Mean inter-item correlation
General domain (9)	Current	2.12 (0.60)*	0.816	.343
	Previous	2.24 (0.48)	0.868	.433
Personal domain (5)	Current	2.73 (0.61)	0.620	.259
	Previous	2.70 (0.55)	0.633	.263

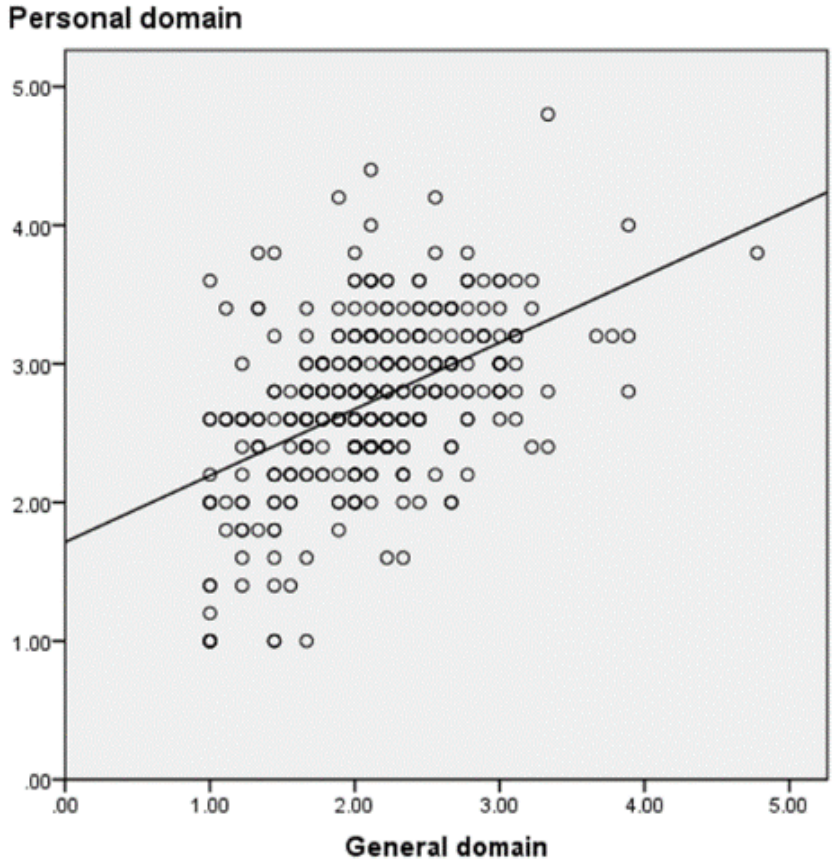
**p*-value is <0.01, as compared to the previous study

Relationship between personal and general domains

The mean score in the personal domain was significantly higher than those in the general domain, using a paired samples t-test (2.73±0.61 vs. 2.12±0.60 respectively, $p < 0.001$). Regression analysis was performed to assess the ability of the score on the general domain to predict the attitudes measured by the personal domain in the PATE scale. The total variance explained by the general domain was only 25.6%, F (1, 225) =

77.53, $p<0.001$, as demonstrated graphically by the scatter plot and linear curve estimation in figure 7-1.

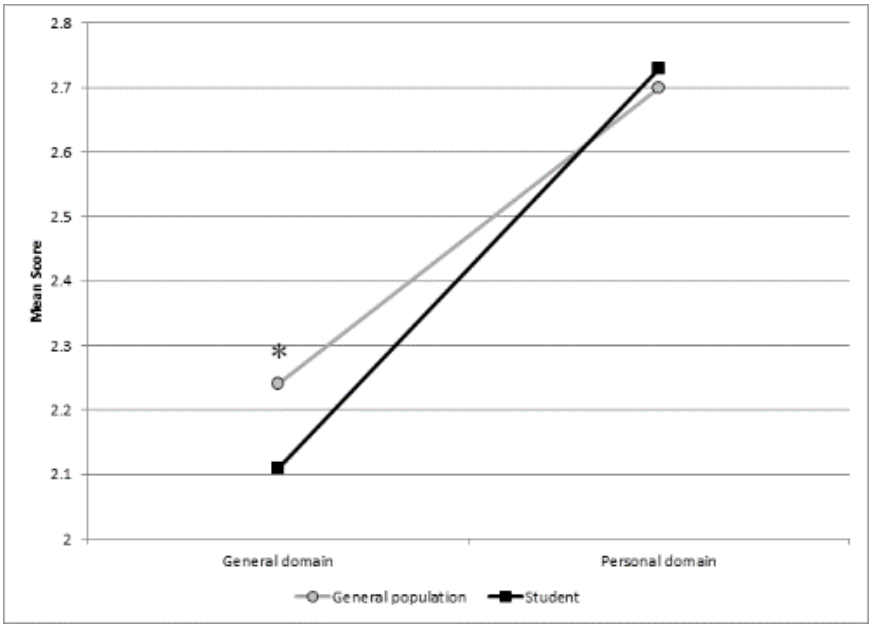
Figure 7-1: Linear curve estimation on how scores on the general domain related to the scores on the personal domain (n=227).



Comparison with previous study

As shown in figure 7-2, the mean score on the general domain was significantly lower than in the previous study performed on a general population ($p<0.01$); whereas there was no significant difference between the mean scores on the personal domain.

Figure 7-2: The mean scores on the personal and general domains of the PATE scale in the current (on students, n=227) and previous (on a general population, n=130) studies.



**p*-value is <0.01 (two-tailed).

Scores by domains and demographic characteristics

The mean scores for the general domain were significantly lower for those with tertiary education (p<0.001), but not correlated with gender and ethnicity. For the personal domain, none of the demographic variables showed significant difference between the subgroups (see Table 7-3)

Table 7-3: Mean scores by domains and demographic characteristics (n=227)

Variable	Group (n)	General domain, Mean score (SD)	Personal domain, Mean score (SD)
Gender	Male (66)	2.16 (0.65)	2.77 (0.73)
	Female (64)	2.08 (0.57)	2.70 (0.52)
Race	Malay (11)	2.23 (0.78)	2.67 (0.78)
	Chinese (194)	2.12 (0.55)	2.79 (0.55)
	Indian (15)	2.24 (0.88)	2.19 (0.78)
	Others (7)	1.48 (0.58)	2.20 (0.64)

Education level	Secondary (29) Pre-university (162) Tertiary (36)	1.99 (0.47) 2.20 (0.61) 1.79 (0.55)*	2.58 (0.54) 2.76 (0.62) 2.69 (0.60)
Family member with epilepsy/seizures	Yes (6) No (221)	1.83 (0.25) 2.12 (0.61)	2.80 (0.67) 2.72 (0.60)

*p-value is < 0.001, as compared to the mean scores for those at either the secondary or pre-university levels

Discussion

This study showed that the PATE scale is a validated and reliable scale to measure attitudes towards epilepsy in a homogenous group, which fulfilled the assumptions of (1) equal item variance, with the items within the same domain having approximately equal variances, (2) internal consistency, with all item-total correlations above 0.4, (3) equal item-total correlation, (4) item discriminant validation, with all items correlating more strongly with their domain total, as compared to their correlation with other domain, and (5) reproducibility, with acceptable Cronbach's α of 0.816 and 0.620 in the general and the personal domains respectively.

The psychometric properties of the PATE scale in the current study were comparable to those found in the previous study, with good item discriminant validation in each domain and internal consistency. The degree of internal consistency as measured by Cronbach's α in the current study was comparable to those in the previous study, i.e. 0.816 vs. 0.868 in the general domain and 0.620 vs. 0.633 in the personal domain. The item-to-total correlations in the current study were all above 0.4, better as compared to some item-to-total correlations in the previous study below 0.4, probably because the current study was performed in a homogenous group.

Although the mean score on the personal domain was significantly correlated with the mean score on the general domain, the correlation coefficient was lower than the internal reliability coefficients, supporting the contention that each domain was measuring a unique concept. Regression analysis demonstrated that only 25.6% of the variance of the score in personal domain was explained by the score in general domain. This indicates that there are other factors, beside those covered by the general domain, that influence the score on the personal domain. Future studies determining the predictive or correlated factors covered by the attitudes in the personal domain will be important to help overcoming stigma in epilepsy.

As shown in this study, the attitudes of the students for the general domain were significantly better than the attitudes of a general population. This is consistent with the findings of previous studies on the public attitudes of students. [1-7] However, such a relationship was not found in the personal domain.

Similarly, a positive correlation between the education level and the attitudes toward epilepsy was noted for the general domain but not for the personal domain. This is consistent with the results noted in the initial PATE study, which reported a positive correlation between increased education and better attitudes towards epilepsy only in the general domain. [10] This supports the notion proposed in that study that there is an isolation of generalized knowledge-based attitude versus an interpersonal emotion-based attitude towards perceiving people with epilepsy.

Limitations

Some concern had been felt that social desirability may have affected the results obtained from the public survey. An interview with paper-and-pencil is more intrusive, causing a tendency to answer more positively. A web-based survey tends to minimize social desirability effects, and thus the results will tend to be more negative, especially when answering the questions in the personal domain. This possibility had to be taken into consideration when interpreting the results.

A second limitation was that the study method required fluency and reading comprehension in English, as well as access to the web, which could have biased the sample. However, learning English is part of the primary and secondary education system in Malaysia, and most families or schools have access to the web.

This study recruited students from private colleges and Chinese secondary school, resulting in majority (85.5%) of the participants were Chinese, which is disproportionate to the ethnic distribution in Malaysia with only 24.6% Chinese.

Study implications

As far as is known, this is the first study on attitudes toward epilepsy using a web-based survey. This ensured an easier, simpler and more reliable data collection, with possibly less social desirability effects. This should enable standardized replication of the study, and increase the ease of comparison, either with other populations or longitudinally in the same population.

This study has demonstrated the validity and reliability of the PATE scale in a homogenous population, and thus allows the scale to be applied to either a general or a specific population. In addition, differences between the scores of different populations can be tested quantitatively.

Conclusion

The PATE scale is a validated and reliable scale to measure attitudes toward epilepsy in a homogenous population, and can be delivered through a web-based survey. The attitudes of secondary and tertiary students are better than the general population for the general domain, but not the personal domain.

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Chapter 8: Attitudes toward epilepsy among teachers in Malaysia, using the Public Attitudes Toward Epilepsy (PATE) scale.

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Abstract

Introduction: There is a lack of study comparing the attitudes toward epilepsy between the teachers and general population, teachers and students, using a similar quantitative scale. **Methods:** This study was performed in one primary and one secondary school in Kuala Lumpur, Malaysia, using the Public Attitudes Toward Epilepsy (PATE) scale. **Results:** A total of 186 teachers aged 39.6 ± 10.4 years completed the questionnaire. The mean scores in both personal and general domains of PATE scale were significantly better in the teachers, comparing to the scores in the secondary and college students reported in previous study (Lim et al., 2013; $p<0.001$ and <0.05 respectively). The mean scores in personal domain was significantly better in the teachers, comparing to the general population reported by Lim et al. (2012; $p<0.001$). This hold true when comparing teachers with general population with tertiary education, suggesting that the better attitude is specific to the job, rather than tertiary education generally. Subanalysis showed that the attitudes of teachers were significantly better than the general population and the students related to employment and social life, but were equally negative on issues directly related to education, such as placing children with epilepsy in regular classes. **Conclusion:** Teachers had more positive attitudes toward epilepsy as

compared with the general population with tertiary education. Attitude to epilepsy may differ specific to types of work.

Introduction

Epilepsy is a disorder of the brain that is characterized by an enduring predisposition to generate seizures and by its neurobiological, cognitive, psychological, and social consequences.[1] People with epilepsy are burdened by a multitude of social, psychological and economic consequences of stigmatization which leads to poor quality of life.[2,3] Teachers' attitudes toward epilepsy can have significant impact on students with epilepsy, and have been extensively studied in Asia as well as Africa, South and North America, and Europe. [4]

However, a systematic review by the first author [4] had concluded that a standard set of questions was not used in most of the previous studies, making direct comparison difficult. In addition, yes-no questions were used in these studies, except two studies [5,6] employed quantitative scale in measuring the attitudes toward epilepsy among teachers, making quantification of the attitudes toward epilepsy impossible.

There was no comprehensive study comparing the attitudes between teachers and students, which may inform the teacher-learner difference in attitudes toward epilepsy. In our previous review [4], we have found that there were limited study using the percentage of participants with negative attitudes towards social contact in epilepsy, teachers had better attitudes in Thailand and Turkey [7,8], but conversely in India [9] as compared to general population or students. There was also no study found examining

whether the better attitudes among the teachers as compared to the general population is due to the effect of tertiary education, or specific to the profession.

The Public Attitudes Toward Epilepsy (PATE) scale was performed in a general population and factored into two domains, i.e. a general domain that required minimal or no consideration of respondents' involvement (e.g., "People with epilepsy have the same rights as all people."), and a personal domain that required a long-term personal commitment or involvement (e.g., "I would date someone even though he/she has epilepsy."). [10] Lower score indicate a more positive attitude. As reported in the previous study, the mean scores of those with tertiary education were significantly lower for the general domain but not the personal domain and age was positively correlated with the mean scores in the personal domain but not the general domain. [10,11]

This study aimed to determine the teachers' attitudes toward epilepsy using a quantitative scale, with direct comparison with the attitudes of students and general population reported in the previous studies using the same scale. [10,11] In addition, this study also aimed to compare the attitudes between the primary and secondary school teachers.

Methodology

1. Sample recruitment

This was the first quantitative study of teachers' attitudes toward epilepsy in Malaysia, as well as in Southeast Asia, and was performed after approval from the ethics committees at the University Malaya Medical Center (MEC Ref No: 878.10). One

primary and one secondary schools were selected from the schools in Kuala Lumpur, a metropolitan city in Malaysia and its adjacent cities through opportunity sampling. Two hundred and seventy teachers were approached and 186 (68.9%) agreed to participate in this study. This consisted of 106 respondents from a primary school and 80 from a secondary school. Answering the questionnaire was regarded as having given consent. All questionnaires were administered anonymously. The attitudes of the general population and students toward epilepsy using the PATE scale were quoted, for direct comparison, from the previous studies performed in the same region by the same research team. In the study on the attitudes of the general population [10], a total of 130 samples was recruited from the public area in same city, using similar approach. In the study on the secondary and college students [11], the sample size was 227, recruited using a web-based survey.

2. Measures

The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy (Lim, 2012)[10]. A 1-5 Likert scale was used for scoring with 1 being strongly disagree and 5 being strongly agree. Some items were reverse scored so that a higher score would indicate a more negative attitude. This scale was performed in a general population and factored into two domains, i.e. a general domain (nine items) that required minimal or no consideration of respondents' involvement, and a personal domain (five items) that required a long-term personal commitment or involvement. This is a validated scale with good internal consistency (Cronbach's alpha of 0.868 and 0.633, in the general and personal domains respectively).

The instructions emphasized that the scale was not a test, but rather an opinion questionnaire. The mean score for all items as well as the mean scores in the general and personal domains were calculated. For subanalysis according to the social aspects of life, the items in the scale were further subcategorized into four groups, i.e. attitudes toward marital relationship (items 2, 3, 5 and 10), employment (items 1 and 7), education (items 12 to 14) and social life (items 4, 6, 9 and 11). Demographic data were also collected on the subject's gender, age, ethnicity, marital status, highest education level, monthly income, and the presence of family member(s) with epilepsy or seizures.

3. Statistical analysis

This study employed the Statistical Package for Social Sciences version 19 (SPSS 19.0) for data analysis. All demographic data was analyzed descriptively, with nominal data presented as frequencies as well as percentages, while continuous data were presented as means and standard variations. Psychometric properties of the PATE scale in teachers was determined by calculating the Cronbach's α and mean inter-item correlation to ensure the consistency of the items in each domain among teachers.

A one-way between-groups analysis of variance was conducted for comparison of the mean scores between the teachers and the general population, and students, followed by a post-hoc comparisons. In order to explore whether education level was a cofactor affecting the difference between the teachers and the general population, a univariate analysis with education level as a cofactor was performed. In addition, the scores of the teachers were compared with those of a subgroup of general population with tertiary education (n=108) extracted from previous study.[10]

Comparison of the scores between the primary and secondary school teachers were performed using independent student t-tests. Because of the difference in ethnicity and education level between the two groups, a univariate analysis with ethnicity and education level as the cofactors was performed to determine whether the difference between the two groups was affected by these factors.

Results

Demographic characteristics of the sample

A total of 186 respondents completed the questionnaire. The mean age of the respondents was 39.6 ± 10.4 years (ranging from 20 to 58 years). The respondents were predominant female (82.8%) and Chinese (76.3%). 75.3% of the respondents were married, 94.1% had tertiary education and 95.2% were employed full-time. 94.1% had income above RM2000 (USD 656) a month. 3.8% of the respondents had family member(s) with epilepsy or seizures.

Psychometric properties of the PATE scale in teachers

The mean score of all 14-item was 2.18 ± 0.53, in which the mean score in general domain was 1.97 ± 0.59, and in personal domain was 2.40 ± 0.61. Cronbach's α for the general domain was 0.815 (within the acceptable range of 0.7-0.9), with a mean inter-item correlation of 0.342. Whereas for the personal domain, Cronbach's α was 0.747 (within the acceptable range of 0.7-0.9) with a mean inter-item correlation of 0.373.

Attitudes toward epilepsy between the groups

Analysis of variance showed that there were a significant difference in the mean scores in both personal (p<0.001) and general (p<0.05) domains among the teachers, students and general population.

Attitudes toward epilepsy between the teachers and students

Post-hoc comparison showed that the mean scores in both personal and general domains of PATE scale were significantly lower in the teachers, comparing to the secondary and college students (p<0.001 and <0.05 respectively), as shown in table 8-1. On item analysis, the teachers scored significantly lower in 8 items and higher in one item (item 10), as compared to the students (Table 8-1). Subanalysis according to social aspects of life showed that the attitudes of teachers were significantly (p<0.001) better than the students toward employment and social life, but not toward marital relationship and education. (Table 8-2)

Table 8-1: The means and standard deviations of the scores in each domain and item, in teachers, students (Lim et al., 2013) and general population (Lim et al., 2012)

ID	Item	Mean (SD)		
		Teachers (n=186)	**Students (n=227)**	**General populations (n=130)**
	Personal domain	2.40 (0.61)	2.73 (0.61) ***	2.72 (0.56)***
1	I feel uncomfortable working with someone who has epilepsy.	1.95 (0.79)	2.62 (0.93)***	2.42 (0.87)***
2	I will advise my family members against marrying someone with epilepsy.	2.58 (0.94)	2.73 (0.92)	2.95 (0.91)***
3	I would marry someone with epilepsy, even though he/she has epilepsy.[#]	2.78 (0.84)	3.01 (0.88)**	3.03 (0.85)*
5	I would date someone even though he/she has epilepsy.[#]	2.63 (0.87)	2.85 (0.94)*	2.78 (0.84)
7	If I am an employer, I would give equal employment opportunities to someone with epilepsy.[#]	2.03 (0.88)	2.42 (1.12)***	2.41 (0.96)***
	General domain	1.97 (0.59)	2.12 (0.60) *	2.09 (0.59)
4	I will not mind being seen in the company with someone known to have epilepsy. [#]	1.97 (1.05)	2.14 (0.86)	2.06 (0.77)
6	I would stay away from a friend if I knew she/he had epilepsy.	1.76 (0.91)	1.96 (0.86)*	2.08 (0.92)**
8	People with epilepsy have the same rights as all people. [#]	1.62 (0.88)	1.96 (1.04)***	2.05 (0.91)***
9	People with epilepsy should be isolated from others.	1.68 (0.85)	2.02 (0.97)***	1.94 (0.84)**
10	People with epilepsy should not marry.	2.19 (0.93)	2.01 (0.92)*	2.06 (0.78)
11	People with epilepsy should not participate in social activities.	1.77 (0.84)	2.00 (0.90)**	2.00 (0.78)*
12	People with epilepsy should not study in college or university.	1.80 (0.79)	1.78 (0.80)	1.82 (0.70)
13	People with epilepsy should study in a special school.	2.50 (1.00)	2.69 (1.08)	2.43 (0.97)
14	Schools should not place children with epilepsy in regular classrooms.	2.41 (1.01)	2.44 (1.03)	2.35 (0.90)

[#]These items were reversely scored. **p*-value is <0.05, ** *p*-value is <0.01 and *** *p*-value is <0.001, as compared to current study.

Table 8-2: The means and standard deviations of the attitude scores toward various social aspect of life in people with epilepsy, in teachers, students (Lim et al., 2013) and general population (Lim et al., 2012)

Attitudes toward various social aspect of life in people with epilepsy	Mean (SD)		
	Teachers (n=186)	Students (n=227)	General populations (n=130)
Marriage	2.55 (0.71)	2.65 (0.65)	2.71 (0.61)*
Employment	1.99 (0.70)	2.52 (0.79)***	2.41 (0.72)***
Social life	1.80 (0.68)	2.03 (0.68)***	2.02 (0.63)**
Education	2.24 (0.73)	2.30 (0.76)	2.20 (0.70)

* *p*-value is <0.05; ** *p*-value is <0.01; and *p*-value is <0.001, as compared to the scores in teachers.

Comparison between the teachers and the general population

Post-hoc analysis comparing the teachers and the general population showed that the mean scores in personal domain of PATE scale were significantly lower in the teachers ($p<0.001$) but not in general domain, as shown in table 8-1. Univariate analysis using education level as a cofactor showed a persistent significant difference in the mean score in personal domain between the teachers and the general population. On item analysis, the teachers scored significantly lower in 8 items, as compared to the general population. (Table 8-1) Subanalysis according to social aspects of life showed that the attitudes of teachers were significantly better than the general population related to employment, social life and marital relationship, but not related to education. (Table 8-2)

A subgroup of general population with tertiary education was extracted from previous study[10] for comparison. Table 8-3 showed significant differences in personal domain, employment and social life subscales between the teachers and general population with tertiary education.

Table 8-3: The means and standard deviations of the attitude scores in each domain and scores toward various social aspect of life in people with epilepsy, in teachers and general population with tertiary education. (Lim et al., 2012)

	Mean (SD)	
	Teachers (n=186)	General population with tertiary education (n=108)
General domain	1.97 (0.59)	2.04 (0.59)
Personal domain	2.40 (0.61)	2.70 (0.59)***
Attitudes toward various social aspect of life in people with epilepsy		
Marriage	2.55 (0.71)	2.68 (0.63)
Employment	1.99 (0.70)	2.41 (0.72)***
Social life	1.80 (0.68)	1.97 (0.61)*
Education	2.24 (0.73)	2.16 (0.73)

* *p*-value is <0.05; and *p*-value is <0.001, as compared to the scores in teachers.

Comparison between the primary and secondary school teachers

Teachers in the primary school were predominantly Chinese (93.4%) as compared to those in secondary school (53.8% vs. 27.5% Malay, 15.0% Indian and 3.7% others). There were no significant differences in other demographic variables.

The mean scores in general domain of PATE scale were significantly lower in the teachers from primary school, comparing to secondary school teachers ($p<0.05$) but not in personal domain, as shown in table 8-4. However, the difference in mean score in general domain between the primary and secondary teachers was not significant if ethnicity and education level were included as cofactors in the univariate analysis. On item analysis, the teachers in primary school scored significantly lower in one item (item 14), as compared to those in secondary school. Subanalysis according to social aspects of life showed that there were no significant differences in the attitudes of the primary and secondary school teachers except attitudes toward education which was less negative among the primary school teachers ($p<0.01$). (Table 8-4) Univariate

analysis for the variation in attitudes toward education with ethnicity and education level as the cofactors showed significant difference ($p<0.05$) between the two groups.

Table 8-4: The means and standard deviations of the scores in each domain and the attitude scores toward various social aspects of life in people with epilepsy, in primary (n=106) and secondary school teachers (n=80)

Score	Mean (SD)	
	Primary school teachers	**Secondary school teachers**
General Domain	1.89 (0.62)*	2.07 (0.52)
Personal Domain	2.35 (0.68)	2.46 (0.51)
Attitudes toward various social aspects of life in people with epilepsy		
Marriage	2.46 (0.78)	2.66 (0.59)
Employment	2.00 (0.77)	1.97 (0.59)
Social life	1.78 (0.74)	1.82 (0.59)
Education	2.10 (0.72)**	2.42 (0.69)

*p-value is <0.05; **p-value is <0.01.

Scores by domains and demographic characteristics

The mean scores for the general and personal domain were not correlated with gender, marital status, education level and ethnicity.

Discussion

This is the first study comparing the attitudes toward epilepsy (1) between teachers and general population and (2) students, as well as (3) between primary and secondary school teachers.

This study showed that the teachers' attitudes toward epilepsy were more positive than general population, as evidenced by better attitude with lower mean score in personal domain, but with no significant difference in general domain. Subanalysis showed that

the positive attitudes in teachers are more toward employment issue in people in epilepsy but not marriage or personal relationship. It is worrying that overall, teachers did not have a significantly different attitude toward education among people with epilepsy from the general population, with similar answers to questions 12 to 14, i.e., people with epilepsy should not study in college or university, should study in a special school, and should not be placed in regular classroom. Specific education should be targeted to overcome this.

Teachers in this cohort were predominantly female, with higher marital rate and education level, as compared with the general population cohort reported in previous study.[10] We have previously shown that education is associated with better scores particularly in the general domain.[10] When we compared the attitudes among the teachers with a subgroup of general population with tertiary education (table 8-3), we found that the teachers also had more positive attitudes than the public with tertiary education, particularly in the personal domain, especially in employment and social life. This suggests that the more positive attitudes in teachers might be directly related to the occupation itself rather than just the higher level of education.

The teachers' attitudes were more positive toward employment but not marriage, and this might be related to the personality of a teacher. Using Myers-Briggs type indicator with four scales including sensing versus intuition[12], American teachers were found to be more sensible than intuitive, i.e. be more factually based, and focus on practical concrete problems.[13] This might explains how teachers deal with the practical issues e.g. employment in a more positive manner, but not in a personal issue such as marriage. However, this postulation requires confirmation from future studies using the appropriate measures.

Teachers' attitudes toward epilepsy were more positive than students in both general and personal domain in PATE scale. This is consistent with the results from indirect comparison using the percentage of participants with negative attitudes towards social contact in epilepsy.[4] The students' attitude is similar to and reflective of the attitude of the general population. Teachers' attitudes have a great impact on students. It is hoped that the better attitude of the teachers might be able to positively influence the students to have a more positive attitudes toward epilepsy.

Primary school teachers scored lower in general domain as compared with those from secondary school, especially in education subscale in this study. Very few studies had been performed on teachers from both primary (elementary) and secondary (middle and high) school. [5,14-17] Although teachers dealing with students from different age groups might have different attitudes toward epilepsy, direct comparison of the attitudes of teachers from various levels of school was only performed in one study on the primary, secondary and tertiary level teachers in a Brazilian city. [15] The result of this study is inconsistent to Dantas' study that primary level teachers had poorer attitudes than the secondary and tertiary level teachers with more believed that epilepsy is contagious and people with epilepsy are less intelligent. It is interesting to note the primary school teachers had a more positive attitude toward education than the secondary school teachers. Primary school education emphasizes the importance of basic education in early childhood development, in contrast to secondary school education which aims to prepare the students to be part of the labor force. This might explain why the primary school teachers are more acceptable to have children with epilepsy in the normal class.

Limitations and study implications

This study was performed in only two schools in a metropolitan city and thus the results cannot be generalized to the general population. However, the previous studies [10,11] were also performed in the same region, which allows direct comparison.

Though the attitudes toward epilepsy were quantified and compared, only demographic factors were included in this study as the possible factors influencing the attitudes. Cultural or psychological factors such as teachers' personality will be included in future study, to depict how they may affect one's attitudes toward epilepsy. This study also forms a basis for qualitative study in understanding these underlying factors.

Using the percentage of teachers agreeing to "Would you object to your children associating with people who sometimes had seizures?" as a mean of comparison, the systematic review by the first author [4] showed that teachers in Korea and India had poorer attitudes as compared with those in Thailand and Turkey. However, a comparison of the overall attitudes toward epilepsy is impossible. Replication of this study using a quantitative scale in other countries will allow a direct comparison of the teachers' attitudes toward epilepsy between different populations.

Conclusion

We were able to show that teachers had more positive attitudes toward epilepsy as compared with the general population and students, this was more than can be accounted for by the tertiary education. We also showed that primary school education had better attitude than secondary school teachers, probably related to the overall goal

of their work. This shows that attitude to epilepsy may differ in different types of work. The roles may change the attitude to epilepsy. It is thus particularly important to study the attitude to epilepsy in members of different professions or opinion leaders that may have greater impact on the quality of life of people with epilepsy, such as teachers, school counselors, media workers, and human resource officers, and parents.

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Chapter 9: Attitudes towards epilepsy among Malay population in Southeast Asia, using the Public Attitudes Toward Epilepsy (PATE) scale, a preliminary study in Malaysia

Abstract

Introduction: The people with epilepsy in rural population had been shown to encounter greater stigmatization, probably secondary to poorer attitudes toward epilepsy. This survey aimed to ascertain the variation in attitudes toward epilepsy between rural and urban Malays in Malaysia, using a validated Malay version of Public Attitudes Toward Epilepsy (PATE) scale.

Method: 253 Malay subjects (57.3% female) with a mean age of 38.93±13.49 years were recruited, 160 from Kuala Lumpur (urban) and 93 from Kelantan (rural).

Results: The rural Malay population in this survey were significantly older, less educated, less full-time employed and had lower monthly income ($p<0.001$). There was no significant different in the mean total scores in the personal and general domains of the PATE scale. On subcategory analysis, the rural group showed more favorable attitude in items related to marriage ($p<0.05$). Item analysis showed that the rural population had more negative attitude against epilepsy person participate in social activities (item 4).

Conclusion: There were no significant differences in general attitudes toward epilepsy between rural and urban Malay population. However, rural Malays were more positive toward marriage in people with epilepsy.

Introduction

Epilepsy is a disorder of the brain that is characterized by an enduring predisposition to generate seizures and by its neurobiological, cognitive, psychological, and social consequences.[1] Epilepsy is one of the most common serious neurological disorders, affecting approximately 50 million of human beings nationwide,[2] especially in developing countries[3,4]. Yet, 60% to 90% of individuals with epilepsy in developing countries remain untreated due to various reasons including inadequacy in health care resources and social stigma[5,6].

Quality of life of epileptic person is mainly determined by duration of disease and extent of seizure control, and other non-epileptic parameters such as social stigma attributed significantly too[7-9]. Social stigma affliction attached to epilepsy has been revealed to be more devastating than the disease itself [10,11]. The degree of stigmatism varies greatly in terms of socio-economic variance which had been acknowledged through studies especially in between the countries in Asia and the West.[12]

Malaysia is a multiethnic developing country with limited studies available on public awareness and attitude towards epilepsy. Rural and sub-urban areas are usually with higher prevalence of epilepsy as well as higher treatment gap.[4,13]. Besides that, rural individuals with lower education level and socioeconomic status have been found to have more negative attitudes towards epilepsy, deeply discrediting for an epileptic individual with higher level of stigmatization.[14-19]

Surveys conducted on Taiwan population stated rural group had greater objection towards person with epilepsy to be employed under comparison with urban group (38%

vs. 75%, respectively).[20] Moreover, rural population in USA demonstrated greater negative stereotype than urban population.[21] On the other hand, turkey population study found that urban population had more negative attitudes toward epilepsy with 20% believed epilepsy is a form of insanity, significantly higher than 10% in rural population.[22] Whereas a previous study conducted on Malaysian Chinese population showed non-significant differences between rural Chinese and urban Chinese in the attitudes toward epilepsy.[23]

Malay community is the largest community (50.4%) in Malaysia. However, studies on the Malay population were limited and none have ever compared the attitude toward epilepsy between the rural and urban Malay population. Identification of the predictors of the attitude differences between the urban and rural populations using an objective scale, would elucidate psychosocial understanding and aid in future intervention designation.

This study aimed to quantify the differences in attitudes toward epilepsy between rural and urban Malay population in Malaysia, using the Public Attitudes Toward Epilepsy (PATE) scale.

Method

Study population

A total of 253 respondents were recruited through convenient sampling with a mean age of 38.93±13.49 years, 160 respondents from Kuala Lumpur and Petaling Jaya (urban region) and 93 respondents from Kubang Kerian, Kelantan (rural region). Verbal

consents were obtained in agreement to carry out survey and all questionnaires were administered anonymously. The selection criteria given that subjects must not be an epileptic person and that they should be permanent residents of the district studied. Ethical approval from the ethics committee at University Malaya Medical Center (MREC no.: 878.10) and University of Science Malaysia (USM no.: 260.3(3)) were obtained.

Measures

Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scales measuring attitudes towards epilepsy among public[24]. A 5-point Likert scale with reversed scoring system was adopted, 1 being strongly disagree and 5 being strong agree. It is conceptualized into two domains: a total of 9 items loading on general domain which required minimal or no consideration of subject's personal involvement and personal domain which constituted of 5 items which involved long-term personal commitment such as marrying to epileptic individual, working with them or employed epileptic candidate. Higher PATE scores indicated more negative attitude through reversely scored of positively stated items. The interviewers were encouraged to provide only necessity explanation for point's clarification in order to minimize results deviation.

The Malay version of PATE scale is a reliable and validated scale with good internal consistency for both general and personal domains (Cronbach's coefficient 0.868 and 0.633, respectively).[25]

Demographic data were collected on the subject's race, age, gender, marital status, education status, employment status, occupation, income level, and family history for descriptive and continuous analysis.

Statistical analysis

Statistical Package for Social Sciences version 19 (SPSS 19.0) was adopted for data analyses. Descriptive analyses were depicted using mean, standard deviation and simple percentages as appropriate. The differences in socio-economic variables between the two groups were assessed using Chi-square tests. Comparisons of mean scores in the personal domain, general domains, as well as individual items were performed using student's *t*-test. Univariate analysis were performed to determine the impacts of demographic variables on the differences between the urban and rural groups. In addition, the items were further subcategorized into various socio-economic subgroups according to previous publication, i.e. categorize question of "I will advise my family members against marrying someone with epilepsy." into marriage related item[26] and the urban-rural differences of the mean subcategory scores were assessed using independent sample student's *t*-test. Significant level was set at $p<0.05$ (2-tailed).

Results

1. Demographic characteristic of samples

A total of 253 respondents were recruited. The rural Malay population in this survey were significantly older, less educated, less full-time employed and had lower monthly income, than the urban group (*p*-value <0.001, as shown in Table 9-1)

Table 9-1: Demographic characteristics of rural and urban Malay groups (N=93 and 160, respectively).

Demographic Variables	Group	
	Rural Malay (N= 93)	Urban Malay (N= 160)
Gender: Female, n (%)	60 (64.5%)	85 (53.1%)
Age, mean ±SD	43.63±13.54	36.19±12.72*
Marital Status: married, n (%)	73 (78.5%)	106 (66.3%)
Education Level: Tertiary level, n (%)	15 (16.1%)	49 (30.6%)*
Employment Status: Full time, n (%)	24 (25.8%)	98 (61.3%)*
Income: RM2000 and above, n (%)	21 (22.6%)	80 (50%)*

**p*-value is <0.001, as compared to the rural group.

3.2 Attitudes toward epilepsy in rural and urban Malay, using PATE scale

Generally, the mean score in general domain was higher than those in the personal domain in both urban and rural populations (*p*-value <0.001), as shown in Table 9-2. There were no significant differences in the total mean scores as well as the mean scores in the general and personal domains in PATE scale between the urban and rural groups.

Table 9-2. Means and standard deviation (SD) of each domain in rural (n=93) and urban Malay (n=160) groups.

Domain (Number of items)	Rural Malay, mean (SD)	Urban Malay, mean (SD)
General Domain (9)	2.08 (0.55)	2.08 (0.52)
Personal Domain (5)	2.38 (0.54)	2.50 (0.63)
Total (14)	2.19 (0.48)	2.23 (0.48)

3.3 Subcategory analysis

On subcategory analysis, the rural population was found to have more positive attitudes toward marriage in comparison with the urban group (2.37±0.57 vs. 2.55±0.63 respectively, $p<0.05$), but have no significant differences in the employment, education and social life subcategories, as shown in table 9-3. Univariate analysis using age, employment status and education level as covariates showed that employment status and education level were significant covariates of the difference in the mean score of marriage subcategory between the urban and rural groups.

Table 9-3. Mean scores by subcategory and group. (n=253)

Subcategory Variables	Items involved	Mean (SD)	
		Rural group (n=93)	Urban group (n=160)
Marital	Item 6,10,11,13	2.37 (0.57)	2.55 (0.63)*
Employment	Item 12,14	2.10 (0.69)	2.11 (070)
Education	Item 1,8,9	2.40 (0.77)	2.45 (0.79)
Social life	Item 2,3,4,5,7	1.95 (0.62)	1.90 (0.53)

* *p*-value is <0.05; as compared to the rural group.

3.4 Item analysis

There were significant differences in the scores in items 4, 11 and 13 between the rural and urban groups as shown in table 9-4. Univariate analysis showed that employment status and monthly income were significant covariates on the difference in item 11 (I will marry to someone with epilepsy, even though she/he has epilepsy) between the urban and rural groups, but not on items 4 and 13.

Table 9-4. Means and standard deviations of the items in each group.

Item	Rural Malay (n=96), means (SD)	Urban Malay (n=160), means (SD)
1. People with epilepsy should not study in college or university.	2.19 (1.14)	2.00 (0.93)
2. People with epilepsy have the same rights as all people.	1.76 (0.95)	1.87 (0.90)
3. People with epilepsy should be isolated from others.	1.75 (0.84)	1.87 (0.81)
4. People with epilepsy should not participate in social activities.	2.49 (1.14)	1.99 (0.92)***
5. I will not mind being seen in the company with someone known to have epilepsy.	2.02 (0.98)	1.90 (0.87)
6. People with epilepsy should not marry.	1.78 (0.72)	1.91 (0.79)
7. I would stay away from a friend if I know she/he has epilepsy.	1.74 (0.83)	1.87 (0.90)
8. People with epilepsy should study in a special school.	2.52 (1.16)	2.69 (1.16)
9. Schools should not place children with epilepsy into regular classrooms.	2.49 (1.08)	2.66 (1.08)
10. I would date someone even though he/she has epilepsy.	2.74 (0.92)	2.71 (0.89)
11. I would marry someone with epilepsy, even though he/she has epilepsy.	2.67 (0.77)	2.90 (0.90)*
12. I feel uncomfortable working with someone who has epilepsy.	2.26 (0.90)	2.19 (0.84)
13. I will advise my family members against marrying someone with epilepsy.	2.31 (0.87)	2.68 (0.97)**
14. If I am an employer, I would give employment opportunity to someone with epilepsy.	1.94 (0.85)	2.04 (0.97)

* *p*-value is <0.05; ** *p*-value is <0.01; and ***p-value is <0.001, as compared to the rural group.

Discussion

This study showed that there were no significant differences in attitudes toward epilepsy between rural and urban Malay population generally, based on the mean scores in the personal and general domains in PATE scale. However, on subcategory and item analysis, the rural Malay had shown a more positive attitudes toward marriage in people with epilepsy, as compared with the urban Malay population.

Absence of urban-rural difference in the attitudes toward epilepsy was similarly reflected in the study performed on the Chinese population in Malaysia.[23] This is in contrary to studies reporting better attitudes toward epilepsy in the urban[20,21] or in the rural[22] population.

In Malaysia, all Malay population believe in the same religion, which is Islam, and practice the religious customs following the same scripture, irrespective of the residential region. Therefore, the urban-rural boundary is demarcated by socio-economic differences, as shown in table 1, but not the cultural or religious differences. The absence of urban-rural difference in attitudes toward epilepsy in Malaysian Malay suggests that public attitudes are probably more culturally dependent rather than socio-economically dependent.

This study showed that rural Malay population had more positive attitude toward marriage in people with epilepsy than the urban group, affected by socioeconomic factors. It is postulated to be related to the difference in mate selection between the urban and rural population. In a modern society, mate selection preference is determined by nonphysical characteristics that maximize the survival or reproductive prospects,[27]

compatible with the findings in a study in Taiwan which stated that those with higher education were more prejudiced against marrying an epileptic person.[28] In rural, ability to reproduce is still one of the main mate selection criteria. This might explain being an epileptic is not an exclusion criteria in mate selection in rural population, thus less prejudice against marrying someone with epilepsy in this group of people.

Item analysis showed that the rural population had more negative attitude against epilepsy person participate in social activities (item 4). This reflects the overprotective attitudes especially in rural area, as supported by many studies demonstrated a significant social deficit among rural populations in Asian countries.[29,30] Similar attitude was also found in the research conducted by Saengsuwan in Thailand showing that 90% of participants would believe person with epilepsy cannot live in the society like healthy people do[31].

Future Implication

Findings in this study were similar to previous study in Chinese population of Malaysia[23], revealing the urban-rural differences in attitudes toward certain social aspects of life in people with epilepsy. This will serve as a guide for the development of social intervention among the Malay population in various parts of Malaysia.

Conclusion

There were no significant differences in general attitudes toward epilepsy between rural and urban Malay population. However, on subcategory analysis, the rural Malay had

shown a more positive attitudes toward marriage in people with epilepsy, as compared with the urban Malay population.

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Chapter 10: Attitudes towards epilepsy among Chinese population in Malaysia, using the Public Attitudes Toward Epilepsy (PATE) scale.

Abstract

Introduction: Comparison of attitudes toward epilepsy among populations using a standard and quantitative scale was not available. This study aimed to determine the differences between the rural and urban Chinese populations in Malaysia, and between the Chinese and Malay populations, using the Public Attitudes Toward Epilepsy (PATE) scale. *Method*: A total of 348 respondents, with a mean age of 38.7±15.2 years (range 18-76), of which 188 from Kuala Lumpur and Petaling Jaya (urban) and 160 from Sekinchan (rural), were recruited. *Results*: The mean score in personal domain was significantly lower in the rural group, as compared with the score in the urban group ($p<0.05$, adjusted for age and gender). On subcategory analysis, the rural population was found to have more positive attitudes toward marriage and employment in comparison with the urban group ($p<0.05$). The mean score in both personal and general domains of the Chinese population were lower than those in the Malay population but not statistically different. Chinese population had a lower mean scores in the social life subcategory than the Malay ($p<0.01$). *Conclusion*: The rural Chinese had a more positive personal attitudes toward epilepsy than the urban group. There was no significant differences between the Chinese and Malay population.

Keywords: attitudes, epilepsy, Chinese

Introduction

Epilepsy is a disorder of the brain that is characterized by an enduring predisposition to generate seizures and by its neurobiological, cognitive, psychological, and social consequences.[1] 60% to 90% of individuals with epilepsy in developing countries remain untreated due to various reasons including inadequacy in health care resources and social stigma[2,3]. Social stigma affliction attached to epilepsy has been revealed to be more devastating than the disease itself [4,5]. The degree of stigmatism varies greatly in terms of socio-economic variance which had been acknowledged through studies especially in between the countries in Asia and the West.[6]

Rural and sub-urban areas are usually with higher prevalence of epilepsy as well as higher treatment gap.[7,8]. Besides that, rural individuals with lower education level and socioeconomic status have been found to have more negative attitudes towards epilepsy, deeply discrediting for an epileptic individual with higher level of stigmatization.[9-14] Surveys conducted on Taiwan population stated rural group had greater objection towards person with epilepsy to be employed under comparison with urban group (38% vs. 75%, respectively).[15] Moreover, rural population in USA demonstrated greater negative stereotype than urban population.[16] On the other hand, turkey population study found that urban population had more negative attitudes toward epilepsy with 20% believed epilepsy is a form of insanity, significantly higher than 10% in rural population.[17] Whereas a previous study conducted on Malaysian Chinese population showed non-significant differences between rural Chinese and urban Chinese in the attitudes toward epilepsy.[18]

Malaysia is a multiethnic developing country with limited studies available on public awareness and attitude towards epilepsy. Chinese community is the second largest community (24.6%) in Malaysia, after the Malay community. Surveys on public attitudes toward epilepsy in Malaysian Chinese and Malay had been performed previously.[6,18,19] However, a standard and quantitative scale was not used in these studies, resulting in difficulty in comparing the results.

This study aimed to quantify the attitudes toward epilepsy among Chinese population in Malaysia, to determine the differences in attitudes toward epilepsy between the rural and urban Chinese, and between the Chinese and Malay populations by comparing to a similar study on the Malay population[20], using the Public Attitudes Toward Epilepsy (PATE) scale.

Method

Study population

A total of 348 respondents were recruited through convenient sampling, of which 188 respondents were from Kuala Lumpur and Petaling Jaya (urban region) and 160 respondents from Sekinchan (rural region). Verbal consents were obtained in agreement to carry out survey and all questionnaires were administered anonymously. The selection criteria given that subjects must not be an epileptic person and that they should be permanent residents of the district studied. Ethical approval from the ethics committee at University Malaya Medical Center (MREC no.: 878.10).

Measures

The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy (Lim, 2012)[21]. A 1-5 Likert scale was used for scoring with 1 being strongly disagree and 5 being strongly agree. Some items were reverse scored so that a higher score would indicate a more negative attitude. This scale was performed in a general population and factored into two domains, i.e. a general domain (nine items) that required minimal or no consideration of respondents' involvement, and a personal domain (five items) that required a long-term personal commitment or involvement. This is a validated scale with good internal consistency (Cronbach's alpha of 0.868 and 0.633, in the general and personal domains respectively).

This study was performed using either the original or the Chinese PATE scales. The Chinese version of PATE scale is a validated translated version with good internal consistency in both general and personal domains (Cronbach's coefficient 0.868 and 0.633, respectively).[22]

Demographic data were collected on the subject's race, age, gender, marital status, education status, employment status, occupation, and income level for descriptive and continuous analysis.

Statistical analysis

Statistical Package for Social Sciences version 19 (SPSS 19.0) was adopted for data analyses. Descriptive analyses were depicted using mean, standard deviation and simple percentages as appropriate. The differences in demographic variables between two groups were assessed using Chi-square tests and student's *t*-test. Comparisons of mean

scores in the personal and general domains as well as individual items were performed using student's *t*-test. Adjustment for the demographic differences between groups was performed using a one-way between-group analysis of variance. In addition, the items were further subcategorized into various socio-economic subgroups according to previous publication, i.e. categorize question of "I will advise my family members against marrying someone with epilepsy." into marriage related item[23] and the urban-rural differences of the subcategory mean scores were assessed using student's *t*-test.

The mean scores in the domains and subcategories were also compared with the mean scores of a Malay population of 253 subjects (57.3% female) with similar mean age of 38.93±13.49 years, recruited from both urban and rural areas.[20] Recoding of the item answers to reflect the percentage of respondents with negative attitudes toward each item was performed, as shown in table 10-7. This is to enable a direct inspection of the attitudes toward epilepsy among various ethnic groups, and the comparison was tested with Chi-square tests. Significant level was set at $p<0.05$.

Results

1. Demographic characteristic of samples

A total of 348 respondents, with a mean age of 38.7±15.2 years (range 18-76) and 46.0% rural, were recruited. (Table 10-1) The rural Chinese population were significantly younger, male predominant, less educated, and less full-time employed, than the urban group (*p*-value <0.001).

Table 10-1: Demographic characteristics of the total participants (N=348), and the urban and rural subgroups (N=188 and 160, respectively).

Demographic Variables	Total	Group	
		Urban Chinese	Rural Chinese
Gender: Female, n (%)	160 (46.0)	104 (55.3)	56 (35.0)*
Age, mean ±SD	38.7 ±15.2	42.0 ±15.2	34.7 ±14.2*
Marital Status: Single, n (%)	149 (42.8)	114 (60.6)	81 (56.0)
Education Level: Tertiary level, n (%)	157 (45.1)	121 (64.4)	36 (22.5)*
Employment Status: Full time, n (%)	165 (47.4)	96 (51.1)	69 (43.1)*
Income: RM2000 and above, n (%)	148 (42.5)	88 (46.8)	60 (37.7)
Presence of family history, n (%)	16 (4.6)	9 (4.8)	7 (4.4)

*p-value is <0.001, as compared to the urban group.

2. Attitudes toward epilepsy according to demographic characteristics

The mean score in personal domain was significantly lower in the rural group, as compared with the score in the urban group (p<0.01), as shown in Table 10-2. A univariate analysis was performed to determine the effect of age and gender on the urban-rural difference in the mean score in personal domain. After adjusting for age and gender, the difference in the mean score in personal domain between the urban and rural groups was still statistically significant. (p<0.05) Those who were single and with monthly income less than RM2000 had lower mean scores in the general domain, as compared with the others (p<0.05), but had no significant difference in the mean scores in personal domain.

Table 10-2: Mean scores and standard deviations by domains and demographic characteristics (n=348)

Variable	Group (n)	General domain	Personal domain	Total
Age[1]		-0.009	0.067	0.024
		Mean score (SD)		
Geographical location	Urban (188) Rural (160)	2.08 (0.54) 1.99 (0.54)	2.46 (0.63) 2.28 (0.64)**	2.22 (0.49) 2.10 (0.52)*
Gender	Male (188) Female (160)	2.06 (0.52) 2.02 (0.55)	2.39 (0.66) 2.36 (0.62)	2.18 (0.50) 2.14 (0.51)
Marital status	Single (149) Others (199)	2.11 (0.55) 1.99 (0.51)*	2.41 (0.59) 2.35 (0.68)	2.22 (0.51) 2.12 (0.50)
Education level	Tertiary (157) Others (191)	2.04 (0.54) 2.04 (0.53)	2.40 (0.62) 2.36 (0.66)	2.17 (0.50) 2.16 (0.52)
Employment status	Employed full time (165) Others (183)	2.01 (0.56) 2.07 (0.51)	2.33 (0.64) 2.42 (0.65)	2.13 (0.51) 2.19 (0.50)
Monthly income in Ringgit Malaysia	2000 and above (200) Others (148)	1.98 (0.56) 2.09 (0.51)*	2.32 (0.69) 2.42 (0.60)	2.10 (0.53) 2.20 (0.49)
Family member with epilepsy/seizures	Yes (16) No (332)	2.02 (0.58) 2.04 (0.53)	2.30 (0.65) 2.38 (0.64)	2.12 (0.57) 2.16 (0.51)

[1]Based on Pearson correlation; *p-value is < 0.05; and **p-value is < 0.01, when compared between groups.

3. Comparison of attitudes toward epilepsy between urban and rural Chinese: subcategory and item analyses

On subcategory analysis, the rural population was found to have more positive attitudes toward marriage and employment in comparison with the urban group ($p<0.05$), but have no significant differences in the education and social life subcategories, as shown in table 10-3.

Table 10-3. Mean scores by subcategory and group. (N=348)

Subcategory Variables	Items involved	Total (N=348)	Urban group (N=188)	Rural group (N=160)
		Mean (SD)		
Marital	Item 6,10,11,13	2.47 (0.70)	2.55 (0.68)	2.38 (0.70)*
Employment	Item 12,14	2.09 (0.72)	2.16 (0.65)	2.00 (0.78)*
Education	Item 1,8,9	2.37 (0.73)	2.39 (0.71)	2.34 (0.75)
Social life	Item 3,4,5,7	1.81 (0.62)	1.84 (0.57)	1.78 (0.68)

* *p*-value is <0.05; as compared to the urban group.

The rural subgroup had significantly lower item mean scores in items 2, 9, 10 and 13 as compared with the urban group. (Table 10-4)

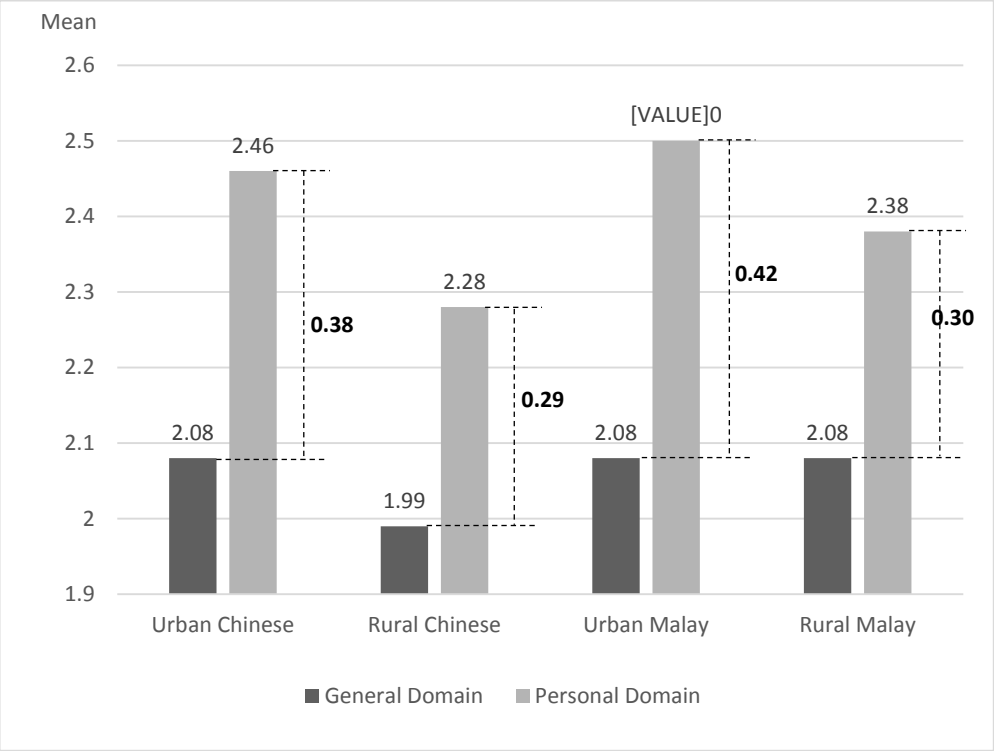
Table 10-4. Item means and standard deviations of the total participants (N=348), and the urban and rural subgroups (N=188 and 160, respectively).

Item	Total	Urban	Rural
	Mean (SD)		
1. People with epilepsy should not study in college or university.	1.95 (0.90)	1.90 (0.85)	1.99 (0.94)
2. People with epilepsy have the same rights as all people. #	1.85 (0.92)	1.98 (0.95)	1.70 (0.85)**
3. People with epilepsy should be isolated from others.	1.69 (0.76)	1.76 (0.78)	1.61 (0.73)
4. People with epilepsy should not participate in social activities.	1.93 (0.88)	1.90 (0.81)	1.97 (0.95)
5. I will not mind being seen in the company with someone known to have epilepsy. #	1.93 (1.00)	1.94 (0.90)	1.91 (1.12)
6. People with epilepsy should not marry.	2.18 (0.94)	2.23 (0.88)	2.11 (1.00)
7. I would stay away from a friend if I know she/he has epilepsy.	1.71 (0.85)	1.77 (0.86)	1.63 (0.83)
8. People with epilepsy should study in a special school.	2.76 (1.11)	2.72 (1.01)	2.81 (1.22)
9. Schools should not place children with epilepsy into regular classrooms.	2.39 (1.03)	2.54 (1.000	2.22 (1.04)**
10. I would date someone even though he/she has epilepsy. #	2.45 (0.85)	2.54 (0.86)	2.34 (0.83)*
11. I would marry someone with epilepsy, even though he/she has epilepsy. #	2.84 (0.90)	2.90 (0.90)	2.76 (0.91)
12. I feel uncomfortable working with someone who has epilepsy.	1.99 (0.86)	2.06 (0.83)	1.91 (0.96)
13. I will advise my family members against marrying someone with epilepsy.	2.42 (0.99)	2.53 (0.96)	2.29 (1.01)*
14. If I am an employer, I would give employment opportunity to someone with epilepsy. #	2.18 (0.91)	2.27 (0.87)	2.09 (0.94)

These items were reversely scored. * *p*-value is <0.05; and ** *p*-value is <0.01, as compared to the urban group.

Figure 10-1 demonstrated that the discrepancies between the mean scores in the personal and general domains (dotted line) were bigger in the urban Chinese (0.38) and urban Malay (0.42), as compared with the rural Chinese (0.42) and rural Malay (0.30).

Figure 10-1: Comparison of the mean scores in general and personal domains in PATE scale between the rural and urban Chinese and Malay.



The dotted lines indicate the discrepancy between the mean scores in the personal and general domains.

4. Comparison of attitudes toward epilepsy between Chinese and Malay population, using PATE scale

The Chinese cohort had less female and more with single marital status, as compared with the Malay cohort. (Table 10-5)

Table 10-5: Demographic characteristics of the total participants (N=348), and the urban and rural subgroups (N=188 and 160, respectively).

Demographic Variables	Chinese	Malay
Gender: Female, n (%)	160 (46.0)	145 (57.3)*
Age, mean ±SD	38.7±15.2	38.9±13.6
Marital Status: Single, n (%)	149 (42.8)	65 (25.7)*
Education Level: Tertiary level, n (%)	157 (45.1)	130 (51.4)
Employment Status: Full time, n (%)	165 (47.4)	122 (48.2)
Income: RM2000 and above, n (%)	148 (42.5)	101 (39.9)

*p-value is <0.01, as compared to the urban group.

The mean score in both personal and general domains of the Chinese population were lower than those in the Malay population but not statistically different, as shown in Table 10-6. Chinese population had a lower mean scores in the social life category than the Malay (p<0.01), indicating that Chinese had a better attitudes toward social contact with people with epilepsy.

Table 10-6. Means and standard deviation (SD) of each domain and subcategory in Chinese (n=348) and Malay (n=253) populations.

	Chinese, mean (SD)	Malay, mean (SD)
Domain (Number of items)		
General Domain (9)	2.04 (0.53)	2.08 (0.55)
Personal Domain (5)	2.37 (0.64)	2.46 (0.60)
Total (14)	2.16 (0.51)	2.22 (0.49)
Subcategory (Items included)		
Marital (6,10,11,13)	2.47 (0.70)	2.49 (0.63)
Employment (12,14)	2.09 (0.72)	2.09 (0.68)
Education (1,8,9)	2.37 (0.73)	2.43 (0.78)
Social life (3,4,5,7)	1.81 (0.62)	1.95 (0.63)*

* p-value is <0.01; as compared to the Chinese population.

The responses were recoded into agree and disagree by merging the answers 1 and 2 in the Likert's scale into "disagree" and answers 4 and 5 into "agree" as shown in Table 10-7. There was less Chinese respondents with negative attitudes toward items 1, 3, 4, 9 and 10, as compared with the Malay. There were a total of 28.7% among Chinese

respondents and 26.1% among Malay respondents who thought “people with epilepsy should study in a special school” (item 8). For item 10, 11 and 13 related to marriage, there were less than 20% of the respondents, either Malay or Chinese, with answers indicative of negative attitudes toward marriage with people with epilepsy.

Table 10-7. Percentage of subjects agree and disagree with the items, comparison between the Chinese and Malay populations (N=348 and 253 respectively).

Item	Agree/Disagree (%) [1]	
	Chinese	Malay
1. People with epilepsy should not study in college or university.	7.5/84.5*	9.1/76.7
2. People with epilepsy have the same rights as all people.	87.4/7.5	88.9/5.5
3. People with epilepsy should be isolated from others.	2.9/90.2*	4.3/83.4
4. People with epilepsy should not participate in social activities.	8.0/84.5***	13.4/70.8
5. I will not mind being seen in the company with someone known to have epilepsy.	83.6/10.1	84.2/7.5
6. People with epilepsy should not marry.	7.8/69.0***	2.8/83.4
7. I would stay away from a friend if I know she/he has epilepsy.	4.3/91.1	5.5/88.5
8. People with epilepsy should study in a special school.	28.7/47.1	26.1/54.2
9. Schools should not place children with epilepsy into regular classrooms.	16.4/62.9*	24.5/53.0
10. I would date someone even though he/she has epilepsy.	59.2/10.1***	43.1/17.8
11. I would marry someone with epilepsy, even though he/she has epilepsy.	35.1/18.7	32.8/17.0
12. I feel uncomfortable working with someone who has epilepsy.	6.6/79.3	9.1/73.1
13. I will advise my family members against marrying someone with epilepsy.	13.2/55.7	15.4/47.8
14. If I am an employer, I would give employment opportunity to someone with epilepsy.	70.4/8.9**	81.8/5.9

[1] The percentage is the total of those who answered either 1 and 2 as disagree, or 4 and 5 as agree. * *p*-value is <0.05; ** *p*-value is <0.01; and *p*-value is <0.001 as compared to the Malay population.

Discussion

This study showed that the rural Chinese population had a more positive attitudes toward epilepsy, related to items in the personal domain which required a long-term personal commitment, especially on marital and employment aspects. When compared with the Malay population, Chinese had a better attitudes toward social contact with people with epilepsy.

The urban-rural difference in the attitudes toward epilepsy in this study is in contrary to the previous study with a more positive attitudes in the urban population among the Malaysian Chinese[18] and the Turkish populations.[17] However, this is comparable to studies reporting better attitudes toward epilepsy in the urban[15,16].

Table 10-2 demonstrated that the urban-rural difference was only significant in the domain required long-term personal commitment (personal domain) but not in the general domain. There is a bigger discrepancy between the mean scores in the personal and general domains in the urban population (figure 10-1), suggesting that their attitudes toward epilepsy were less consistent across all domains, when compared with the rural Chinese. This discrepancy is consistent with the previous studies using the PATE scale. This is an important finding indicating that understanding the public attitudes toward epilepsy from general point of view is inadequate in the social stigma studies in epilepsy, especially in the urban Chinese population.

Chinese population in Malaysia has great variation in the cultural and religious practices, as contrast with the Malay which believe in the same religion, which is Islam. Therefore, as compared with the absence of urban-rural difference in attitudes toward epilepsy in Malay, the difference in the mean scores in the personal domain in this study is likely

secondary to the socio-economic differences which demarcated the urban-rural boundary.

This study showed that rural Chinese population had a more positive attitude toward marriage and employment in people with epilepsy than the urban group, compatible with the finding in a study on Malay population (Ref) as well as a Taiwan study which stated that those with higher education were more prejudiced against marrying an epileptic person.[15] The industry in urban city is highly skill-based and more competitive, as compared with small or labor-based industry in the rural area. (Ref) This might explain how the rural population perceive the capability of the people with epilepsy in coping with a less skill-based employment.

There were more than 25% of the respondents think that people with epilepsy should study in special school. Only slightly more than 50% think that people with epilepsy should be placed into regular classrooms. This indicated a strongly negative attitudes among Malaysian Chinese and Malay populations toward education in people with epilepsy. This is likely to have a significant impact on children with epilepsy. Future study should focus on understanding of the underlying reasons leading to this negative attitudes toward education in epilepsy, as well as the magnitude of impact of this public attitudes on children with epilepsy.

Future Implication

Findings in this study were similar to previous study in Chinese population of Malaysia[18], revealing the urban-rural differences in attitudes toward certain social

aspects of life in people with epilepsy. This will serve as a guide for the development of social intervention among the Chinese population in various parts of Malaysia.

Conclusion

The rural Chinese had a more positive attitudes toward epilepsy as compared with the urban group, based on the mean scores in the personal domain in PATE scale. There was no significant differences between the Chinese and Malay population.

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Chapter 11: Attitudes toward epilepsy among the Indonesian, a preliminary study in Manado

Abstract

Introduction: Till date, there were only two studies on attitudes toward epilepsy performed in Indonesia. This study aimed to understand the public attitudes toward epilepsy in Manado, which is the capital city of the North Sulawesi province of Indonesia, using a quantitative PATE scale. **Methodology**: A total of 100 general public with a mean age of 31.7±12.3 years (range 17-60) were recruited through convenient sampling from Manado, Indonesia. **Results**: Those with tertiary education level had lower mean score in the general domain (p<0.01) but not in the personal domain. The mean score in both personal and general domains of the Indonesian population were significantly higher than those in the Malaysian population. Indonesian population had a lower mean scores in the all subcategories than the Malaysian. **Conclusion**: This study showed a significant poorer attitudes toward epilepsy among the Indonesian in Manado, as compared to the Malay in Malaysia as well as the Malaysian Chinese.

(153 words)

Introduction

Indonesia is a republic country in Southeast Asia, with both Dutch and Islamic influence but at the same time has its own unique cultural characteristics. Indonesia consists of hundreds of distinct native ethnic and linguistic groups, but yet have a shared identity, defined by their national language. Its ethnic diversity and religious pluralism

provide a rich resource to understand the variation in social stigma among the Indonesians.

Till date, there were only two studies on attitudes toward epilepsy performed in Indonesia, one among the publics[1] and one among the school teachers in Medan in 2001.[2] These studies demonstrated a significantly negative attitudes towards epilepsy in Indonesia as evidenced by more than half of the respondents objected their children marrying a person with epilepsy, and thought that epilepsy was a mental illness[1], and 17% of the publics believed that saliva of the patients was able to spread the infections[2].

The Public Attitudes Toward Epilepsy (PATE) scale was developed to measure the public attitudes toward epilepsy quantitatively and factored into two domains, i.e. a general domain that required minimal or no consideration of respondents' involvement, and a personal domain that required a long-term personal commitment or involvement.[3] This scale was performed among the general population in Malaysia, a neighbouring country with similar cultural background especially among the Muslims.

This study aimed to understand the public attitudes toward epilepsy in Manado, which is the capital city of the North Sulawesi province of Indonesia, using a quantitative PATE scale, with direct comparison with the attitudes among Malaysian populations reported in the previous studies using the same scale.[4,5]

Methodology

Study population

A total of 100 respondents were recruited through convenient sampling from Manado, Indonesia. Verbal consents were obtained in agreement to carry out survey and all questionnaires were administered anonymously. The selection criteria given that subjects must not be an epileptic person and that they should be permanent residents of the district studied. Ethical approval from the ethics committee at University Malaya Medical Center (MREC no.: 878.10).

Measures

The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy (Lim, 2012)[3]. A 1-5 Likert scale was used for scoring with 1 being strongly disagree and 5 being strongly agree. Some items were reverse scored so that a higher score would indicate a more negative attitude. This scale was performed in a general population and factored into two domains, i.e. a general domain (nine items) that required minimal or no consideration of respondents' involvement, and a personal domain (five items) that required a long-term personal commitment or involvement. This is a validated scale with good internal consistency (Cronbach's alpha of 0.868 and 0.633, in the general and personal domains respectively).

This study was performed using the modified Malay PATE scales according to the Indonesian Malay language. The Malay version of PATE scale is a reliable and validated scale with good internal consistency for both general and personal domains (Cronbach's coefficient 0.868 and 0.633, respectively).[6]

Demographic data were collected on the subject's race, age, gender, marital status, education status, employment status, occupation, and income level for descriptive and continuous analysis.

Statistical analysis

Statistical Package for Social Sciences version 19 (SPSS 19.0) was adopted for data analyses. Descriptive analyses were depicted using mean, standard deviation and simple percentages as appropriate. The differences in demographic variables between two groups were assessed using Chi-square tests and one-way ANOVA. Comparisons of mean scores in the personal and general domains between the Indonesian and the Malaysian Malay and Chinese were performed using one-way ANOVA. In addition, the items were further subcategorized into various socio-economic subgroups according to previous publication, i.e. categorize question of "I will advise my family members against marrying someone with epilepsy." into marriage related item[7].

Results

1. Demographic characteristic of samples

A total of 100 respondents, with a mean age of 31.7±12.3 years (range 17-60) were recruited. (Table 11-1) The Indonesian cohort was significantly younger, female predominant, higher single marital status and less full-time employed, than the Malaysian cohort (*p*-value <0.01)

Table 11-1: Demographic characteristics of the total Indonesian cohort (N=100), and the Malaysian Malay and Chinese cohort (N=253 and 348, respectively).

Demographic Variables	Indonesia	Malay	Chinese
Gender: Female, n (%)	58 (58.0)**	145 (57.3)	160 (46.0)
Age, mean ±SD	31.7 ± 12.3***	38.9 ± 13.6	38.7 ±15.2
Ethnicity			
- Jawa	9 (9.0)		
- Sumatera	1 (1.0)		
- Sulawesi	84 (84.0)		
- Native	3 (3.0)		
- Others	3 (3.0)		
Marital Status, n (%):			
- Single	48 (48.0)***	65 (25.7)	149 (42.8)
- Married	50 (50.0)		
- Widowed	2 (2.0)		
Education Level, n (%):			
- Primary level	6 (6.0)		
- Secondary level	43 (43.0)		
- Tertiary level	51 (51.0)	130 (51.4)	157 (45.1)
Employment Status n (%):			
- Student	25 (25.0)		
- Housewife	12 (12.0)		
- Employed part-time	15 (15.0)		
- Employed full-time	14 (14.0)***	122 (48.2)	165 (47.4)
- Unemployed	11 (11.0)		
- Retired	3 (3.0)		
- Others	20 (20.0)		
Income, n (%)			
- None	45 (45.0)		
- < IDR 1.5 million (USD 150)	17 (17.0)		
- IDR 1.5-10 million (USD 150-1000)	38 (38.0)		

***p*-value is <0.01, ****p*-value is <0.001, as compared to the Malaysian participants.

2. Attitudes toward epilepsy according to demographic characteristics

Those with tertiary education level had lower mean score in the general domain ($p<0.01$) but not in the personal domain. Age, gender and marital status had no significant impact on the mean scores in both general and personal domains. (Table 11-2)

Table 11-2: Mean scores and standard deviations by domains and demographic characteristics (n=100)

Variable	Group (n)	General domain	Personal domain	Total
Age[1]		0.136	-0.062	0.055
		Mean score (SD)		
Gender	Male (42)	2.46 (0.58)	3.00 (0.49)	2.72 (0.46)
	Female (58)	2.48 (0.73)	2.89 (0.57)	2.68 (0.56)
Education level	Tertiary (51)	2.27 (0.52)	2.84 (0.51)	2.56 (0.42)
	Others (49)	2.68 (0.74)*	3.01 (0.56)	2.84 (0.57)*
Marital status	Single (48)	2.35 (0.62)	2.90 (0.53)	2.62 (0.49)
	Others (52)	2.59 (0.69)	2.95 (0.55)	2.77 (0.54)

[1]Based on Pearson correlation; *p-value is < 0.01, when compared between groups.

3. Comparison of attitudes toward epilepsy between the Indonesian and Malaysian cohorts, using PATE scale

The mean score in both personal and general domains of the Indonesian population were significantly higher than those in the Malaysian population, as shown in Table 11-3. Indonesian population had a lower mean scores in the all subcategories than the Malaysian (p<0.01), indicating that Indonesian had a poorer attitudes toward all social aspects of life in epilepsy. On item analysis (Table 11-4), Indonesian had poorer attitudes in most items except items 2 and 8.

Table 11-3. Means and standard deviation (SD) of each domain and subcategory in the Indonesian (n=100), Malaysian Chinese (n=348) and Malay (n=253) populations.

	Indonesia	Malaysian Chinese	Malaysian Malay
	Mean (SD)		
Domain (Number of items)			
General Domain (9)	2.47 (0.67)*	2.04 (0.53)	2.08 (0.55)
Personal Domain (5)	2.92 (0.54)*	2.37 (0.64)	2.46 (0.60)
Total (14)	2.70 (0.52)*	2.16 (0.51)	2.22 (0.49)
Subcategory (Items included)			
Marital (6,10,11,13)	2.94 (0.61)*	2.47 (0.70)	2.49 (0.63)
Employment (12,14)	2.59 (0.70)*	2.09 (0.72)	2.09 (0.68)
Education (1,8,9)	2.75 (0.78)*	2.37 (0.73)	2.43 (0.78)
Social life (3,4,5,7)	2.38 (0.77)*	1.81 (0.62)	1.95 (0.63)*

* *p*-value is <0.001; as compared to the Malaysian population.

Table 11-4. Percentage of subjects agree and disagree with the items, comparison between the Indonesian and the Malaysian Chinese and Malay populations (N=100, 348 and 253 respectively).

Item	Agree/Disagree (%) [1]		
	Indonesian	Malaysian Chinese	Malaysian Malay
1. People with epilepsy should not study in college or university.	31.0/63.0**	7.5/84.5	9.1/76.7
2. People with epilepsy have the same rights as all people.	81.0/11.0	87.4/7.5	88.9/5.5
3. People with epilepsy should be isolated from others.	15.0/71.0**	2.9/90.2	4.3/83.4
4. People with epilepsy should not participate in social activities.	23.0/60.0**	8.0/84.5	13.4/70.8
5. I will not mind being seen in the company with someone known to have epilepsy.	70.0/19.0**	83.6/10.1	84.2/7.5
6. People with epilepsy should not marry.	14.0/74.0**	7.8/69.0	2.8/83.4
7. I would stay away from a friend if I know she/he has epilepsy.	17.0/75.0**	4.3/91.1	5.5/88.5
8. People with epilepsy should study in a special school.	30.0/44.0	28.7/47.1	26.1/54.2
9. Schools should not place children with epilepsy into regular classrooms.	24.0/51.0*	16.4/62.9	24.5/53.0
10. I would date someone even though he/she has epilepsy.	16.0/36.0**	59.2/10.1	43.1/17.8
11. I would marry someone with epilepsy, even though he/she has epilepsy.	12.0/39.0**	35.1/18.7	32.8/17.0
12. I feel uncomfortable working with someone who has epilepsy.	16.0/58.0**	6.6/79.3	9.1/73.1
13. I will advise my family members against marrying someone with epilepsy.	26.0/34.0**	13.2/55.7	15.4/47.8
14. If I am an employer, I would give employment opportunity to someone with epilepsy.	59.0/23.0**	70.4/8.9	81.8/5.9

[1] The percentage is the total of those who answered either 1 and 2 as disagree, or 4 and 5 as agree. * *p*-value is <0.05; and ** *p*-value is <0.001 as compared to the Malaysian population.

Discussion

This study showed that there was a significant poorer attitudes among the Indonesian in Manado toward epilepsy, either in the personal or general domains in the PATE scale, as well as in all social aspects of life such as employment, education, marriage and

social contact. This is the first direct comparison of the attitudes toward epilepsy between Indonesian and other country.

An indirect comparison of the attitudes toward epilepsy between the Indonesian[2] and other Asian countries was performed in a systematic review[8] which showed that there was more Indonesian who think epilepsy is a mental illness. As compared to the similar studies in Malaysia[9,10], this review also showed that Indonesian had poorer attitudes toward marriage, employment and social contact.

Those with higher education level was found to have better attitudes toward epilepsy in the general attitudes (general domain in the PATE scale) but not in the personal attitudes. This finding is persistently demonstrated in studies using PATE scale.[3,4,6]

Limitations

This is a preliminary study performed in the Manado, Indonesia, and will not be representative of the Indonesian population in general, which is ethnically and religiously very diverse.

Conclusion

This study showed a significant poorer attitudes toward epilepsy among the Indonesian in Manado, as compared to the Malay in Malaysia as well as the Malaysian Chinese.

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Chapter 12: Cultural and ethnic differences in attitudes toward epilepsy

Abstract

Introduction: No studies had ever compared the percentage of negative responses using different type of questions and toward various aspects of social life. **Method**: Data from the previous studies using PATE scale among 100 Indonesian, 253 Malaysian Malay and 348 Malaysian Chinese respondents were extracted for analysis. **Results**: The percentages with negative response to a general item, i.e. “people with epilepsy should not marry” were significantly lower than those to items required personal commitment such as “I would marry someone with epilepsy, even though he/she has epilepsy”. The percentage with negative response toward dating and marriage did not differ much in Malaysian Malay (17.8% vs. 17.0%) and in Indonesian (36.0% vs. 39.0%); whereas among the Malaysian Chinese, there were less respondents with negative response toward dating as compared with those toward marriage (10.1% vs. 18.7%). The Malaysian Chinese had a higher percentage of respondents with negative response toward employing someone with epilepsy than toward working with someone with epilepsy (20.7% vs. 14.1%), and the percentages were reverse in the other two groups. The mean scores for the social contact category was lower than the employment category, followed by the education and marriage categories, in the Indonesian and Malaysian populations. **Conclusion**: Attitudes toward epilepsy differ with the type of questions, as well as the social category. There was also cultural variation in the pattern of attitudes toward marriage and employment in epilepsy.

(231 words)

Introduction

A systematic review by the first author revealed a marked variation in the questions used to measure the attitudes toward epilepsy.[1] Some questions have been phrased in the form of a general statement; whereas some questions required personal consideration, for example a marriage involving the participants or their children. A general statement tended to produce more positive results. Questions which required personal consideration, were more reflective of the actual stigmatization, and this tended to skew the results negatively. Comparison between two studies using different type of questions on the same social issue such as employment, may give us a false impression of the actual difference between the two studied populations.

The initial survey on attitudes toward epilepsy performed by Caveness in 1949 focused on three social issues i.e. employment, social contact and marriage.[2] These three aspects of social life had been the main themes of most studies on attitudes toward epilepsy. People may tend to answer more positively to certain social issues such as having a social contact with a person with epilepsy. Reversely, more may answer negatively toward marrying or working with someone with epilepsy. However, none of the studies had ever compared the percentage of negative responses toward various aspects of social life.

This study aimed to determine (1) whether the attitudes toward an aspect of social life, i.e. marriage or employment, changed with the way how the questions are asked, and (2) whether there were differences in the magnitude of negative attitudes toward various aspects of social life, including social contact, education, employment and marriage.

Methodology

Data of the previous studies[3-5] using PATE scale among 100 Indonesian, 253 Malaysian Malay and 348 Malaysian Chinese respondents were extracted for analysis.

The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy (Lim, 2012)[6]. A 1-5 Likert scale was used for scoring with 1 being strongly disagree and 5 being strongly agree. Some items were reverse scored so that a higher score would indicate a more negative attitude.

The results of selective items related to marriage (items 6, 10, 11 and 13) and employment (items 12 and 14) were used for comparison between groups. Recoding of the item answers to agree (4 and 5 in the Likert's scale) or disagree (1 and 2 in the Likert's scale) was performed, similarly to previous study.[3] In addition, the categorization of the items into various socio-economic subgroups was performed according to previous publication[1], for example, question of "I will advise my family members against marrying someone with epilepsy" was categorized into marriage category.

Results

1. Attitudes toward marriage

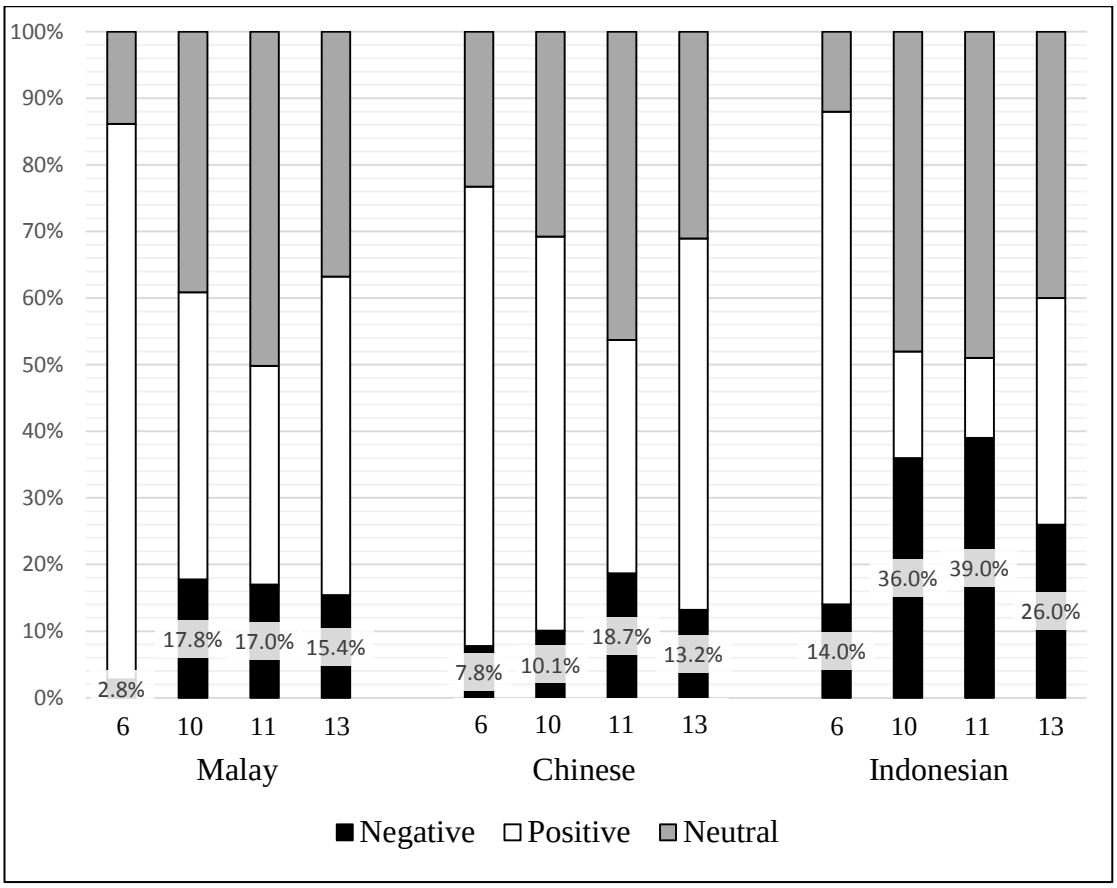
The percentages with negative response to item 6 in the PATE scale, i.e. agree with "people with epilepsy should not marry" were significantly lower than to items 10, 11 and 13, in both Malaysian and Indonesian cohorts, as shown in Figure 1. (Note: Item 10

is “I would date someone even though he/she has epilepsy”, 11 “I would marry someone with epilepsy, even though he/she has epilepsy” and 13 “I will advise my family members against marrying someone with epilepsy”.)

Among the Malaysian Malay and Indonesian populations, the percentage with negative response to item 10 and 11, i.e. attitudes toward dating and marriage, did not differ much (17.8% vs. 17.0% in Malaysian Malay and 36.0% vs. 39.0% in Indonesian); whereas among the Malaysian Chinese, there were less respondents with negative response toward dating (10.1%) as compared with those toward marriage (18.7%).

Among the Indonesian and Malaysian Chinese, the percentages of those against their family members marrying someone with epilepsy were lower than the percentages of those would not marry with someone with epilepsy themselves (26.0% vs. 39.0% in Indonesian, and 13.2% vs. 18.7% in Chinese cohorts). However, the difference in percentages of these two items was not much in Malaysian Malay (15.4% vs. 17.0%).

Figure 12-1: The percentages of responses to items related to marriage in Malaysian Malay (n=253) and Chinese (n=348), and in Indonesian (n=100) cohorts.

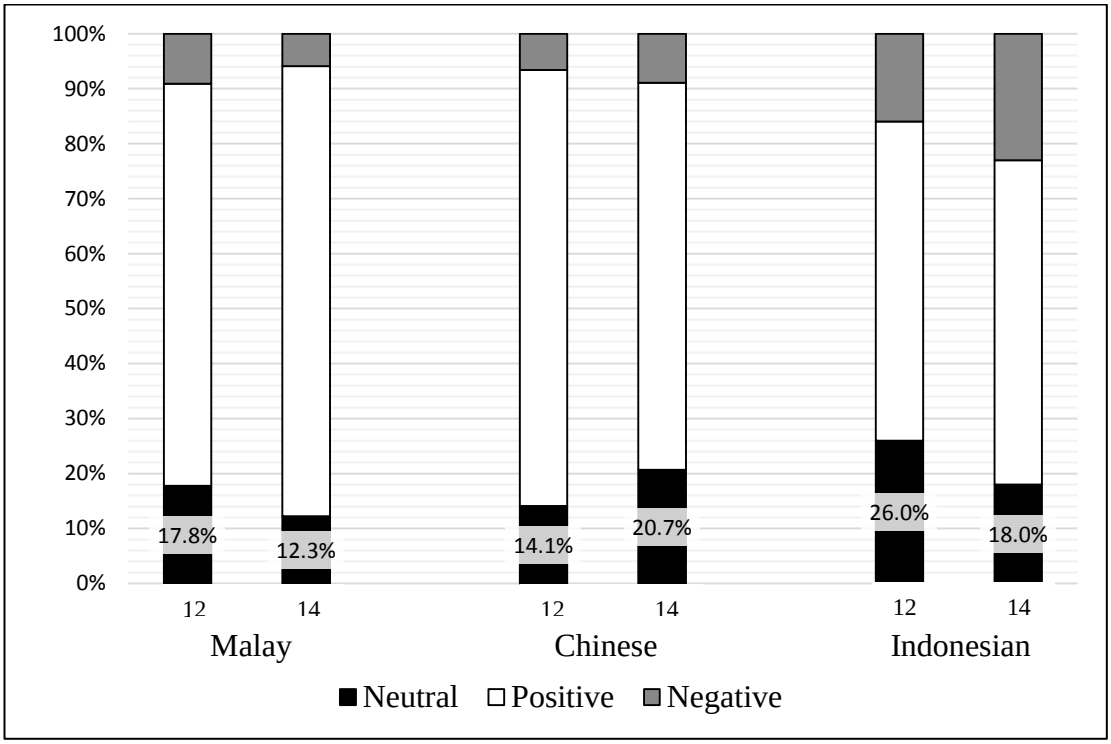


Items 6: “People with epilepsy should not marry”; **10**: “I would date someone even though he/she has epilepsy”; **11**: “I would marry someone with epilepsy, even though he/she has epilepsy”; and **13**: “I will advise my family members against marrying someone with epilepsy”.

2. Attitudes toward employment

The Malaysian Chinese had a higher percentage of respondents with negative response toward employing someone with epilepsy than toward working with someone with epilepsy (20.7% vs. 14.1% respectively). In contrast, the Malaysian Malay and Indonesian participants had a higher percentage of respondents with negative response toward working with someone with epilepsy. (Figure 2)

Figure 12-2: The percentages of responses to items related to employment in Malaysian Malay (n=253) and Chinese (n=348), and in Indonesian (n=100) cohorts.

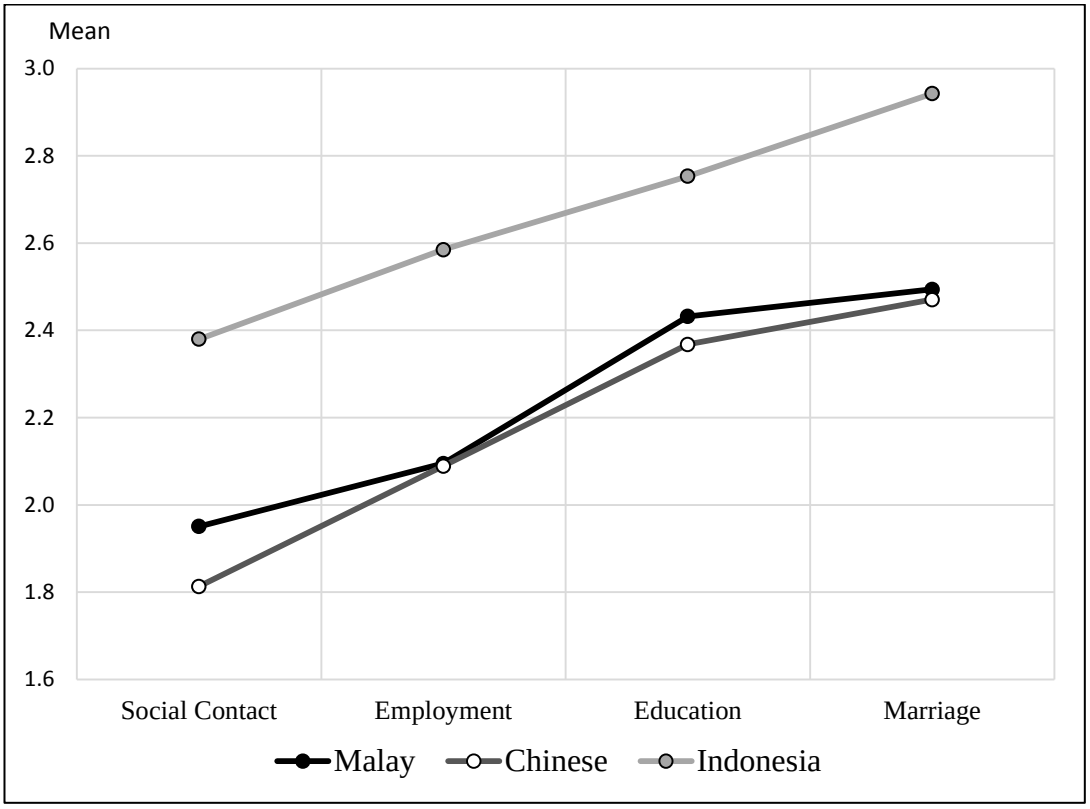


Items 12: "I feel uncomfortable working with someone who has epilepsy", and **14**: "If I am an employer, I would give equal employment opportunities to someone with epilepsy".

3. Attitudes toward various social categories

Figure 3 showed that the mean scores for the social contact category was lower than the employment category, followed by the education and marriage categories, in the Indonesian and Malaysian populations.

Figure 12-3: Mean scores of each category in the Indonesian (n=100), Malaysian Malay (n=253) and Chinese (n=348) populations



Discussion

This study has proven that the attitudes toward marriage and employment changed with the type of question. A general statement regarding marriage in people with epilepsy had produced a less negative response, as compared to items required long term personal commitment or involvement.

Response to different items were also shown to be affected by cultural factors. For example, dating and marriage with people with epilepsy appeared to result in similar response among the Indonesian and Malaysian Malay, but not among the Chinese. This is suggestive of a difference in the degree of personal commitment between dating and marriage among the Chinese respondents, i.e. Chinese is less reluctant to date a person

with epilepsy but not marrying them. Whereas among the Malaysian Malay and the Indonesian in Manado, the results suggested that dating and marrying a person with epilepsy might require the same degree of commitment, which is probably influenced by the Muslim beliefs.

More Chinese respondents were against employing someone with epilepsy than working together with them. This can be understood as employer will experience a higher direct loss if employed someone with epilepsy, as compared with a worker having a colleague with epilepsy. However, unexpectedly, more Malaysian Malay and the Indonesian were against working with someone with epilepsy, rather than employing them.

Figure 3 demonstrated that the negativity of the attitudes toward epilepsy increased gradually from social contact to marriage. This indicated that the resistance to have social contact among people with epilepsy is lower comparing to finding a job, completing a basic education and engaging in a marital relationship.

Future implications

This study implied that study on questions or scales used in study on attitudes toward epilepsy shall be standardized to enable useful and valid cross-sectional and longitudinal comparison.

The perceptions of each items and various social aspects of life were also affected by the ethnicity or cultural factors. Thus, cultural comparison of the attitudes toward epilepsy is essential to guide understanding of the variation in social stigma in different

culture, ethnicity, or geographical region. This will form the basis of a more effective strategy against social stigma in different cultures or regions.

Conclusion

Attitudes toward epilepsy differ with the type of questions, as well as the social category. There was also cultural variation in the pattern of attitudes toward marriage and employment in epilepsy.

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Chapter 13: Knowledge and public attitudes toward epilepsy, using EKQ and PATE scale

(Submitted to *Neurology Asia* on 7 December 2013)

Abstract

Introduction: None of the identified studies employed a quantitative scale in understanding the correlation between the knowledge and attitudes toward epilepsy. **Method**: This study aimed to study the relationship between the knowledge and attitudes toward epilepsy, using the Epilepsy Knowledge Questionnaire (EKQ) and the Public Attitudes Toward Epilepsy (PATE) scale, via a convenient sampling during a health fair in Kuala Lumpur, Malaysia, as part of a research project by the Malaysian Society of Epilepsy. **Results**: A total 279 publics with a mean aged of 36.55±14.65 years (ranged from 15-77 years), 50.8% female with majority (63.0%) Chinese, 49.5% with tertiary education level, were recruited. The mean score of epilepsy knowledge questionnaire (EKQ) was 21.05±3.92 (95% confidence interval, CI: 20.57-21.48). Most (78.8%) of the respondents scored <25 and only 1.3% respondents scored ≥30. Almost 60% of the items were incorrectly answered by more than 25% of the respondents. Higher score in EKQ was associated with higher education level, and Chinese and Indian ethnicity (p<0.01). The total score in the EKQ was correlated negatively with the mean scores in the PATE scale (p<0.001), as well as the mean scores in both the personal domain and general domains in the PATE scale (p<0.001). Eight items (1, 4, 5, 6, 8, 11, 15 and 32) were associated significantly with the mean scores in the personal domain, and 4 items (3, 14, 25 and 26) were with the general domain of the PATE scale. **Conclusion**: This study showed that the knowledge toward epilepsy is significantly

associated with better attitudes toward epilepsy. On item analysis, only certain aspects of knowledge in epilepsy affected the attitudes toward epilepsy significantly.

(271 words)

Keywords: knowledge, attitudes, epilepsy, scale

Introduction

Knowledge about epilepsy is an important factor associated with the attitudes toward epilepsy. Studies show that people with less knowledge about epilepsy, or without personal contact with someone with epilepsy, have poorer attitudes.[1-9] The magnitude of the negative attitudes seems to be aggravated by the presence of misconception of epilepsy, which include the perception of epilepsy as a form of insanity[1,3,4], being untreatable[2,10], contagious[11], hereditary[10], or a form of mental retardation.[4]

Intervention studies using educational programs or material about epilepsy showed that there was significant improvement in the attitudes towards epilepsy together with the improvement in knowledge.[2,12-16] However, none of the studies employed a quantitative scale of the knowledge and attitudes toward epilepsy.

The Epilepsy Knowledge Questionnaire (EKQ) is a 55-item questionnaire[17] assessing the knowledge of epilepsy, of which 34 items were on the medical aspects of epilepsy. These included the causes, manifestations, diagnosis, treatment and prognosis of epilepsy. Higher score in the knowledge on the medical aspects of epilepsy in EKQ was

significantly associated with better psychological adjustment to epilepsy but also more perceived stigma among people with epilepsy.[18]

The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy.[19] It was developed to be applied cross-culturally and is factored into two domains, i.e. a general domain (nine items) which requires minimal or no consideration of respondents' involvement, and a personal domain (five items) which requires a long-term personal commitment or involvement such as marrying a person with epilepsy, working with them or employing them.

This study aimed to study the relationship between the knowledge and attitudes toward epilepsy, using EKQ and PATE scale.

Methodology

1. Sample Recruitment

A total 279 general populations were included in the survey via a convenient sampling during a health fair in Kuala Lumpur, Malaysia, as part of a research project by the Malaysian Society of Epilepsy. Consent is regarded as automatically given by the public when they agreed to answer the questionnaire. All questionnaires were administered anonymously. The survey was only performed in English. Ethical approval was obtained from the ethics committee at University Malaya Medical Center (MREC no.: 878.10).

2. Measures

The Epilepsy Knowledge Questionnaire (EKQ) is a 55-item questionnaire[17], with 34 items on knowledge about medical aspects of epilepsy and 21 on knowledge of social aspects of epilepsy. Informants are asked to answer "true" or "false" to each statement. In this study, only the 34 items relating to medical aspects of epilepsy were used, so that possible scores ranged from 0 to 34. Higher score indicating better knowledge in epilepsy. The respondents were also categorized into low scorers as defined as those scoring <25, medium scorers as those scoring ≥25 but <30, and high scorers, as those scoring ≥30, for comparison with other countries. The 21 "social" aspects items were not included because of the limitation in cross-cultural application. This questionnaire has been standardised on a U.K. population,[17,20] but not in the Asian population.

The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy.[19] A 5-point Likert scale was used for scoring with 1 being strongly disagree and 5 being strongly agree. Positively stated items were reversely scored so that a higher score would indicate a more negative attitude. This scale was performed in a general population and factored into two domains, i.e. a general domain (nine items) that required minimal or no consideration of respondents' involvement, and a personal domain (five items) that required a long-term personal commitment or involvement such as marrying a person with epilepsy, working with them or employing them. This is a validated scale with good internal consistency (Cronbach's alpha of 0.868 and 0.633, in the general and personal domains respectively).

3. Statistical analysis

Statistical Package for Social Sciences version 19 (SPSS 19.0) was employed for data analyses. Descriptive analyses were depicted using mean, standard deviation with 95% confidence interval and simple percentages as appropriate. The score of EKQ in our study was compared with those reported previously.[18] Student T-test and one-way analysis of variance (ANOVA) was conducted for mean scores comparison. Non-parametric correlation analyses were performed between the scores in the EKQ and the mean scores of the PATE and its domains to determine how the variables correlated with others. Spearman's rho > 0.5 was considered to have a strong correlation, 0.3-0.5 as moderate, and <0.3 as weak.

Results

A total of 297 participants with a mean aged of 36.55±14.65 years (ranged from 15-77 years) were recruited, 50.8% female with majority (63.0%) Chinese, 49.5% with tertiary education level and 56.9% with full time employed and 45.1% married and 6.7% of the participants had family member who is diagnosed with epilepsy. (Table 1)

Table 13-1: Demographic profile of the respondents. (n=297)

Demographic Variable	
Age, Mean ± SD	36.55±14.65
	N (%)
Gender	
Female	151 (50.8)
Male	146 (49.2)
Race	
Chinese	187 (63.0)
Malay	48 (16.2)
Indian	50 (16.8)
Others	12 (4.0)
Marital Status	
Married	134 (45.1)
Single	153 (51.5)
Divorced/widow	10 (3.3)
Highest Education	
Secondary or lower	50 (16.8)
Pre-university/Diploma	73 (24.6)
Degree	147 (49.5)
Postgraduate	27 (9.1)
Employment Status	
Full time student	40 (13.5)
Full time House Duties	7 (2.4)
Employed part time	12 (4.0)
Employed full time	169 (56.9)
Retired	20 (6.7)
Unemployed	32 (10.8)
Others	17 (5.7)
Monthly income (1 USD = 3.2 RM*)	
None	57 (19.2)
RM1000 or below	12 (4.0)
RM1000-RM2000	58 (19.5)
RM2000 and above	169 (56.9)
Family History (Do you have any family members with epilepsy?)	
Yes	20 (6.7)

*USD, United States dollar; RM, Ringgit Malaysia.

1. Knowledge of Epilepsy

a) Mean score of epilepsy knowledge questionnaire (EKQ)

The mean score of epilepsy knowledge questionnaire (EKQ) was 21.05±3.92 (95% confidence interval, CI: 20.57-21.48), the second lowest as compared to the scores in

other countries. Most (78.8%) of the respondents scored <25 and only 1.3% respondents scored ≥30.

Table 13-2: Mean score of EKQ (34 items) by country

Country	Mean score (95% CI)	High Scorer (scoring ≥30), %	Medium Scorer (≥25 and <30), %	Low Scorer (<25), %
Malaysia	21.05 (20.57-21.48)	1.3	19.9	78.8
Published Results[18]				
Turkey	20.81 (20.53–21.09)	0.9	11.6	87.5
Portugal	21.44 (21.15–21.74)	0.9	19.7	79.4
Poland	22.67 (22.41–22.94)	0.9	28.8	70.3
Belgium	24.12 (23.69–24.55)	1.7	41.7	56.6
Spain	23.60 (22.97–24.24)	2.9	39.1	58.0
France	25.75 (25.40–26.10)	7.7	56.6	35.7
Italy	25.69 (25.31–26.08)	7.4	57.0	35.6
Netherlands	26.65 (26.38–26.92)	11.3	60.1	28.6
Germany	27.49 (27.17–27.81)	17.5	64.1	18.4
U.K.	27.88 (27.66–28.10)	21.1	61.9	17.0

b) EKQ and the demographic variables

One way ANOVA showed that there were significant association between the EKQ score and the ethnic group and education level (p<0.01) and monthly income (p<0.05). Chinese and Indian had same EKQ mean score (21.22), significantly higher than Malay subgroup (19.77), indicated a better knowledge in epilepsy among the Chinese and Indian. The mean EKQ score increased gradually with the level of education. There was no significant association between the other demographic variables and the EKQ score.

Table 13-3: Comparison between demographic characteristics and mean scores of EKQ in 297 respondents.

Demographic	Knowledge score, mean and SD	*p*-value
Gender		NS
• Female (n=151)	21.06±3.96	
• Male (n=146)	21.04±3.89	
Age (Pearson Correlation)	21.05±3.92	NS
Ethnic group		<0.01
• Chinese (n=187)	21.22±3.61	
• Indian (n=50)	21.22±4.33	
• Malay (n=48)	19.77±3.90	
Marital status		NS
• Single (n=153)	21.19±4.07	
• Married (n=134)	20.94±3.77	
Education level		<0.01
• Secondary or lower (n=50)	20.08±4.06	
• A level/STPM/Diploma (n=73)	20.21±3.72	
	21.54±3.81	
• Degree (n=147)	22.44±4.09	
• Post graduate (n=27**)**		
Employment status		NS
• Full time employment (n=169**)**	20.92±3.63	
	21.22±4.28	
• Others (n=128)		
Monthly income (1 USD = 3.2 RM*)		<0.05
	21.44±3.78	
• RM2000 and above (n=169**)**	20.53±4.05	
• Below RM 2000 (n=128)		
Family History		NS
• Yes (n=20)	22.20±3.37	
• No (n=277)	20.97±3.95	

*USD, United States dollar; RM, Ringgit Malaysia.

c) Item analysis

A total of 9 items (26.4%), i.e. items 1, 9, 10, 13, 20, 27, 30, 31 and 33, were answered correctly by less than 50% respondents. (Table 4) Almost two-third (20/34, 58.8%) of the items were incorrectly answered by more than 25% of the respondents.

Table 13-4: Percentage of correct answer in the EKQ items, and association with the mean scores in the personal and general domains in the PATE scale.

Items (answer)	Answer correctly (%)	Personal Domain	General Domain
		p-value	
1. Epilepsy is always caused by brain damage (FALSE)	43.1	**	
2. Epilepsy is not infectious (TRUE)	81.5		
3. Epilepsy is a symptom of mental illness (FALSE)	64.0		*
4. All people with epilepsy have similar symptoms (FALSE)	55.2	*	
5. Almost anyone can have a seizure given the appropriate circumstances (TRUE)	67.3	*	
6. An EEG can be used to help diagnose epilepsy (TRUE)	77.4	*	
7. If an EEG is abnormal, this is a definite sign of epilepsy (FALSE)	54.9		
8. An EEG is designed to detect electrical activity from the brain (TRUE)	79.1	*	
9. All people with epilepsy lose consciousness during seizures (FALSE)	37.7		
10. An epileptic seizure can be described as a temporary lack of oxygen to the brain (FALSE)	30.6		
11. Some seizures may last for a matter of seconds and not be noticed by others (TRUE)	83.8	**	
12. All seizures affect both sides of the brain (FALSE)	56.2		
13. Certain forms of brain damage always cause epilepsy (FALSE)	33.7		
14. A normal EEG means that you do not have epilepsy (FALSE)	52.9		*
15. For most people, doctors can effectively treat epilepsy with drugs (TRUE)	65.7	*	
16. All those who start drugs for their epilepsy have to take them for life (FALSE)	50.8		
17. Increasing the dose of antiepileptic drugs increases the chances of side effects (TRUE)	75.1		
18. An epileptic seizure can be described as an abnormality in the function of nerve cells in the brain (TRUE)	87.9		
19. For antiepileptic drugs to be successful, they must be taken regularly (TRUE)	82.2		
20. If you forget to take antiepileptic drug for a day, it is usually OK to take two doses together (TRUE)	17.5		
21. Some people get a warning or feeling shortly before a seizure (TRUE)	77.4		
22. Blood samples can be used to measure the	82.4		

concentrations of antiepileptic drugs in the system (TRUE)			
23. People taking a combination of antiepileptic drugs are more likely to have side effects than are those taking only one (TRUE)	65.3		
24. Most people's seizures are well controlled soon after starting regular drug treatment (TRUE)	83.5		
25. It is always helpful to take extra doses of antiepileptic drugs when not feeling well (FALSE)	85.5		**
26. If seizures stop with antiepileptic drugs, this means your epilepsy has been cured (FALSE)	78.1		**
27. Few people with a diagnosis of epilepsy are taking antiepileptic drugs (FALSE)	24.2		
28. Some people have been taught to control their seizures by psychological methods (TRUE)	69.4		
29. There is no need to continue taking antiepileptic drugs if your seizures stop (FALSE)	62.6		
30. Brain surgery is still used as a method of preventing seizures (TRUE)	39.4		
31. Most mothers taking antiepileptic drugs are able to breastfeed (TRUE)	41.1		
32. Too much alcohol may make seizures more likely (TRUE)	75.7	*	
33. Most seizures result in brain damage (FALSE)	41.1		
34. Stress may cause some seizures (TRUE)	82.5		

*p<0.05, and **p<0.01. In all items with significant p-values, those who answered correctly had lower mean scores in either the personal or the general domains in the PATE scale (i.e. had better attitudes toward epilepsy).

2. Knowledge and attitudes

The total score in the EKQ was correlated negatively with the mean scores in the PATE scale (p<0.001), as well as the mean scores in both the personal domain and general domains in the PATE scale (p<0.001). This indicated that the higher the score in the EKQ, the better the attitudes toward epilepsy. (Table 5) On item analysis, different items associated with the mean scores in the personal and general domains differently,

as shown in Table 4. There were only eight items (1, 4, 5, 6, 8, 11, 15 and 32) associated significantly with the mean scores in the personal domain, and 4 items (3, 14, 25 and 26) were with the general domain.

Table 13-5: Correlations between the total score in the EKQ and the mean score in the PATE scale (n=297).

	EKQ (34 items)
PATE (14 items)	-0.299*
Personal Domain (5 items)	-0.248*
General Domain (9 items)	-0.265*

* *p*-value is <0.001

Discussion

This study correlating the knowledge and attitudes toward epilepsy using a quantitative scale, i.e. the Epilepsy Knowledge Questionnaire (EKQ) and the Public Attitudes Toward Epilepsy (PATE) scale, showed that the overall knowledge toward epilepsy is significantly associated with a better attitudes toward epilepsy. This is consistent with the previous studies.[1-9] However, not all items in the knowledge questionnaire were correlated with the attitudes.

On item analysis, only 8 out of 34 items (23.5%) associated significantly with the mean scores in personal domain and 4 (11.8%) with those in general domain. These include items on causes of epilepsy such as brain damage (item 1) and mental illness (item 3), consistent with the studies testing the perception of epilepsy as a form of insanity.[1,3,4] In contrary to the previous study[11], item 2, which assessed whether epilepsy is contagious, was not associated with attitudes toward epilepsy. This is likely because in our cohort, majority knew that epilepsy is not infectious.

Knowing that epilepsy can be treated effectively for most people (item 15) was associated with better attitudes toward epilepsy, compatible with previous results correlating epilepsy being untreatable with poorer attitudes.[2,10] In addition, the association between knowing seizures can present differently (item 4), and can be brief (item 11) with better attitudes toward epilepsy was not previously described.

Nonetheless, knowledge on most other medical aspects of epilepsy (22 out of 34 items in EKQ), such as diagnosis methods especially EEG, the medical and surgical treatment, and underlying pathophysiology and precipitating factors, was not proven to affect the attitudes in this study significantly.

There were more items correlated with the attitudes in the personal domain than in the general domain, and items correlated with attitudes in one domain were not correlated with the other. This implied that different aspects of knowledge in epilepsy affected the attitudes toward epilepsy differently. It is postulated that knowledge plays a more important role when a personal involvement such as marrying a person with epilepsy or employing someone with the condition. However, this postulation is not proven in this study using EKQ.

The recruitment was performed in a health fair in the capital city in Malaysia and only involved the English speaking publics. We assume that this group of people has relatively higher healthcare awareness and higher education level, of which more than 50% of them have graduate or postgraduate qualifications. Despite being in a higher educated group, the mean score of EKQ was lower than most of the reported results in

the European countries, indicating that there is a significant knowledge gap in epilepsy in Malaysia.

The level of knowledge, as measured by EKQ, improved gradually with the level of education, compatible with the previous reports in the Europe[18], as well as the Thai population[21]. Malaysian education system has tried to improve the standard of healthcare awareness by integrating this subject in their standard curriculum. However, this effort only covers basic hygiene, improving lifestyle and adopting healthy diet. There was no emphasis given on more detailed subjects such as epilepsy. This result indicated that the level of formal education has an impact on the knowledge on health. This is likely related to better recognition and improved learning behavior in the educated group. This is supported by a study conducted in Kuwait which showed that respondents with high educational levels often stated willingness for more information about epilepsy.[22] The level of knowledge also differed with ethnicity. In this study, the Chinese and Indian ethnic group had better knowledge in epilepsy, as compared with the Malay, suggesting that there might be a variation in the degree or scope of health awareness in different ethnic groups. This will thus guide the emphasis of health awareness campaign especially on special ethnic subgroup.

The questions in the EKQ were relatively difficult for the Malaysian participants. Majority of the respondents were low scorer with scoring <25. Almost two-third (20/34, 58.8%) of the items were incorrectly answered by more than 25% of the respondents. However, there are some variation in answering the questions between the Malaysian population and the European. A good example of this would be from item 28 “Some people have been taught to control their seizures by psychological methods”. There were more respondents who answered correctly, as compared with those in Europe (69%

vs. 44%), suggesting that it may be a common practice in Malaysia or even in Asia to use alternative method in stopping or controlling the seizures. For item 27, the answer can be true in countries with wider treatment gap, and for item 20, the answer can be false if the patient is taking an older generation of antiepileptic drug with narrow therapeutic index, such as phenytoin.

No specific area of knowledge can be identified in this study that the respondents were in particularly poor or better in. However, there were 9 items with more than 50% incorrectly answered by our respondents, especially only 37.7% of respondents were aware that seizures can occur despite retained awareness, and only 39.4% know that brain surgery is another treatment option.

1. Limitation

This study was performed using a convenient sampling in a health fair and only in English, and thus not representative of the general population in Malaysia. Nonetheless, this group of participants represented a group with higher health consciousness and a better education level. Adaptation of the EKQ to cultural factors or regional practice was not performed to allow direct comparison of the results of this and the previous studies. Though the validity of the EKQ to be applied in the Malaysian or Asian population was not previously tested, the significant correlation between the knowledge and the attitude will support the construct validity of this questionnaire.

2. Implications

Intervention studies showed that there was significant improvement in the attitudes towards epilepsy together with the improvement in knowledge.[2,12-16] However, different aspect of knowledge affected the attitudes differently. This study supports the need to have a more comprehensive review in understanding how various aspects of knowledge affect the attitudes toward epilepsy, thus develop an attitude-specific epilepsy knowledge scale. This will then determine which aspect of knowledge to be emphasized in the awareness campaign or reading material, and allow the measurement of improvement in knowledge that will affect attitudes toward epilepsy.

Conclusion

This study showed that the knowledge toward epilepsy is significantly associated with better attitudes toward epilepsy. On item analysis, only certain aspects of knowledge in epilepsy affected the attitudes toward epilepsy significantly.

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Chapter 14: Conclusion: conceptual changes and future implications

It is essential to study the public attitudes toward epilepsy as supported by a significant unemployment rate and lower income among the people with epilepsy. Systematic review revealed a need to develop a cross-culturally applicable quantitative scale in measuring the public attitudes toward epilepsy. The PATE was developed, validated and translated, and applied in various specific and general populations.

Key findings

The study on students showed that the scale is easily applied among a homogenous group and can be used in a web-based design. Attitudes of students were only better than the general population in the general domain but not in the personal domain, indicating that a significant discrepancy between the personal and general attitudes toward epilepsy. The study on teachers which showed a significant better attitudes among teachers as compared to the general population with tertiary education, suggesting that attitudes toward epilepsy may be job specific.

Population studies showed that there was no significant differences in attitudes toward epilepsy between the Chinese and Malay populations. Despite having cultural similarities, the Indonesian demonstrated a significantly poorer attitudes toward epilepsy as compared to the Malaysian. On subcategory analysis, Chinese had better attitudes toward social contact with people with epilepsy, indicating that Chinese patients with epilepsy might have less social restriction as compared with the Malay. In addition, the studies also demonstrated a unique urban-rural as well as cultural and ethnic differences in attitudes toward epilepsy.

Conceptual changes

The development and application of the 14-item PATE scale in various specific and general populations has led to changes in the concept of attitudes toward epilepsy.

1. Attitudes shall be understood from both personal and general perspectives

Attitudes toward epilepsy had been previously understood and studied as a general concept. The attitude was classified as positive or negative as a whole. The division of PATE scale into personal and general domains has led to the understanding of the attitudes toward epilepsy in two different perspectives, based on the degree of personal commitment. A person will show a more positive attitude toward a general statement when a personal commitment is less required. However, what affects the people with epilepsy directly especially on their marriage and employment might be the personal attitudes, as measured by the personal domain in the PATE scale. In a community with a relatively more positive attitude toward epilepsy, there may be still people with epilepsy who are unemployed as a result of some employers with negative personal attitude; and vice versa. The scoring system in the PATE scale allows us to determine the overall attitudes toward epilepsy, but at the same time, the mean score of the domains allows us to understand the attitudes from two different perspectives.

2. Attitudes vary in different social aspects of life

A person with a very negative attitude toward marriage and employment in people with epilepsy can have an open attitude being friend with people with epilepsy or accepting

them to be in the same class in school. The attitudes toward epilepsy are also vary from community to community. A community with positive attitudes toward social participation of people with epilepsy may have a negative attitudes on them studying in a normal class or employing them. The division of attitudes toward epilepsy according to social category allows us to understand the challenges of people with epilepsy according to the aspects of social life.

3. Better knowledge does not equivalent to better attitude

People with higher education level may have a more positive attitude in the general domain, but not in the personal domain. People in the urban may have higher education level but not have a better attitude toward marriage. The sub-study correlating knowledge and attitude indicates that only certain aspect of epilepsy knowledge has direct correlation with the attitudes toward epilepsy.

Future implications

The PATE scale allows us to measure the public attitudes toward epilepsy from different aspects, i.e. (1) the overall attitude toward epilepsy by measuring the total mean score, (2) the personal and general attitudes by measuring the mean scores in each domains, (3) the attitudes toward different aspects of life by measuring the mean scores of the social subcategories, and (4) the attitudes according to the degree of personal commitment by measuring the score in the individual items. This enables the PATE scale as an effective measure of specific attitudes toward epilepsy.

1. Factors affecting attitudes toward epilepsy

Cross-sectional comparison between different nations, ethnicities or geographical regions, as well as longitudinal study, will enable us to understand how socio-cultural or socio-economic factors affecting the attitudes toward epilepsy. In addition, it is also important to determine how various aspects of epilepsy knowledge and perceptions toward epilepsy affect the various types of attitudes. The design of the PATE scale enables it to be applied cross-culturally and also enables us to determine which types of attitudes that correlate with these factors. It is essential to identify factors that not only change the general attitudes, but also the personal attitudes. If a certain psychosocial aspect such as employment is studied, it is important to apply a specific and relevant measure such as the employment subscale in the PATE scale.

2. Designing an effective and specific intervention program

It has been difficult to design an effective intervention program aiming to improve the public attitudes and awareness because there is lack of an objective and specific attitudes scale previously. Certain awareness campaign may result in an improvement in the general attitudes but not the personal attitudes. For a population with more negative attitudes toward a certain aspect of social life such as marriage, the emphasis of the intervention should also be specific aiming to change the attitudes related to marriage. In addition, for a specific group such as teachers, emphasis will therefore be on the change of attitudes toward education. Application of the PATE scale is therefore essential to measure the effectiveness of these intervention programs in changing the specific attitude.

Conclusion

Shifting from the era of understanding attitude as only one aspect, this research has led us to understand attitude toward epilepsy from multiple aspects. Therefore, it is important not only to study the factors affecting attitude in general, but also factors related to a specific type of attitude such as attitude toward employment. This will then allow us to design a specific and effective intervention targeting on certain type of attitude.