Only certain aspects of knowledge have impact on attitudes toward epilepsy

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Abstract

Introduction: None of the identified studies employed quantitative scales correlating 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. *Results:* A total of 279 publics with a mean age of 36.6±14.7 years (ranged from 15-77 years), 50.8% female with majority (63.0%) Chinese, and 49.5% with tertiary education level, were recruited. The mean score of epilepsy knowledge questionnaire (EKQ) was 21.05±3.92 (95% CI: 20.57-21.48). Higher score in EKQ was associated with higher education level ($p<0.01$). The total score in the EKQ correlated negatively with the mean scores in the PATE scale, as well as the mean scores in both the personal domain and general domains in the PATE scale ($p<0.05$). Only 8 out of 34 items in EKQ were associated significantly with the mean scores in the personal domain, and 4 other items were with the general domain of the PATE scale.
Conclusion: This study showed that although the overall knowledge in epilepsy is significantly associated with better attitudes toward epilepsy, only certain aspects of knowledge in the scale contributed to this association.

INTRODUCTION

Knowledge in epilepsy is an important factor associated with the attitudes toward epilepsy. Studies showed that people with less knowledge about epilepsy, or without personal contact with someone with epilepsy, had poorer attitudes.[1-9] The magnitude of the negative attitudes was shown 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 quantitative scales 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. This questionnaire has been standardised on a U.K. population, and was proven to have good internal and test-retest reliability, and be valid to measure differences in knowledge.[17,18] Higher score in the knowledge on the medical aspects of epilepsy in EKQ was significantly associated with better psychological adjustment to epilepsy and lower perceived stigma among people with epilepsy.[19] The EKQ has been applied in a number of studies,[19,20] but not culturally validated in the Asian population.

Quantitative study design using a scale allows us to measure the degree of social stigma leading to the design of interventional strategies to break the stigma cycle of epilepsy. The scales included the Public Attitudes Toward Epilepsy (PATE)[21], the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale[22], the Attitudes Toward Persons with Epilepsy (ATPE)[23,24] the Epilepsy Attitude Scale[25], and the Elementary School Epilepsy Survey (ESES)[26] for elementary school children. The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy and was designed to be applied cross-culturally. This scale was proven to be a

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validated scale with good internal consistency (Cronbach's alpha of 0.868 and 0.633, in the general and personal domains respectively)[21] and was applied among students[27] and teachers[28], as well as general publics.

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

METHODS

Sample Recruitment

A total 297 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).

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.

The Public Attitudes Toward Epilepsy (PATE) scale is a 14-item scale measuring the public attitudes toward epilepsy.[21] 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 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.

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.[19] Student T-test and one-way analysis of variance (ANOVA) were 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, controlling for demographic variables with significant impact on the attitudes and knowledge toward epilepsy. 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, 56.9% with full time employed, 45.1% married and 6.7% of the participants had family member who is diagnosed with epilepsy. (Table 1)

Knowledge and attitudes

The total score in the EKQ was correlated significantly and negatively with the mean scores in the PATE scale (r= -0.182, $p<0.01$), as well as the mean scores in both the personal domain and general domains in the PATE scale (r= -0.144, $p<0.05$ and r= -0.171, $p<0.01$ respectively), controlling for education level, but the correlations were small (r=.10 to .29)[29]. On item analysis, different items associated with the mean scores in the personal and general domains differently, as shown in Table 2. There were only eight out of 34 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.

Knowledge of epilepsy

(a) Mean score of epilepsy knowledge questionnaire (EKQ)

The mean score of epilepsy knowledge

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

Demographic Variable	
Age, Mean ± SD	36.6±14.7,
	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.

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.[19] Most (78.8%) of the respondents scored <25 and only 1.3% respondents scored ≥30, as shown in Table 3.

(b) EKQ and the demographic variables

One way ANOVA showed that there were significant associations between the EKQ score and the ethnic group and education level ($p<0.01$), and monthly income ($p<0.05$), as shown in Table 4. The mean EKQ score increased gradually with the level of education. Chinese and Indian had same EKQ mean score (21.22), significantly higher than Malay subgroup (19.77), which was still significant ($p < 0.05$) when controlling for education level, but the effect size was very small (partial eta square = .032). There was no significant association between the EKQ score and the other demographic variables. Those with family history of epilepsy scored higher than those without family history, but the difference was not statistically significant ($p = 0.056$) as limited by small sample size.

(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 2) Almost

Table 2: 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
		Correlation coefficient	
1. Epilepsy is always caused by brain damage (FALSE)	43.1	0.164**	
2. Epilepsy is not infectious (TRUE)	81.5		
3. Epilepsy is a symptom of mental illness (FALSE)	64.0		0.178*
4. All people with epilepsy have similar symptoms (FALSE)	55.2	0.164*	
5. Almost anyone can have a seizure given the appropriate circumstances (TRUE)	67.3	0.173*	
6. An EEG can be used to help diagnose epilepsy (TRUE)	77.4	0.122*	
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	0.154*	
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	0.165**	
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		0.121*
15. For most people, doctors can effectively treat epilepsy with drugs (TRUE)	65.7	0.106*	
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 concentrations of antiepileptic drugs in the system (TRUE)	82.4		
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	0.184**
26. If seizures stop with antiepileptic drugs, this means your epilepsy has been cured (FALSE)	78.1	0.195**
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	0.136*
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).

two-third (20/34, 58.8%) of the items were incorrectly answered by more than 25% of the respondents.

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 although the overall knowledge in epilepsy was significantly associated with a better attitudes toward epilepsy, only eight out of 34 items (23.5%) in the knowledge questionnaire were proven to affect the attitudes toward epilepsy significantly.

Table 3: 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[19]				
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

Table 4: 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	
• Degree (n=147)	21.54±3.81	
• Post graduate (n=27)	22.44±4.09	
Employment status		NS
• Full time employment (n=169)	20.92±3.63	
• Others (n=128)	21.22±4.28	
Monthly income (1 USD = 3.2 RM*)		<0.05
• RM2000 and above (n=169)	21.44±3.78	
• Below RM 2000 (n=128)	20.53±4.05	
Family History		NS
• Yes (n=20)	22.20±3.37	
• No (n=277)	20.97±3.95	

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

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 contagious.

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 there is 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,[19] , 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[19] , as well as the Thai population[30]. Malaysian education system has tried to improve the standard of healthcare awareness by integrating this subject in the 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.[31] 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, when controlled for education level, 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 on few people with epilepsy taking antiepileptic drugs, the answer can be true in countries with wider treatment gap. For item 20 on taking two doses of antiepileptic drugs when forget for a day, 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.

The main limitation of this study was that it 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.

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 in a specific community and culture, and allow the measurement of improvement in knowledge that will affect attitudes toward epilepsy.

In conclusion, this study showed that although the overall knowledge toward epilepsy is significantly associated with better attitudes toward epilepsy, only certain aspects of knowledge in the scale contributed to this association.

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DISCLOSURE

Conflicts of interest: None

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