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Improving awareness, knowledge, and attitude among Malaysian parents of children with epilepsy using an Interactive Animated Epilepsy Education Programme (IAEEP)

Choong Yi Fong [a],*, Seet Yee Hong [a,b], Lai Choo Ong [a], Wei Kang Lim [a], Pei Lin Lua [c]

[a] Division of Paediatric Neurology, Department of Paediatrics, Faculty of Medicine, University Malaya, Kuala Lumpur, Malaysia
[b] Paediatric Department, Hospital Raja Permaisuri Bainun, Ipoh, Perak, Malaysia
[c] Faculty of Health Sciences, Universiti Sultan Zainal Abidin, Kuala Nerus, Terengganu, Malaysia

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ABSTRACT

Background: An information technology (IT)-based epilepsy educational program, the Interactive Animated Epilepsy Education Programme (IAEEP), can potentially help improve awareness, knowledge, and attitude (AKA) of parents of children with epilepsy (CWE) enabling CWE to lead a normal life. Our study aimed to assess the following: i) baseline level of epilepsy AKA of Malaysian parents of CWE and explore potential characteristics associated with low levels of AKA; ii) effectiveness of the IAEEP in improving parental AKA, and whether these effects remained stable over time; and iii) effects of the IAEEP on parental mental state and perception of their child's quality of life.
Methods: This prospective study includes parents of CWE aged 8–18 years old with no comorbidities. Epilepsy education was delivered using the IAEEP. Parents completed an AKA questionnaire before (time point 1 [TP1]), immediately after (TP2), and 4–6 months (TP3) after the provision of IAEEP. Parent proxy report of Health-Related Quality of Life Measurement for Children with Epilepsy (CHEQOL)-25 questionnaire and Depression, Anxiety, and Stress Scale (DASS)-21 questionnaire was completed at TP1 and TP3.
Results: A total of 78 parents participated in the study. At baseline (TP1), parental responses were rated as “moderate” for awareness domain, “high” for knowledge domain, “very positive” for attitude domain, and “good” for total AKA score domain. No epilepsy or parental characteristics were associated with the low baseline parental AKA levels. After IAEEP intervention, there was a significant increase in all AKA subdomain scores. Post-IAEEP, the AKA of parents were rated as “very high” for awareness domain, “very high” for knowledge domain, “very positive” for attitude domain, and “excellent” for total AKA domain at both TP2 and TP3. Parent proxy CHEQOL-25 report showed significant increments in interpersonal/social and secrecy scale scores between TP1 and TP3. There were no significant differences in the DASS-21 scores between TP1 and TP3.
Conclusion: The IAEEP is an effective epilepsy educational tool to increase the levels of AKA among parents of CWE. Following the use of the IAEEP, parents of CWE also reported an improvement of their child's quality of life in the interpersonal/social and epilepsy secrecy CHEQOL-25 domains. There was no impact on parental mental health following exposure to the IAEEP.

1. Introduction

Despite epilepsy being the most common childhood neurological disorder, negative public attitudes still prevail especially in the non-Western populations with lower standards of living [1]. This invariably impacts on the lives of the children with epilepsy (CWE) and their families. In an international survey across North America, Europe, and Asia, CWE and their parents expressed common concerns about the impact of epilepsy, notably worries about future employment and independence even among the majority who were in mainstream education [2].

Previous studies on public awareness, knowledge, and attitude (AKA) of epilepsy in Malaysia have yielded mixed results, with better AKA among the Chinese in urban areas and university students than those in rural areas and of Malay ethnicity [3–6]. People with epilepsy from a rural setting in Malaysia were found to have low to moderate levels of AKA [7]. Even less is known about the levels of AKA among parents of CWE in Malaysia, with only a small study on parental knowledge performed twenty years ago [8]. People with epilepsy who possess good AKA about their condition reported significantly better quality

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* Corresponding author at: Division of Paediatric Neurology, Department of Paediatrics, Faculty of Medicine, University of Malaya, 50603 Kuala Lumpur, Malaysia.
E-mail address: cyfong@ummc.edu.my (C.Y. Fong).

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of life (QOL) compared with those with poor AKA levels [7]. Similarly, better knowledge and attitude about epilepsy among CWE and their parents have been found to be associated with less perceived stigmatization and social isolation [9].

Hence, epilepsy education programs for parents of CWE represent an important component of epilepsy healthcare as they can provide medically accurate information and address some of the misperceptions of people living with epilepsy. A recent systematic review found some benefit of psychosocial interventions targeting parents of CWE in improving epilepsy knowledge, QOL, and psychological outcomes, although the evidence base was limited by methodological issues [10]. We previously showed that an IT-based Interactive Animated Epilepsy Education Programme (IAEEP) was effective in improving the AKA among Malaysian school teachers and secondary school students [11]. To our knowledge, to date, there have been no studies to evaluate the effectiveness of an IT-based epilepsy education program in improving the AKA and QOL among parents of CWE.

The primary objectives of this study were to i) determine the baseline level of epilepsy AKA of Malaysian parents of CWE; and ii) assess the effectiveness of IAEEP on parents AKA and whether these effects remained stable over time. The secondary objectives of this study were to i) explore potential epilepsy and parenteral characteristics that were associated with poor baseline levels of epilepsy AKA; and ii) assess the effects of IAEEP on parental mental state and their report on the child's QOL.

2. Method

2.1. Patient recruitment

This was a prospective study of all parents of CWE conducted at 2 urban tertiary hospitals, University Malaya Medical Centre (UMMC) Kuala Lumpur and Hospital Raja Permaisuri Bainun (HRPB) Ipoh, from January 2016 to June 2017. Parents of CWE aged 8–18 years old with at least 6 months' duration of epilepsy and attending mainstream education were eligible for inclusion in this study. Exclusion criteria included children with learning disability, physical impairment (motor, visual, or hearing), or any chronic diseases that could independently have an impact on QOL. The parents were given patient information sheet with verbal explanation, and written informed consent was obtained. Information about epilepsy was delivered using the IAEEP in the clinic. This study was approved by the UMMC Medical Research Ethics Committee (MREC) MREC ID: 24145-276, and the Malaysia National Medical Research Register (NMRR) NMRR-14-888-21585.

2.2. Data collection

i) Standard data proforma form was used to obtain the following:

- Clinical data including baseline demographic data and socio-demographic data (ethnicity, family income, parental occupation, parental level of educational attainment)
- Epilepsy history including seizure type and frequency, number of regular antiepileptic drugs (AEDs) the patient was on, presence of nocturnal seizures, and duration of epilepsy.

ii) AKA epilepsy questionnaire

A validated English and Malay language AKA epilepsy questionnaire was used [5]. The questionnaire has 17 items yielding three domains (awareness, knowledge, and attitude regarding epilepsy). Each response is scored from 0 to 10. The awareness domain contained 5 items with a total score ranging from 0 to 50, where 0–10 = very low, 11–20 = low, 21–30 = moderate, 31–40 = high, and 41–50 = very high. The knowledge domain contained 8 items with a total score ranging from 0 to 80, where 0–16 = very low, 17–32 = low, 33–48 = moderate, 49–65 = high, and 66–80 = very high. The attitude domain contained 4 items with a total score ranging from 0 to 40, where 0–7 = very negative, 8–15 = negative, 16–23 = indifferent, 24–31 = positive, and 32–40 = very positive. Finally, the total AKA score was generated by summation of all three domain scores to provide the general AKA level of all respondents. The total AKA score ranges from 0 to 170, where 0–33 = very poor, 34–67 = poor, 68–101 = moderate, 102–135 = good, and 136–170 = excellent.

The AKA questionnaire was completed by the same parent at three time points (TPs); the initial visit (TP1) before and immediately after provision (TP2) with IAEEP; and on the follow-up visit 4–6 months later (TP3).

iii) Health-Related Quality of Life Measurement for Children with Epilepsy (CHEQOL)-25

The parental perception of their child's health-related QOL was assessed at TP1 and TP3 using the CHEQOL-25. Health-Related Quality of Life Measurement for Children with Epilepsy-25 is the only epilepsy-specific QOL instrument that is able to measure both child's QOL and parent proxy rating. Both the Malay and Mandarin versions have been validated and showed good psychometric properties [12,13]. The use of the CHEQOL-25, authored by Dr. Gabriel Ronen et al., was made under license from McMaster University, Hamilton, Canada. The parent proxy report was used for this study, consisting of 25 items that yield 5 following subscales: interpersonal/social, present worries and concerns, intrapersonal/emotional, epilepsy secrecy, and future worries and concerns. Each item is scored on a scale of 1–4, and the sum of all items of the subscale will give its total score. These scores range from 5 to 20, with higher scores reflecting a more positive perception in that domain and indicating a better QOL. Either mother or father was accepted as proxy raters as their responses have been reported to be similar with no significant differences [14].

iv) Depression, Anxiety, and Stress Scale (DASS)-21 – Short Form

This questionnaire was administered at TP1 and TP3 to ascertain if the IAEEP had an impact on parental mental state. The DASS-21 questionnaire is a self-report scale to measure emotional distress [15] that has been validated in the Malay language [16]. There are 21 items that yield three following scales: depression, anxiety, and stress. All answers are based on a 4-point Likert scale, with higher scores indicating a more negative state of mind. Cutoff scores have been developed for defining normal, mild, moderate, severe, and extremely severe scores for each DASS-21 domain. For the depression domain, the scores were 0–4, 5–6, 7–10, 11–13, and >13 for each category; for the anxiety domain, the scores were 0–3, 4–5, 6–7, 8–9, and >9 for each category; and for the stress domain, the scores were 0–7, 8–9, 10–12, 13–16, and >16 for each category.

v) IAEEP

The IAEEP was developed and validated in July 2013 by University Sultan Zainal Abidin and Hospital Sultanah Nur Zahirah (Neurology and Paediatric departments) in Terengganu, Malaysia [17]. In September 2014, the University Malaya Paediatric Neurology division further revised and improved the contents of IAEEP. The revised version was used among Malaysian teachers, secondary school students, parents of CWE, and CWE and shown to be easily understandable with a high positive feedback [11,18]. The IAEEP can be installed with Windows software on laptops & tablets. It covers 10 topics of epilepsy (what is epilepsy, safety tips, medication, school life, dealing with epilepsy, first aid, teenage years, sudden unexpected death in epilepsy (SUDEP), and leading a healthy life) and takes about 20 min to complete. Feedback about the IAEEP was obtained through a series of questions of whether they liked the program, thought the program was beneficial, attracted their interest, simple and easy to understand, if they would like to keep a copy of the video, and if they would recommend it to others by using a "yes" or "no" response.

2.3. Statistical analysis

Statistical analyses were performed using Statistical Package for Social Sciences (SPSS) for Windows version v22.0 (SPSS Inc., Chicago, IL, U.S.A.). Kolmogorov–Smirnov test was used to determine normality of the data. Descriptive statistics were reported as frequencies, percentages, median, and interquartile range (IQR). As the CHEQOL scores were normally distributed data, a parametric paired sample *t*-test was used to determine the score differences between TP1 and TP3. As the AKA data were not normally distributed data, a nonparametric Wilcoxon Signed Rank Test was used for differences in AKA scores between the three TPs, and the McNemar test was used to assess the change in the distribution of the AKA correct responses compared with incorrect and not sure responses of each question between pre- and post-IAEEP. The McNemar test was also used to assess the differences in DASS-21 categories between TP1 and TP3. A P-value of <0.05 was considered statistically significant.

Based on a previous Malaysian AKA study of adults with epilepsy where the awareness score was 18 and our objective was to potentially increase the score to another category by a score increment of 10 points, a sample size of 77 (beta: 20%, alpha: 5%) was needed [7].

3. Results

3.1. Patient characteristics

Seventy-eight participants completed our study, of which 49 were recruited from HRPB Ipoh and 29 were recruited from UMMC Kuala Lumpur. Participant characteristics are shown in Table 1. Two-thirds of the respondents were mothers. The majority of CWE were male (61.5%), more than 10 years old (71.8%), and their parental education levels were at least secondary or tertiary level (69.2%). Only two (2.6%) were from single parent families. Most (73.1%) of the CWE had low seizure frequency (≤4 seizures/year) or were seizure-free, with 78% being either on monotherapy AED or not on any AED. None of the CWE had experienced status epilepticus in the previous 6 months.

3.2. AKA scores and responses

At recruitment (TP1), the baseline pretest AKA domain scores showed that majority of parents of CWE had good to excellent total AKA score (67.9%), high to very knowledge domain (82.1%), and positive to very positive attitude domain (85.9%). In contrast, a lower proportion of parents (35.9%) had high to very high awareness domain. In the univariate analysis shown in Table 1, there was no significant association between the attitude, knowledge, awareness and total AKA categories with the participant characteristics and epilepsy variables.

Table 1
Parental characteristics and seizure-related factors associated with awareness, knowledge, attitude, and total AKA scores (N = 78).

	Participant	Awareness		P-value	Knowledge		P-value	Attitude		P-value	Total AKA score		P-value
		Very low to moderate	High to very high		Very low to moderate	High to very high		Very negative to indifferent	Positive to very positive		Very poor to moderate	Good to excellent	
Gender of child													
Male	48 (61.5%)	33	15	0.279	6	42	0.113	7	41	0.877	14	34	0.493
Female	30 (38.5%)	17	13		8	22		4	26		11	19	
Age (years)													
<10	22 (28.2%)	14	8	0.957	3	19	0.534	5	17	0.170	7	15	0.978
≥10	56 (71.8%)	36	20		11	45		6	50		18	38	
Ethnicity													
Malay	29 (37.2%)	16	13	0.206	5	24	0.900	3	26	0.463	10	19	0.723
Non-Malay	49 (62.8%)	34	15		9	60		8	41		15	34	
Household income													
≤RM 4000	54 (69.2%)	35	19	0.844	10	44	0.844	8	46	0.786	19	35	0.374
>RM 4000	24 (30.8%)	15	9		4	20		3	21		6	18	
Parental education level													
Primary	24 (30.8%)	17	7	0.707	1	23	0.095	3	21	0.289	5	19	0.220
Secondary	39 (50.0%)	24	15		10	29		4	35		16	23	
Tertiary	15 (19.2%)	9	6		3	12		4	11		4	11	
Seizure type													
Generalized	55 (70.5%)	39	16	0.053	7	48	0.063	7	48	0.063	16	39	0.386
Focal	23 (29.5%)	11	12		7	16		4	19		9	14	
Number of AEDs													
0	24 (31%)	18	6	0.348	3	21	0.648	5	19	0.338	7	17	0.320
1	37 (47%)	21	16		7	30		3	34		10	27	
>1	17 (22%)	11	6		4	17		3	14		8	9	
Epilepsy duration (years)													
≤5	38 (48.7%)	26	12	0.438	8	30	0.486	6	32	0.677	14	24	0.377
>5	40 (51.3%)	24	16		6	34		5	35		11	29	
Seizure frequency													
Monthly or more	21 (26.9%)	14	7	0.774	5	16	0.413	4	17	0.446	9	12	0.215
1–4/year or seizure-free	57 (73.1%)	36	21		9	48		7	50		16	41	
Nocturnal seizures													
Yes	18 (23.1%)	10	8	0.389	3	15	0.872	3	46	0.786	5	13	0.658
No	60 (76.9%)	40	20		11	49		8	21		20	40	

Table 2
Scores and categories of awareness, knowledge, attitude, and total AKA scores at 3 time points (n = 78).

Scale scores and categories	Time point 1	Time point 2	Time point 3	P-value
Awareness				
Median score (IQR)	30.0 (30–40)	50.0 (40–50)	50.0 (40–50)	<0.001
Median score category interpretation	Moderate	Very high	Very high	
Very low to moderate	43 (55.1%)	9 (11.6%)	10 (12.8%)	
High to very high	35 (44.9%)	69 (88.4%)	68 (87.2%)	<0.01
Knowledge				
Median score (IQR)	60.0 (50–70)	80.0 (60–80)	80.0 (60–80)	<0.001
Median score category interpretation	High	Very high	Very high	
Very low to moderate	14 (17.9%)	5 (6.4%)	9 (11.5%)	0.017
High to very high	64 (82.1%)	73 (93.6%)	69 (88.5%)	
Attitude				
Median score (IQR)	40.0 (30–40)	40.0 (40–40)	40.0 (40–40)	<0.001
Median score category interpretation	Very positive	Very positive	Very positive	
Very negative to indifferent	11 (14.1%)	4 (5.1%)	6 (7.7%)	0.039
Positive to very positive	67 (85.9%)	74 (94.9%)	72 (92.3%)	
Total AKA				
Median score (IQR)	130.0 (110–140)	160.0 (140–170)	160.0 (138–170)	<0.001
Median score category interpretation	Good	Excellent	Excellent	
Very poor to moderate	18 (23.1%)	9 (11.5%)	12 (15.5%)	0.05
Good to excellent	60 (76.9%)	69 (88.5%)	66 (84.5%)	

Significant P-value ($P < 0.05$).

Following provision of IAEEP, there was a statistical significant increase in number of parents of CWE who reported high to very high awareness domain (88.4%), high to very high knowledge domain (93.6%), and positive to very positive attitude domain (94.9%) from TP1 to TP2, and this increase in AKA remained significant at TP3 (Table 2). Similarly, post-IAEEP, there was a significant rise in median scores in all domains of the AKA questionnaire ($P < 0.001$) as shown in Table 2. An increment of 2 category levels were seen in the awareness domain, and an increment of 1 category level was seen in the knowledge and total AKA score domains both at TP2 and TP3.

Table 3 shows the individual parent responses to the AKA domain questions in our study in the 3 TPs. In the awareness domain, at TP1, despite having a child with epilepsy, only 64.1% of parents with CWE had read about epilepsy, and the percentage increased to 97.4% and 100% at TP2 and TP3, respectively. Only 5 (6.4%) had ever attended a talk or course about epilepsy, but the proportion had increased to 56 (71.8%) and 55 (70.5%) at TP2 and TP3, respectively. In the knowledge domain, there was an increase in participants who knew the causes of epilepsy rising from baseline 33.3% (TP1) to 80.8% (TP2) and 76.9% (TP3). There was also an increase in participants who reported that they knew how to perform first aid emergency measures in the event of a seizure, rising from baseline 67.9% (TP1) to 85.9% (TP2) and 88.5% (TP3). In the attitude domain, there was an increase in participants who thought that patients with epilepsy can drive rising from baseline 65.4% (TP1) to 80.8% (TP2) and 82.1% (TP3). Questions that drew consistently positive responses over the 3 TPs were whether

Table 3
Awareness, knowledge, attitude epilepsy questionnaire responses at the 3 time points (N = 78).

Questions	Correct response	Time point 1		Time point 2		P-value Time point 1 versus time point 2	Time point 3		P-value Time point 1 versus time point 3
		Correct response (%)	Incorrect response or not sure (%)	Correct response (%)	Incorrect response or not sure (%)		Correct response (%)	Incorrect response or not sure (%)	
Awareness									
Have you heard or read anything about epilepsy?	Yes	50 (64.1)	28 (35.9)	76 (97.4)	2 (2.6)	<0.001*	78 (100)	0 (0)	<0.001*
Have you attended any seminar or lecture about epilepsy?	Yes	5 (6.4)	73 (93.6)	56 (71.8)	22 (28.2)	<0.001*	55 (70.5)	23 (29.5)	<0.001*
Have you seen anyone having an epilepsy attack?	Yes	71 (91.0)	7 (9.0)	77 (98.7)	1 (1.3)	0.014*	75 (96.2)	3 (3.8)	0.102
Have you given any emergency help for epilepsy?	Yes	57 (73.1)	21 (26.9)	60 (76.9)	18 (23.1)	0.366	57 (73.1)	21 (26.9)	1.000
Does any of your family member has epilepsy?	Yes	58 (74.4)	20 (25.6)	64 (82.1)	14 (17.9)	0.014*	63 (80.3)	15 (19.2)	0.132
Knowledge									
Do you know what causes epilepsy?	Yes	26 (33.3)	52 (66.7)	63 (80.8)	15 (19.2)	<0.001*	60 (76.9)	18 (23.1)	<0.001*
Do you think epilepsy is infectious?	No	71 (91)	7 (9.0)	72 (92.3)	6 (7.7)	0.655	71 (91)	7 (7)	1.000
Do you think epilepsy is an inherited disease?	No	32 (41.0)	46 (59.0)	55 (70.5)	23 (29.5)	0.336	55 (70.5)	23 (29.5)	0.314
Do you think epilepsy is a mental disease?	No	63 (80.8)	15 (19.2)	71 (91.0)	7 (9.0)	0.083	70 (89.7)	8 (10.3)	0.467
Do you think epilepsy is caused by evil spirits?	No	71 (91.0)	7 (9.0)	70 (89.7)	8 (10.3)	0.180	75 (96.2)	3 (3.9)	0.206
Do you think epilepsy can cause death?	Yes	57 (73.1)	21 (26.9)	68 (87.2)	10 (12.8)	0.003*	65 (83.3)	13 (16.7)	0.248
Do you think epilepsy is curable?	Yes	69 (88.5)	9 (11.5)	75 (96.2)	3 (3.8)	0.015	72 (92.3)	6 (7.7)	0.574
Do you know how to perform an emergency help for epilepsy?	Yes	53 (67.9)	25 (32.1)	67 (85.9)	11 (14.1)	0.004*	69 (88.5)	9 (11.5)	0.026*
Attitude									
Do you think that patient with epilepsy can participate in sporting activities?	Yes	68 (87.2)	10 (12.8)	74 (94.9)	4 (5.1)	0.030*	70 (89.7)	8 (10.2)	0.771
Do you think patient with epilepsy can drive?	Yes	51 (65.4)	27 (34.6)	63 (80.8)	15 (19.2)	0.001*	64 (82.1)	14 (17.9)	0.004*
Do you think patient with epilepsy can get married and have family?	Yes	73 (93.6)	5 (6.4)	76 (97.4)	2 (2.6)	0.102	76 (97.4)	2 (2.6)	0.258
Do you think patient with epilepsy can socialize with the community?	Yes	78 (100)	0 (0)	78 (100)	0 (0)	1.000	77 (98.7)	1 (1.3)	0.317

* Significant P-value ($P < 0.05$).

Table 4
Scores of CHEQOL-25 and DASS-21 time points 1 and 3 (n = 78).

Questionnaire domains and scores	Time point 1	Time point 3	P-value
CHEQOL-25 parent proxy report			
Interpersonal/social			
Mean score (SD)	15.82 (3.02)	16.62 (2.99)	0.020*
Present worries			
Mean score (SD)	11.95 (2.38)	11.78 (2.26)	0.519
Future worries/concern			
Mean score (SD)	12.88 (2.67)	13.12 (2.84)	0.435
Intrapersonal/emotional			
Mean score (SD)	13.74 (2.72)	14.03 (3.12)	0.414
Secrecy			
Mean score (SD)	13.77 (2.12)	14.33 (2.13)	0.039*
Total score			
Mean score (SD)	68.17 (8.32)	69.87 (9.20)	0.071
DASS-21 scores			
Depression			
Median score (IQR)	0 (0–3)	0 (0–3)	0.368
Anxiety			
Median score (IQR)	0.5 (0–3)	0 (0–3)	0.458
Stress			
Median score (IQR)	1 (0–5)	0.5 (0–4.25)	0.315

* Significant P-value (P < 0.05).

they thought if i) epilepsy was curable (89%–92%), ii) patients with epilepsy could get married and have children (93%–98%), ii) patients can socialize in the community (99%–100%), and iv) patients can participate in sports (87%–95%). Very few of the parents thought epilepsy was infectious or caused by evil spirits, and this was consistent over the 3 TPs (all less than 10%).

3.3. CHEQOL and DASS-21 scores

Tables 4 and 5 show the CHEQOL and DASS-21 scores with its categories at the various TPs. There was a statistically significant increase in CHEQOL scores for the personal social and the epilepsy secrecy domains from TP1 to TP3 as shown in Table 4. For the DASS-21, there were no significant changes in depression, anxiety, or stress categories or median scores between TP1 and TP3 following IAEEP provision. None of the participants who were categorized as severely or extremely severe in any of the three domains of the DASS-21 attributed their high DASS-21 scores to their child's epilepsy. None requested for additional psychological intervention, and all of them agreed to continue with the participation of our study at TP3. All participants indicated a positive feedback on the IAEEP.

4. Discussion

Our study highlights that the majority of parents of CWE had high to very high knowledge (82.1%) and positive to very positive attitude (85.9%), while a lower proportion (35.9%) had high to very high awareness on epilepsy. This was also reflected in the median scores, where the median score for the awareness domain fell into the moderate category while the score for the knowledge domain was in the high category and that for the attitude domain in the positive category. By providing the IAEEP, we showed that it was effective in improving the baseline AKA among parents of CWE, with significant improvements in their AKA categorical scores and the positive effects remained stable 4–6 months following IAEEP provision. Following IAEEP provision, we also showed an effect in the CHEQOL parent proxy scores with higher scores seen in the interpersonal/social and secrecy subscale.

Table 5
Levels of emotional distress based on DASS-21 categories (n = 78).

	Time point 1	Time point 3	P-value
Depression			
Normal to moderate	76 (97.4%)	78 (100.0%)	0.157
Severe to extremely severe	2 (2.6%)	0 (0.0%)	
Anxiety			
Normal to moderate	74 (94.9%)	74 (94.9%)	1.00
Severe to extremely severe	4 (5.1%)	4 (5.1%)	
Stress			
Normal to moderate	77 (98.7%)	78 (100%)	0.317
Severe to extremely severe	1 (1.3%)	0 (0.0%)	

Our overall high to very high knowledge domain scores are in contrast to other Malaysian studies. Studies using the same AKA questionnaire reported lower knowledge domain scores in the low to moderate range among adult patients with epilepsy in a Malaysian rural setting and among school teachers in a Malaysian urban setting [7,11]. Another Malaysian study on parents of CWE, performed twenty years ago in the same urban setting at UMMC but using a different questionnaire, reported large gaps of knowledge; this could have been due to the lower educational level and socioeconomic status of the study population [8]. Elsewhere, studies on parental knowledge of epilepsy showed heterogenous results across different populations and time periods, with some reporting poor knowledge [19–21] and others reporting high levels of knowledge comparable to ours [9,22–25]. Direct comparison is difficult because of the heterogeneity of the questionnaires used, study population (age range, comorbidities, and epilepsy severity), and healthcare systems. While some studies found an association between parental knowledge and educational level [9,22–26], our study and others [8,21] did not.

A large proportion (86%) of our parents had positive attitudes towards their child's epilepsy, with 99% agreeing that CWE can socialize in the community and 87% agreeing that their children can participate in sports. While some studies [22,25] reported that parents of CWE would disclose their child's condition to the community and believe CWE can participate in social activities, there were other studies where a sizeable proportion of parents of CWE (27–62%) who believed that their children should not participate in sports [9,20,21,24]. There were also disparities between our study and others for attitudes concerning the child's future. While 93% of our parents of CWE believe that people with epilepsy can get married and have children, only 35–47% of parents in other studies believed so [9,23]. Studies have highlighted parental concern and attitudes in the area of educational and career opportunities [9,20,22–24] even among CWE without comorbidities [9,22]. In a systematic review on attitudes towards epilepsy, published papers from Asia and Africa reported more respondents with negative attitudes towards epilepsy compared with those from North America or Australia [1]. A local study showed that only 64.3% of people with epilepsy had a high employability, and that important factors affecting employability included education level, type of epilepsy, self-motivation, and family overprotection [27]. Using education programs like the IAEEP to enhance positive attitudes among parents of CWE may potentially allow these children to transition to adulthood with better opportunities in education, employment, and social engagement.

We had expected a high level of awareness of epilepsy in our participants as CWE in our study must have been diagnosed as having epilepsy for more than six months. The lower than expected awareness scores with 35.9% of our parents have high to very high awareness scores may in part be due to the nature of questions asked; only a small proportion of parents answered “yes” when asked if they had read (37.9%) or attended talks (6.4%) on epilepsy. This provides some insight into the information seeking behavior of our population, suggesting that traditional reading media is not a popular medium for parents to actively seek out information about epilepsy. A study from Jordan noted that half of the parents used the internet as their source of information about epilepsy, but the majority still preferred future education to be provided by the treating physician [24]. Other studies reported that the attending neurologist was the main source of information (more than 85%), while only 10–15% obtained information through the internet [21,22]. In a previous Malaysian study on SUDEP, only a third of parents had independently sourced for SUDEP information from the internet, and the majority (more than 95%) felt that the most appropriate way to provide information was via a leaflet/internet/computer program combined with a face-to-face discussion with a health professional [18].

Exposure to the IAEEP during a scheduled clinic visit improved the immediate post recall AKA among parents of CWE. The positive effects were stable 4–6 months following provision of the IAEEP, with the greatest effect seen in the awareness domain with a categorical rise by 2 categories, followed by the knowledge domain and total AKA score domain with a categorical rise by 1 category. The IAEEP had the least effect on the attitude domain. This is explained by the fact that our study population already had a high baseline attitude scores with a large proportion (more than 85%) in the positive attitude category prior to IAEEP provision. Our study shows that the IAEEP is an effective education program among parents of CWE in raising the AKA particularly in the awareness and knowledge domain of parents of CWE. There are other studies that have demonstrated improved and sustained epilepsy knowledge following intervention programs, but different psychoeducational modules and outcome measures were employed [26,28,29]. Given the fact that the Malaysian public has low to moderate AKA for epilepsy [7,11], it would be interesting to see if the IAEEP will have a bigger impact on parents of children with new onset epilepsy.

None of our participants reported any increased feelings of depression, anxiety, and stress attributed to the IAEEP provision which indicated that our epilepsy education had no significant adverse effect on the parental mental state. Our findings also indicated that the IAEEP had a potential empowering effect on the parental reported QOL with a significant increase in CHEQOL-25 scores between TP1 and TP3 that were seen in two parent proxy domains of interpersonal/social and epilepsy secrecy suggesting that improving parental AKA had a positive impact on these domains. A large study using a modular service package for parents of CWE in Germany and Austria reported decreased epilepsy related fears and improved speaking about epilepsy with their affected child [28]. Another study in Germany, using a different psychoeducational program, demonstrated that parents of the intervention group reported improved self-management and communication skills of their child [26]. Two smaller studies, using different intervention modalities, also demonstrated improvement in parent proxy reports of prosocial behavior [30] and QOL [29]. These studies support our findings that an educational program may improve parental perception of the child's social behavior and encourage disclosure of their child's condition.

As with previous Malaysian IAEEP studies, all parents in this study provided positive feedback and found the IAEEP acceptable and useful [11,18]. This reaffirms that the IAEEP is a potential invaluable educational tool to improve the AKA among parents of CWE. The IAEEP could particularly be useful in providing epilepsy education in a busy clinic setting, where there are constraints in time and human resources as the program is simple, relatively quick to complete yet still having a high educational content. However, it was not within the scope of this study to demonstrate that the positive effects in AKA would translate into improved seizure management.

There are several limitations in our study. Given the relatively small numbers of parents with poor AKA, the sample size in this study may have been insufficient to find an association between epilepsy and parental characteristics with poor AKA. The study group was from two urban tertiary hospitals and comprised school-aged children without comorbidities, hence, the results may not be generalized to the entire Malaysian epilepsy population. Our study did not explore the child's perspective, partly because the AKA questionnaire has not been validated for use in children. Potential confounding factors, such as changes in seizure frequency and AED intake over time, were not considered when analyzing pre- and posttest scores. Although the IAEEP was demonstrated to have improved AKA scores, other relevant outcome measures such as parental coping and seizure management were not studied. There are also pitfalls in relying on parent proxy reports alone as a measure of the child's QOL as we have previously shown poor to moderate agreement between CWE and their parents on the CHEQOL-25 [31].

5. Conclusion

The IAEEP is an effective IT-based epilepsy educational tool to increase the levels of AKA among Malaysian parents of CWE. Following the use of the IAEEP, parents of CWE also reported an improvement of their child's QOL in the CHEQOL-25 parent proxy interpersonal/social and epilepsy secrecy domains.

Disclosure of conflicts of interests

The authors have no conflict of interest to disclose. We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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