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Seizure

Awareness, knowledge and attitudes towards epilepsy among rural populations in East Coast Peninsular Malaysia: A preliminary exploration

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ABSTRACT

This study was carried out to gauge the preliminary insight regarding epilepsy among the rural society. The purposes of this study were: (1) to determine general level of awareness, knowledge and attitudes (AKA) towards epilepsy among rural communities, (2) to compare the AKA level based on socio-demographic characteristics and (3) to investigate rural cohort's perception of the best epilepsy treatment, preference for epilepsy information delivery and preference for mode of transportation to seek medical treatment. This prospective, cross sectional study included a sample of 615 rural residents enrolled via cluster sampling in East Coast region of Peninsular Malaysia (mean age = 41.6 ± 18.02, female = 56.6%, married = 65.5%, Malay = 94.0%, monthly income $\leq$ RM 500 = 56.9%). The Total AKA level was generally low (2.66 ± 0.7). Gender-wise no significant difference was shown regarding AKA level ($p > 0.05$). However, respondents with higher education significantly possessed better attitudes and higher Total AKA level compared to those with lower education level ($p < 0.001$). Employed respondents reported significantly more favourable attitudes than unemployed respondents ($p = 0.011$). Additionally, higher income rural cohorts possessed both significantly better attitudes and better AKA. These rural communities perceived modern medicine as the best epilepsy treatment (56.60%), preferred to obtain direct epilepsy-related information from health personnel (60.4%) and chose to use their own car to seek medical treatment in hospital (76.30%). The outcomes of this preliminary study signified the need to devise a dedicated epilepsy education program for implementation among rural residents. Increased AKA level in the society could enhance the people's acceptance, reduce stigmatisation and improve health-related quality of life (HRQoL) for epilepsy patients and their family.

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1. Introduction

Epilepsy is one of the oldest known brain disorders[1] which is characterised by recurrent seizures, as a result of sudden excessive electrical discharges in the brain cells. According to the World Health Organization (WHO) definition, "a diagnosis of epilepsy is reserved for those who have recurring seizures, at least two unprovoked ones".[2] The consequences of epilepsy in terms of morbidity, mortality, quality of life (QoL), and stigma differ around the world, depending on the cultural, economic, and community health background.[3]

The WHO estimates that eight people per 1000 worldwide have this disease[4] of which the prevalence in developing countries is usually higher than in developed countries. Although substantial economic development and improvement of health services have taken place, Asia is a heterogeneous and resource-constrained continent. Over half of the 50 million people with epilepsy

worldwide are estimated to live in Asia. The lifetime prevalence of epilepsy varied among countries from 1.5 to 14.0 per 1000 in Asia. The median lifetime prevalence in Asia is estimated at 6 per 1000, which is lower than in developing countries in other areas of the world, 15 per 1000 in sub Saharan Africa and 18 per 1000 in Latin America.[5]

Although epilepsy is one of the most prevalent neurological pathologies, this subject is surrounded by stigmas and prejudice among the population, the people's awareness and attitudes towards the disease being widely discussed in the literature. It has been observed that much of the discrimination against people with this disease is motivated by the mistaken idea of impotence, fragility and mental impairment of the patient, besides fear of having to witness and deal with a seizure.[6]

Although the causes of stigma are complex, a lack of knowledge about epilepsy has been considered to be an important determinant factor in the negative attitudes towards people with this clinical condition.[7] Study on public awareness, attitude and knowledge towards epilepsy is useful in decreasing discrimination and stigmatization. By identifying misunderstanding and misconception in the population, campaigns can be targeted and cross-

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cultural comparison can improve management strategy. Previous studies of public awareness, understanding, and attitudes towards epilepsy in Chinese had shown higher levels of discrimination against epilepsy in China[8] and Taiwan[9] as compared to United States.[10] The discrimination might be an inherent feature of Chinese cultures regardless of their location in Asia.[11]

The public awareness and understanding of a medical illness is crucial in the prophylaxis, early treatment, and compliance of the modern therapy in a community. In epilepsy, the lack of it probably contributes to the high treatment gap seen in many developing countries. The related phenomenon is that the patients may exhaust their limited resources in non-evidence based alternative therapies. The public awareness and understanding may also be important in the formulation of public health policy and allocation of fund. An accurate knowledge of the public attitudes towards epilepsy is also important as misconception and social misunderstanding may affect the QoL of the patients more than the seizure itself. In the recent years, surveys to assess the awareness, understanding and epilepsy have been conducted among the public in some of the Asian countries, including China,[8] Taiwan,[9] India,[12,13] Malaysia,[14] Singapore,[15] among the school teachers in Thailand[16] and patients in Pakistan.[17] These studies generally showed a similar level of awareness, but more negative attitudes towards epilepsy when compared to the developing countries in the West. The previous Malaysian study was carried out among ethnic Chinese in an urban and rural areas around Kuala Lumpur.[14] As Malaysia is a multi-racial country where ethnic Chinese constitutes 25% of the population, it is important to extend the study to other population groups[18] of which the rural communities represent a vital cohort.

Thus, this study aimed to provide a preliminary insight into the awareness, knowledge and attitudes towards epilepsy among rural communities specifically in East Coast Peninsular Malaysia so that accurate measures could be formulated via effective tools to enhance awareness, knowledge and attitudes (AKA) level and eventually improve health-related quality of life (HRQoL) for epilepsy patients and their families.

2. Methods

2.1. Study design and sample selection

This prospective, cross sectional study was carried out in three different states: Terengganu, Kelantan and Pahang among populations in rural areas in the region of East Coast Peninsular Malaysia. It was conducted over a three-month period from June until August 2009. The definition and identification of rural areas were confirmed using maps of local districts from "Jabatan Perangkaan dan Statistik Malaysia". The sample was selected via cluster sampling method and the sample size determined according to comparative cross-sectional study formula.[19–22] According to the formula, at least 588 respondents were needed for this study.

Formula calculation

$$n = \frac{P_1(1 - P_1) + P_2(1 - P_2)}{(P_1 - P_2)^2}(Z_\alpha + Z_\beta)^2$$

where n = required sample size; P_1 = expected proportion = 0.1; P_2 = previous proportion from previous study = 0.2; power of 80% = 0.80; α = level of significance = 0.05; Z_α = value of the standard normal distribution cutting off probability α in one tail for a one-sided alternative or $\alpha/2$ in each tail for a two-sided alternative; Z_β = value of the standard normal distribution cutting off probability β. Commonly used values are: Z_α = 1.96 for α = 0.05

(two-tailed) or 2.58 for α = 0.01 (two-tailed); Z_β = 0.84 for 80% power or Z_β = 1.28 for 90% power.

Hence,

$$n = \frac{0.1(0.9) + 0.2(0.8)}{(0.1)^2}(1.96 + 0.84)^2 = 196 \text{ for each state}$$

∴ If three states, $n \times 3$ = 196 × 3; N = 588.

2.2. Data collection procedure

At the first meeting, the researcher or the trained research assistants explained about the study and invited the potential respondents to participate in the study. Potential respondents were defined as rural residents within the selected cluster of locality who met all the inclusion criteria. Inclusion criteria for the respondents were: (1) any volunteer rural area residents who aged 18 years old and above, (2) should be able to either understand, read, speak or write in Malay language and (3) capable to answer the questions either in written form or by interview. On the other hand, the exclusion criteria were: (1) respondents below 18 years old, (2) unable to neither understand, read, speak nor write in Malay language and (3) incapable of answering the questions neither in written form nor by interview. An information sheet about the study was distributed to the respondents to enhance their understanding about the study. Respondents could clarify about the particulars needed, instruments used, and the study requirement. Those agreeing signed a written consent form and proceeded to complete the Personal Particular Forms and the modified *Malay AKA Epilepsy* questionnaire.

2.3. Instrument

The instrument employed was the modified *Malay AKA Epilepsy* which been used in a previous study.[23] This instrument contained three domains: *Awareness, Knowledge* and *Attitudes*. Each response score was range from 0 to 10. The first domain was to detect Awareness level which contained 5 items with total score range from 0 to 50. The scores were grouped as follows: 0–10 = 1, 11–20 = 2, 21–30 = 3, 31–40 = 4 and 41–50 = 5 and interpreted as such: 1 = very low, 2 = low, 3 = moderate, 4 = high and 5 = very high. The second domain was to determine Knowledge level which contained 8 items with total score range from 0 to 80. The scores were grouped as follows: 0–16 = 1, 17–32 = 2, 33–48 = 3, 49–65 = 4 and 66–80 = 5. Score interpretation of knowledge level: 1 = very low, 2 = low, 3 = moderate, 4 = high and 5 = very high. The last domain measured Attitude level which was sampled by 4 items with total score range from 0 to 40. The scores were again grouped as follows: 0–9 = 1, 10–19 = 2, 20–29 = 3, 30–39 = 4 and 40–49 = 5. Score interpretation of attitude level: 1 = very negative, 2 = negative, 3 = indifferent, 4 = positive and 5 = very positive. Finally the Total AKA, score was generated via the summation of all three domain scores to give the general AKA level of all respondents. The score range from 0 to 170 with score interpretation of Total AKA level: 1 = very poor, 2 = poor, 3 = moderate, 4 = good and 5 = excellent. Finally there were also individual items for the *perception of the best epilepsy treatment, preference for epilepsy information delivery and preference for mode of transportation to seek medical treatment* respectively. Overall there were three domains with 20 items for the respondents to answer.

2.4. Statistical analysis

This study employed Statistical Package for Social Sciences version 14 (SPSS 14) for data analyses. All socio-demographic data

was analysed descriptively and presented as frequencies as well as percentages. Wherever relevant, chi square test for goodness of fit was used for the analysis of single categorical variable. Test of normality was also employed to test data distribution of the variables. General AKA level was initially presented descriptively in the form of mean and standard deviation. Independent t-test was utilised to test for group score comparisons for AKA level based on socio-demographic variables which were presented in the form of mean, standard deviation, confidence intervals and p value. The last three items on perception of the best epilepsy treatment, preference for epilepsy information delivery and preference for the mode of transportation to seek medical treatment was analysed descriptively and presented in the form of frequencies and percentages.

3. Results

3.1. Socio-demographic characteristics

Six hundred and fifteen respondents (Terengganu = 435, Kelantan = 95 and Pahang = 85) participated in this study. The mean age was 41.6 ± 18.0 years, ranging from 18 to 98 years. The male to female ratio was 1:1.3. Majority of respondents were Malay (94.0%), Muslim (95.3%), married (65.5%), lived with spouse or family (88.6%), education level at SPM or equivalent (33.3%), self-employed (36.4%) and earned not more than RM 500 (56.9%) monthly. On the other hand, the very least proportion of respondents comprised of other races in Malaysia (0.3%), Hindu or others (0.2%), widower (4.4%), rented a room (0.3%), education level degree or equivalent (1.6%), retiree (1.6%) and earned more than RM 2500 (1.4%) monthly. Further details are shown in Table 1.

3.2. Reliability of Malay AKA Epilepsy

Internal consistency reliability (Cronbach's α) for overall and each domain in AKA Epilepsy emerged as high (0.775–0.811) whereby: Knowledge (Cronbach's α = 0.775), Attitude (Cronbach's α = 0.840) and Total AKA (Cronbach's α = 0.811) except for the domain Awareness (Cronbach's α = 0.531). The item number 2 in domain Awareness, "Have you ever attend any talk or lecture on epilepsy?" was identified as a 'problematic item' because almost none of our respondents has ever attended any talk or lecture on epilepsy hence the lack of its relevance. Nevertheless, because it may be useful for educational programme and that the value of Cronbach's α was moderately satisfactory, this item was retained due to its importance. Refer to Table 2 for further details.

3.3. Validity of Malay AKA Epilepsy

Principal component factor analysis produced three clear components which explained 47.1% of the total variance. These were identified as Attitude, Knowledge and Awareness in which items belonging to their respective subscale loaded highly as expected ($r > 0.40$), with the exception of only items 1 (whether respondent ever heard or know about epilepsy) and item 2 (whether respondent ever attended any talk or lecture on epilepsy). This analysis provided evidence of the construct validity of the Malay AKA Epilepsy instrument. Additionally, evidence of convergent and divergent validity were shown whereby the correlation between subscales Awareness, Knowledge and Attitudes with Total AKA Score were high and significant ($r \geq 0.50$, $p < 0.05$). On the other hand, the Awareness, Knowledge and Attitudes subscales produced low and insignificant correlation with non-AKA items such as treatment, information and transportation ($r \leq 0.02$, $p > 0.05$). Refer to Table 2.

Table 1
Socio-demographic characteristics of sample respondents (n = 615).

Variables	Mean	Standard deviation	Median	Minimum–maximum
Age	41.57	18.02	40.00	18–98

	Frequency (n)	Percentage (%)	p value[*]
Gender			0.001
Male	267	43.40	
Female	348	56.60	
Marital status			<0.001
Married	403	65.50	
Single	185	30.10	
Widowed	27	4.40	
Race			<0.001
Malay	578	94.00	
Chinese	32	5.20	
Indian	3	0.50	
Others	2	0.30	
Religion			<0.001
Muslim	586	95.30	
Buddhist	24	3.90	
Hindu	1	0.20	
Christian	3	0.50	
Others	1	0.20	
Education level			<0.001
No formal education	66	10.70	
Primary school	174	28.30	
SRP/PMR or equivalent	97	15.80	
SPM or equivalent	205	33.30	
STPM	39	6.40	
Diploma or equivalent	24	3.90	
Degree or equivalent	10	1.60	
Occupation			<0.001
Professional	12	2.00	
Supportive	73	11.90	
Self-employed	224	36.40	
Housewife	96	15.60	
Retiree	10	1.60	
Student	85	13.80	
Unemployed	115	18.70	
Monthly income			<0.001
RM 500 and below	350	56.90	
RM 501–RM 1000	115	18.70	
RM 1001–RM 1500	103	16.70	
RM 1501–RM 2000	29	4.70	
RM 2001–RM 2500	10	1.60	
RM 2501 and above	8	1.40	
Living arrangement			<0.001
Alone	35	5.70	
With spouse/family	545	88.60	
With friend	33	5.40	
Rent a room	2	0.30	

[*] Chi-square test for goodness of fit.

3.4. General AKA level

Generally, AKA level of rural communities in East Coast Peninsular Malaysia was in the poor category (mean = 2.67 ± 0.7) 0.7) with scores ranging from 1 to 5. Among the three domains, Attitudes (3.47 ± 1.37) emerged with the highest mean followed by Knowledge (2.49 ± 0.86) and lastly Awareness (2.05 ± 0.99). Based on the mean score of each domain, our sample of rural populations could be considered as possessing low level of awareness and knowledge and showed indifferent attitudes towards epilepsy. Between the three domains, Awareness level was the poorest while Attitudes level was the best. Further details were shown in Table 3.

3.4.1. Awareness
The awareness level of our rural sample in this study was rather low (mean = 2.05 ± 0.99). When asked if they ever heard or read about epilepsy 94.0% said "Yes" while 6.0% answered "No". However, 97.1% had neither ever attend nor listen to any talk or course about epilepsy compared to a very small number who did (2.9%). There were

Table 2
Internal consistency reliability and validity of the *Malay AKA Epilepsy*.

	Reliability (Cronbach's α)	Validity		
		Construct (rotated component matrix)	Convergent (correlation with Total AKA)	Divergent (correlation with non-AKA items)
Awareness	0.531	0.325 (Item 1) 0.036 (Item 2) 0.700 (Item 3) 0.749 (Item 4) 0.634 (Item 5)	0.621**	–
Knowledge	0.775	0.574 (Item 6) 0.670 (Item 7) 0.677 (Item 8) 0.704 (Item 9) 0.655 (Item 10) 0.501 (Item 11) 0.467 (Item 12) 0.516 (Item 13)	0.652**	–
Attitudes	0.840	0.828 (Item 14) 0.807 (Item 15) 0.818 (Item 16) 0.748 (Item 17)	0.557**	–
Total AKA	0.811	–	–	Treatment: −0.065 Information: 0.022 Transportation: −0.044

For validity, values quoted were correlation coefficients. **$p < 0.01$.

62.6% of the respondents who claimed they had witnessed epilepsy attacks while 79.0% admitted that they had never performed any first-aid seizure management towards epilepsy patients. Nevertheless, 37.4% never witnessed epilepsy attacks but 21.0% of them knew and had performed first-aid seizure management. Majority of rural cohorts denied having epilepsy cases in their family or blood relatives (80.3%) while on the other hand 19.7% admitted having family members with this disease. Refer to Fig. 1.

3.4.2. Knowledge

The knowledge level regarding epilepsy was in general low (mean = 2.49 ± 0.86). Across all respondents, 54.5% did not know the causes of epilepsy and 5.4% believed that it is a contagious disease. Despite 23.7% being unsure about the causes of epilepsy, the majority did not think that epilepsy is a contagious disease (71.5%). There were 33.2% of rural residents who did not think that epilepsy could be inherited genetically although 42.1% agreed that this disease could be genetically inherited. Half of them disagreed that epilepsy is a form of mental disease (50.9%) but 18.2% still believed it is. Despite minority claiming that epilepsy is caused by evil spirit disturbance or demon possession (7.5%), majority disagreed with this belief (66.6%). Apparently, 18.2% did not believe that epilepsy could cause death although 60.3% believed so. Although 47.1% claimed that epilepsy is curable, 27.2% denied the notion while 25.7% were unsure about it. More than half of the respondents did not possess any basic knowledge regarding first-aid seizure management for epilepsy (61.6%). Only 19.1% did possess some knowledge while 19.3% admitted that they were unsure. Refer to Table 4.

Table 3
Overall Awareness, Knowledge, Attitudes and Total AKA level.

Domain	Mean	Standard deviation	Minimum	Maximum	Interpretation
Awareness	2.05	0.99	1	5	Low
Knowledge	2.49	0.86	1	5	Low
Attitudes	3.47	1.37	1	5	Indifferent
Total AKA	2.67	0.70	1	5	Poor

3.4.3. Attitudes

The overall attitude of rural folks towards epilepsy was regarded as indifferent (mean = 3.47 ± 1.37). With regard to involvement in sports activity, 40.2% did not agree that patients should participate in sports, 47.0% did while 12.7% were not certain. Besides that 46.2% of the respondents strongly disagreed that epilepsy patient should drive while the remaining either agreed (39.5%) or were not sure (14.1%). However, 64.4% naturally consented that epilepsy patient should marry while more than two-third supported epilepsy patients' involvement and socialisation in the community (77.9%). Despite that, there were still respondents who had strong objections towards the idea of marriage (21.6%) and socialisation (12.9%) among epilepsy patients (Fig. 2).

3.5. Comparison of AKA level based on socio-demographic characteristics

3.5.1. Gender

Males did not showed significantly better awareness (2.06 ± 0.92), knowledge (2.50 ± 0.89) and attitudes (3.55 ± 1.35) compared to the females' awareness (2.03 ± 1.04), knowledge
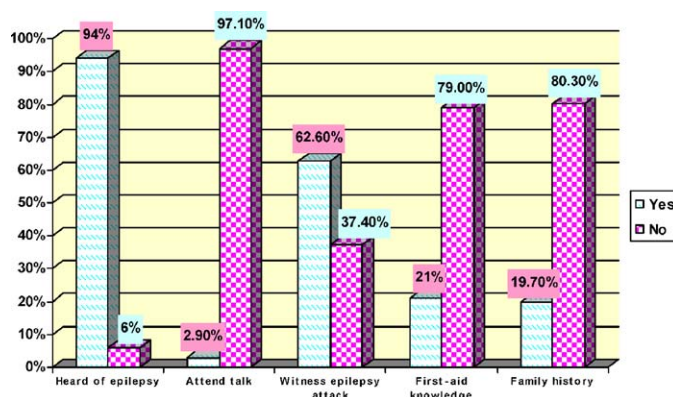

Fig. 1. Responses on the Awareness towards epilepsy (*n* = 615).

Table 4
Knowledge regarding epilepsy (n = 615).

Questions	Yes, n (%)	No, n (%)	Not sure, n (%)
Do you know the cause of epilepsy?	134 (21.8)	335 (54.5)	146 (23.7)
Do you think epilepsy is contagious?	33 (5.4)	440 (71.5)	142 (23.1)
Do you think epilepsy is hereditary?	258 (42.1)	203 (33.2)	152 (24.7)
Do you think epilepsy is a form of mental illness?	112 (18.2)	313 (50.9)	190 (30.9)
Do you think epilepsy is caused by evil spirit or demon possession?	46 (7.5)	410 (66.6)	159 (25.9)
Do you think epilepsy can cause death?	370 (60.3)	112 (18.2)	132 (21.5)
Do you think epilepsy can be cured?	290 (47.1)	167 (27.2)	158 (25.7)
Do you know how to perform first-aid seizure management?	117 (19.1)	379 (61.6)	119 (19.3)

(2.48 ± 0.84) and attitudes (3.41 ± 1.39). Similarly, there was no significant difference in Total AKA level between male and female respondents. Both genders showed the highest mean score for *Attitudes* (male = 3.55 ± 1.35, female = 3.41 ± 1.39). Again, both genders showed the lowest mean score for *Awareness* (male = 2.06 ± 0.92, female = 2.03 ± 1.04). The overall trend indicated that scores for males were generally more favourable compared to females. Table 5 illustrates these differences.

3.5.2. Education level
Expectedly respondents with higher education level possessed significantly better attitudes (4.04 ± 1.16) towards epilepsy compared to those with lower education level (3.40 ± 1.38). Higher education level respondent also possessed significantly higher Total AKA level (2.86 ± 0.69) compared to lower education level respondents (2.63 ± 0.70). Furthermore respondents with higher education level were also reported to have generally better *Awareness* and *Knowledge* (2.07 ± 0.95, 2.63 ± 0.86) compared to those with lower education level (2.04 ± 1.00, 2.47 ± 0.86), but these differences were insignificant (Table 6).

3.5.3. Employment
Employed respondents showed significantly better attitudes (3.61 ± 1.31) compared to unemployed respondents (3.33 ± 1.42). The mean differences between employed and unemployed respondents for *Awareness*, *Knowledge* and *Total AKA* were very small (below 0.1) thus not significantly different. Nonetheless, employed respondents were reported to have higher *Awareness* (2.09 ± 1.00) compared to unemployed respondents (2.00 ± 0.99). On the contrary, they recorded insignificantly lower *Knowledge* (2.44 ± 0.90) than those without employment (2.54 ± 0.82). Refer to Table 7.

3.5.4. Monthly income
Rural residents with higher monthly income showed significantly better *Attitudes* (3.98 ± 1.12) towards epilepsy compared to
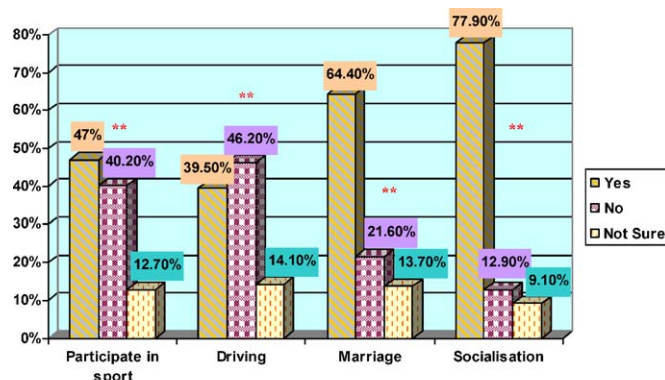
those with lower monthly income (3.31 ± 1.41). The *Total AKA* level of higher monthly income respondents were also significantly higher (2.78 ± 0.72) compared to those with lower monthly income (2.62 ± 0.69). Unexpectedly, respondents with lower monthly income reported insignificantly better *Awareness* (2.07 ± 1.01) compared to their counterparts (1.99 ± 0.94) although they possessed insignificantly lower *Knowledge* (2.48 ± 0.84) compared to those with higher monthly income (2.51 ± 0.94) (Table 8).

3.5.5. Perception and preference: epilepsy treatment, information delivery and mode of transportation
Most of the rural people perceived modern medicine (56.6%) as the best epilepsy treatment compared to traditional medicine, surgery, "shaman/bomoh" and others. A significant proportion preferred to obtain information regarding epilepsy directly from doctors or health personnel (60.2%) rather than through the mass

Table 5
Differences in AKA level based on gender.

Domain	Male (n = 267)		Female (n = 348)		95% CI	p value[*]
	Mean	SD	Mean	SD		
Awareness	2.06	0.92	2.03	1.04	−0.13, 0.19	0.72
Knowledge	2.50	0.89	2.48	0.84	−0.12, 0.16	0.76
Attitudes	3.55	1.35	3.41	1.39	−0.08, 0.36	0.21
Total AKA	2.66	0.68	2.66	0.71	−0.12, 0.11	0.94

[*] Independent t-test.

Table 6
AKA level discrepancies based on education level.

Domain	Tertiary education and above		Secondary education and below		95% CI	p value[*]
	Mean	SD	Mean	SD		
Awareness	2.07	0.95	2.04	1.00	−0.27, 0.22	0.85
Knowledge	2.63	0.86	2.47	0.86	−0.37, 0.52	0.14
Attitudes	**4.04**	**1.16**	**3.40**	**1.38**	−0.98, −0.31	**<0.001**
Total AKA	**2.86**	**0.69**	**2.63**	**0.70**	−0.40, −0.06	**0.01**

[*] Independent t-test.

Table 7
AKA level based on employment status.

Domain	Employed		Unemployed		95% CI	p value[*]
	Mean	SD	Mean	SD		
Awareness	2.09	1.00	2.00	0.99	-0.06, 0.25	0.25
Knowledge	2.44	0.90	2.54	0.82	-0.24, 0.03	0.14
Attitudes	**3.61**	**1.31**	**3.33**	**1.42**	0.06, 0.50	**0.011**
Total AKA	2.67	0.70	2.66	0.70	-0.10, 0.12	0.86

[*] Independent t-test.

Fig. 2. *Attitudes* towards epilepsy among the rural communities (n = 615).

** Contains missing data (n ≠ 615) thus total percentage ≠ 100%

Table 8
AKA level based on monthly income level.

Domain	Above RM 1000		RM 1000 and below		95% CI	p value*
	Mean	SD	Mean	SD		
Awareness	1.99	0.94	2.07	1.01	−0.10, 0.26	0.39
Knowledge	2.51	0.94	2.48	0.84	−0.19, 0.13	0.70
Attitudes	**3.98**	**1.12**	**3.31**	**1.41**	−0.92, −0.42	**<0.001**
Total AKA	**2.78**	**0.72**	**2.62**	**0.69**	−0.28, −0.03	**0.02**

* Independent t-test.

Table 9
Overall perception of the best epilepsy treatment, preference of epilepsy information delivery and preference on mode of transportation to seek medical treatment.

Perception and preference	Frequency (n)	Percentage (%)	p value[a]
Best epilepsy treatment[b]			<0.001
Modern medicine	348	56.6	
Traditional medicine	157	25.5	
Shaman/bomoh	86	14.0	
Others	18	2.9	
Surgery	4	0.7	
Epilepsy information delivery[b]			<0.001
Doctors or health personnel (directly)	370	60.2	
Mass media (TV, radio, magazine etc)	163	26.5	
Internet	35	5.7	
Short messaging system (SMS)	21	3.4	
Others	19	3.1	
Mail (postal)	5	0.8	
Mode of transportation to seek medical treatment[b]			<0.001
Own car	469	76.3	
Others	69	11.4	
Taxi	29	4.7	
Not relevant	29	4.7	
Motorbike	5	0.8	
Bus	2	0.3	
Bicycle	1	0.2	

[a] Chi-square test for goodness of fit.
[b] Contains missing data (n ≠ 615).

media, postal, Internet, short messaging system (SMS) or other ways was highlighted. This remote population preferred using their own car (76.3%) to seek medical treatment in hospital than other modes of transportation such as taxi, bus, motorbike, bicycle, etc. Details are reported in Table 9.

4. Discussion

Two studies in Pakistan[17] and India[24] have indicated that the prevalence of epilepsy was higher in rural areas than in urban areas. Indeed, higher prevalence of epilepsy in rural areas is a common trend in developing countries like Malaysia.[5] Thus this study was carried out in rural areas of East Coast Peninsular Malaysia covering three states: Terengganu, Kelantan and Pahang which have been identified as amongst the least developed regions in Malaysia whereby the prevalence of epilepsy was high. When compared to the states in the West Coast of Peninsular Malaysia, the socioeconomic status in these three states are also comparatively lower. The previous Malaysian study was conducted among ethnic Chinese in urban and rural areas around Kuala Lumpur[14] and another study was carried out in Kelantan[18] which focused on awareness, attitudes and understanding towards epilepsy. Similar study on awareness and knowledge

of epilepsy has also been conducted among students in a Malaysian university.[23]

Public awareness, knowledge and attitudes level towards epilepsy varied between different communities in different countries. Lack of awareness and knowledge might lead to negative attitudes towards epilepsy and could be a factor explaining stigma. Hence this study was a crucial tool to obtain accurate information of the public attitudes towards epilepsy, which has often been subjected to misconception, stigmatisation and social misunderstanding, ultimately affecting the overall HRQoL of the patients more than the disease itself. Enhanced awareness, knowledge and attitudes of this brain disorder among public would allay fears and mistrust about epileptics in the community as well as lessen stigmatisation towards such persons.[25] Furthermore, this study provided a preliminary insight of AKA level among rural communities which could act as a very important basis to formulate an epilepsy educational tool for the public. This was further supported by a study conducted in Northern Nigeria, which claimed that, the low level of knowledge and misconceptions found among respondents demonstrated the need for educational programmes aimed at demystifying epilepsy.[25]

The findings presented in the current study involved rural population's general level of AKA towards epilepsy which was found to be generally low. Similarly, both their awareness' and knowledge' level were also disappointingly low and this was made worse by the indifferent attitudes towards the disease. These outcomes were in contrast with a previous study conducted in Bandung, Indonesia whereby the awareness level amongst general public was reported to be high.[26] There was however, a lot of misunderstanding about the nature of epilepsy which could lead to negative attitudes.[26] Another study among Iranian ethnic had also documented a high level of awareness about epilepsy.[27] Previous studies conducted by Lim et al.[14] also reported a high awareness of epilepsy among Malaysian Chinese. Lai et al.[8] and Chung et al.[9] have found that the Chinese in both Henan and Taiwan were aware of epilepsy with understanding levels comparable to studies in other countries. However, the attitudes towards epilepsy was much more negative in Henan[8] and less so in Taiwan.[9] A lack of knowledge about epilepsy has been considered to be an important determinant factor in the negative attitudes towards people with this clinical condition.[28] Furthermore, lack of knowledge about epilepsy has been shown in a large part of the populations throughout the world.[7] As such, these findings seemed to suggest that the public's attitudes towards epilepsy patients and the disease itself globally need major improvements. Furthermore, the attitudes of various target groups in the society toward epilepsy patients, and vice versa, to some extent could determine the HRQoL of the patients as well as their families.

There was no significant difference in the level of awareness, knowledge or attitudes based on gender among the respondents in this study. The increasingly adopted practice of equal opportunities in Malaysia between males and females in the fields of education, occupation, etc. could probably explain such results. It could also mean that both males and females received equal exposure with regard to this disease in Malaysia. This particular finding was supported by Lim et al.[14] who claimed that gender did not have a significant association with the awareness or familiarity with epilepsy. However, females were found to harbour negative attitudes towards marriage among People With Epilepsy (PWE) while males tended to show negative attitudes towards employment and a prejudice inclination to believe that epilepsy represents a form of insanity.[14] Females have been reported to possess more positive attitudes and less prejudice against epilepsy compared to males according to a study conducted in Hungary.[29] Al-Rashed et al.[30] claimed that females were less likely to believe

that PWE should be restricted from sports, driving, socialising with other people, being employed or getting married. On the contrary, Nyame and Biriwum in Ghana observed that male respondents perceive epileptics more favourably than their female counterparts.[31] From here it can be concluded that results on gender are generally mixed and showed no obvious trend globally.

With respect to educational level, respondents with higher education level possessed significantly better attitudes and higher Total AKA level compared to those with lower education level. These findings were supported by a previous study conducted among students in a Malaysian university, which stated that a higher level of education correlated positively with awareness, knowledge and attitudes concerning epilepsy.[23] Community-based studies have also reported that better-educated individuals offer more favourable opinions and display more positive attitudes.[9,14,29] Studies among Chinese in Malaysia also showed that those who had lower level of education harboured more negative attitudes towards epilepsy.[14] A previous study by Mirnics et al.[29] in Hungary reported that people with higher education possessed higher awareness, better knowledge and more positive and accepting attitudes towards epilepsy compared to their less-educated counterpart. However, urban respondents with higher education in Kelantan unexpectedly exhibited worse attitudes, with strong objection towards marriage for epilepsy patient.[18] In contrast, however, a community-based perception study among teachers perception in Enugu, Nigeria exhibited negative attitudes towards epilepsy despite their high level of education.[32] Similar findings were reported by Millogo and Siranyan[33] in a study among school teachers in Africa.

Employment-wise it was apparent that employed respondents possessed significantly better attitudes towards epilepsy than unemployed respondents. This finding suggested that people could probably improve their attitudes and perceptions towards epilepsy through employment. However, it contrasted with the outcomes of a previous study in Hong Kong which illustrated that employed respondents with medically-related occupation such as doctors, nurses or pharmacists showed more negative regarding attitudes towards epilepsy.[11] Another study conducted among Omani physicians suggested that many doctors in Oman are worryingly harbouring negative attitudes towards people with epilepsy.[1] The previous two studies thus suggested that employment did not have any association with attitudes level towards epileptics. Again, the differences in findings showed that attitudes towards epilepsy with respect to employment varied amongst different communities in different countries, probably due to different sociodemographic background and cultural values.

In terms of monthly income, respondents with higher monthly income possessed better attitudes towards epilepsy and higher Total AKA level than respondents with lower monthly income. Lower income respondents probably have less access to information concerning epilepsy and this has contributed to their erroneous concepts about the disease. This happened mainly due to lack of information in the media accessible to the laypeople.[6] Thus indirectly explaining the higher level of awareness, knowledge and understanding as well as better attitudes towards epilepsy possessed by people in developed countries with higher monthly income and better life-style compared to those in developing countries. Previous studies in some developing Asian countries with lower monthly income rate including China,[8] Taiwan,[9] India,[12,13] Malaysia,[14] Singapore,[15] Thailand[16] and Pakistan[17] generally showed similar level of awareness but more negative attitudes towards epilepsy when compared to the developed countries in the West.[18] Similarly, respondents of different socioeconomic status varied significantly in their knowledge and perceptions of PWE.[30] In support of our findings, it has been demonstrated that higher educational level and socioeconomic status were associated with greater knowledge of and more favourable attitudes towards epilepsy.[29,34–37]

Majority of the rural population in East Coast Peninsular Malaysia perceived that modern medicine is still the best treatment for epilepsy. Their awareness and perception regarding modern treatment for epilepsy was better compared to a previous study in Kelantan whereby strong emphasis on religious practices among predominantly Muslims had led to the use of traditional medicine.[18] Our finding was also supported by a study conducted among rural population in Laos which indicated their preference for modern medicine.[3] This was probably due to the fact that awareness on the effectiveness and reliability of modern medicine among rural communities has improved drastically since a decade ago.[11] Alternative medicine such as herbal medicines and dietary supplements may have disadvantages in patients with epilepsy[38], they may also have adverse effects, interact with modern medicines or possessed contraindications.[39] On the contrary, the Chinese in Malaysia preferred alternative medicine practitioners for healing epilepsy.[14] The recommendation of traditional medicine, herbs and health food by Myanmar people is likely a reflection of their persisting traditional medical belief and practice.[40] Menon et al.[41] has shown that a large treatment gap of epilepsy existed particularly among the rural Malaysians which was mainly attributed to social-cultural factors.

Obtaining epilepsy-related information directly from the doctors and health personnel was highly preferred by the rural population. They seemed to place high trust and confidence towards the health authorities especially the doctors and wished to be informed directly and be allowed to freely ask any question regarding epilepsy without hesitation or delay. Receiving information through the mass media was the second most preferred way to gain knowledge and information since they claimed that each family owned at least a television set or a radio for that matter. Television is one of the most important inventions of the last century.[37] Despite that, respondents argued that the mass media only involved one-way communication which does not offer a convenient and effective way to tackle their enquiries. Even though capable of providing borderless information and useful knowledge, the internet was the least preferred by the respondents given the fact limited internet connection is available in rural areas. On the other hand, mobile phones have become easily available and highly popular since 1990s especially SMS, in which text messages sent and received by mobile phones are increasingly used to access to information.[42] With the exception of mobile phones however, the penetration and accessibility rates of internet connection are below 15% in East Coast region of Peninsular Malaysia.[43] Moreover older respondents were mostly computer illiterate. Thus epilepsy education through the sophisticated Internet system among rural communities in the future might not be successful if these two main obstacles are not appropriately addressed.

Rural communities in East Coast Peninsular Malaysia preferred to use their own car to seek medical treatment. This option was more convenient for them as the majority owned at least a car in a family. They claimed that the unfavourable condition of epilepsy patient required them to be transported immediately by the most convenient mode of transportation. The long waiting period for ambulance could also endanger the patients' health and well-being and place increased risk on their family members. The other transportation option such as the public buses was not preferred possibly due to the long waiting time and delayed transfers which would increase travelling time for patients.[44] Low quality, time-consuming and costly services of the public transportation had been shown to cause frustrations[45] for epilepsy patients seeking medical treatments.

In spite of these disclosures, several drawbacks need to be highlighted in this study. Firstly, bias within data collectors must be considered. Each data collector administered the questionnaires separately than the others thus the process might have introduced inconsistencies questionnaire administration. Secondly, bias in terms of questionnaire administration procedure since our respondents may have probably answered differently in face-to-face interview compared to self-administered questionnaires. Finally, there was language barrier whereby different local dialects are being spoken among different communities in Terengganu, Kelantan and Pahang. Nevertheless, the questions were short and simple. Last but not least the possible sampling bias from epilepsy patient themselves may have arisen. However, the number of respondents who were also epilepsy patients were very small ($n = 5$), thus the number was regarded to be insignificant and negligible.

5. Conclusion

The poor AKA level among rural residents demonstrated by this study strongly supported the need for local studies concerning public awareness, knowledge and attitudes regarding epilepsy which have direct relevance and significance to health education and services. Both education level and monthly income were significantly associated with *Attitudes*, and *Total AKA* while employment status was significantly associated with *Attitudes* hence proving that there were significant associations between certain socio-demographic variables and AKA. The current level of rural public's awareness, knowledge and attitudes towards epilepsy clearly indicated the need for the formulation of improved public epilepsy education model such as IT-based epilepsy education tool for the purpose of achieving better AKA and HRQoL for epilepsy patients and their family. This should represent the next focus for future studies which involve testing of innovative health education methods to benefit the overall public especially those residing in remote places.

Appendix A

MALAY VERSION OF AKA EPILEPSY
SOAL SELIDIK TENTANG PENYAKIT SAWAN

Kami ingin mengetahui kesedaran,pengetahuan dan sikap anda terhadap penyakit sawan.
Sila bulatkan pilihan anda. Tiada pilihan jawapan yang betul atau salah,sila jawab dengan jujur.
Terima kasih.

(A) Kesedaran terhadap penyakit sawan

	Ya	Tidak
1. Pernahkah anda terdengar atau terbaca mengenai penyakit "sawan"?	1	2
2. Pernahkah anda menghadiri seminar atau ceramah mengenai "sawan"?	1	2
3. Pernahkah anda melihat seseorang diserang penyakit "sawan"?	1	2
4. Pernahkah anda melaksanakan pertolongan cemas penyakit "sawan"?	1	2
5. Adakah ahli keluarga anda yang menghidap penyakit "sawan"?	1	2

(B) Pengetahuan tentang penyakit sawan

	Ya	Tidak	Tidak pasti
6. Adakah anda tahu penyebab penyakit "sawan"?	1	2	3
7. Adakah anda fikir penyakit "sawan" boleh berjangkit?	1	2	3
8. Adakah anda fikir penyakit " sawan" adalah satu penyakit keturunan?	1	2	3
9. Adakah anda fikir "sawan"adalah sejenis penyakit mental?	1	2	3
10. Adakah anda fikir penyakit "sawan" adalah disebabkan oleh semangat /roh jahat?	1	2	3
11. Adakah anda fikir penyakit "sawan" boleh menyebabkan kematian?	1	2	3
12. Adakah anda fikir penyakit "sawan" boleh diubati?	1	2	3
13. Adakah anda tahu bagaimana untuk melakukan rawatan kecemasan penyakit "sawan" ?	1	2	3

(C) Sikap terhadap penyakit sawan

	Ya	Tidak	Tidak pasti
14. Adakah anda fikir pesakit "sawan" boleh menyertai aktiviti sukan?	1	2	3
15. Adakah anda fikir pesakit "sawan" boleh memandu?	1	2	3
16. Adakah anda fikir pesakit "sawan" boleh mempunyai pasangan dan berkeluarga?	1	2	3
17. Adakah anda fikir pesakit "sawan" boleh bergaul mesra di dalam masyarakat?	1	2	3

(D) Umum

18. Pada pendapat anda apakah rawatan terbaik untuk mengubati penyakit "sawan"? (sila tanda **SATU** jawapan sahaja)

      ☐ Ubat-ubatan moden   ☐ Pembedahan

      ☐ Rawatan tradisional (herba dll)   ☐ Pawang/bomoh (jampi serapah)

      ☐ Lain-lain.Sila nyatakan:_____

19. Jika diberi pilihan, apakah cara yang anda mahukan untuk mendapatkan maklumat tentang penyakit sawan? (sila tanda **SATU** jawapan sahaja)

      ☐ Penerangan lisan dari pihak kesihatan (doktor, jururawat, dan sebagainya)

      ☐ Media (tv, radio, suratkhabar, majalah, risalah)

      ☐ Maklumat melalui kiriman pos

      ☐ Internet (laman web)

      ☐ Sistem pesanan ringkas (SMS)

      ☐ Lain-lain: Sila nyatakan:_____

20. Sekiranya anda/ahli keluarga menghidap penyakit "sawan" apakah jenis pengangkutan yang sering anda gunakan bagi mendapatkan rawatan daripada pihak hospital? (sila tanda **SATU** jawapan sahaja)

      ☐ Kereta sendiri   ☐ Bas   ☐ Teksi   ☐ Motosikal   ☐ Basikal

      ☐ Lain-lain: sila nyatakan_____   ☐ Tidak berkenaan

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