IMPROVING AWARENESS, KNOWLEDGE AND AWARENESS WITH EPILEPSY EDUCATIONAL PROGRAMME FOR MALAYSIAN PARENTS OF CHILDREN WITH EPILEPSY.

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Field of Study: PAEDIATIRCS

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ABSTRACT

Introduction: Good awareness, knowledge and attitudes of parents of children with Epilepsy (CWE) is important in enabling CWE to lead a normal life with epilepsy. The Interactive Animated Epilepsy Education Programme (IAEEP) is a potential effective epilepsy educational tool that can help improve awareness, knowledge, attitude (AKA) of parents of CWE.

Primary Objectives:

i) To assess the baseline level of epilepsy AKA of Malaysian parents of children with epilepsy (CWE).

ii) To assess the effectiveness of Interactive Animated Epilepsy Education Programme (IAEEP) on improving parents AKA, and whether these effects remained stable over time.

Secondary Objectives:

i) To evaluate epilepsy and parenteral characteristics that are associated with baseline level of epilepsy AKA in parents of CWE.

ii) To assess the effects of IAEEP on parent and child epilepsy Health-related quality of life. (HRQoL)

Methodology: Prospective interventional study of all parents of CWE aged 8-18 years old with at least 6 months' duration of epilepsy, minimum reading level of primary school education Year 1 and attending mainstream education. Information of epilepsy was delivered to child and parents of CWE using IAEEP. Parents completed an AKA questionnaire before (TP 1), immediately after (TP 2) and retested 3-6 months (TP 3) after the epilepsy information provision. Parents and CWE completed parent-proxy and child self- report of Health-Related Quality of Life Measurement for Children with Epilepsy (CHEQOL-25) questionnaire at TP1 and TP3.

Results: A total of 78 participants (both parent and children) participated in the study. After IAEEP intervention, there was a significant increment from TP1 of total parental AKA, awareness, knowledge and attitude score in both TP2 and TP3 (p value <0.001). None of the epilepsy or parental characteristics affected the baseline parental AKA levels. CHEQOL for parents between TP1 and TP3, showed significant increments in interpersonal/social and secrecy subscale scores. CHEQOL for CWE between TP1 and TP3 showed significant increment in interpersonal/social and significant decrement in present worries subscale scores. At TP3, high parental total AKA scores were associated with higher CHEQOL scores for children, [p <0.001 and rs =+0.425(moderate correlation)].

Conclusion: Clinicians should use the IAEEP as part of the care of Malaysian CWE as IAEEP is an effective IT- based epilepsy educational tool to raise the level AKA among parents with CWE. After IAEEP intervention there was an improvement in both parents and child CHEQOL interpersonal/ social subscale and parent CHEQOL secrecy subscale scores. Our study also showed a positive correlation between parent's AKA and child's total CHEQOL scores. Children who receive the IAEEP showed an increase in level of worry, highlighting that CWE should receive ongoing support as they undergo a period of adjustment when dealing with the information provided.

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Lastly, this thesis owes its existence to the inspiration from my wife, Dr Chow Rhuen Chiou and my family for being my pillar of strength through all the trying times during my journey as a Paediatrician.

Dr. Seet Yee Hong

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF SYMBOLS AND ABBREVIATIONS

For examples:

CWE : Children with epilepsy

PWE : People with epilepsy

CHEQOL : Health Related Quality of Life Measure for Children with Epilepsy

UMMC : University of Malaya Medical Centre

HRPB : Hospital Raja Permaisuri Bainun

AKA : Awareness, Knowledge and Attitude

IAEEP : Interactive Animated Epilepsy Education Programme

DASS : Depression Anxiety Stress Scales

TP 1 : Time Point 1

TP 2 : Time Point 2

TP 3 : Time Point 3

P : p-value

SPSS : Statistical Package for the Social Sciences

LIST OF APPENDICES

CHAPTER 1: INTRODUCTION

Epilepsy is the most common childhood neurological disorder. Children with epilepsy (CWE) are at greater risk of having emotional and behavioral problems, increased dependence on parents and reduced quality of life. [1-4] 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." [5] 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. [6]

Despite epilepsy being one of the most prevalent neurological pathologies, it is still surrounded by stigma and prejudice among the general population. [7] To improve the quality of life (QoL) of CWE, to enhance their level of acceptance into society, as well as to reduce he public's stigmatization, it is necessary that the general population has a high AKA of pilepsy. [8] Identifying the misconceptions on epilepsy and improving the awareness, nowledge and attitude (AKA) among the public including parents of CWE are useful steps n decreasing stigmatization and improving QoL among CWE. [5,8 9]

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Often CWE are at a greater risk of having emotional and behavioral problems, increased their dependence on their parents or caretakers and thus lower quality of life. [1-4] Health education programmes have been developed to provide information to families with chronic conditions such as asthma and diabetes mellitus. [10, 11] Within the last five years, one of digital tools that has become the choice of educational institutions to help students learn is the tablet computer. The reason for this popularity within a short period of time lies on its ability to capture the intuitive nature of people of all ages. [12]

In Malaysia, among the general public there is a lack of awareness and limited knowledge, accompanied by false beliefs and negative attitudes toward epilepsy. [5,8] At present to our knowledge there are no published studies on AKA among parents of CWE and there have been no studies to evaluate if an epilepsy educational programme can improve AKA and HRQoL among parents of CWE.

CHAPTER 2: LITERATURE REVIEW

2.1 Epilepsy and stigmatization

Epilepsy is one of the oldest known brain disorders [13], characterized by recurrent seizures, as a result of sudden excessive electrical discharges in the brain cells. World Health Organization (WHO) defines it as those who have recurring seizures, at least two unprovoked ones. [5] Despite it being one of the oldest and prevalent neurological pathologies, it still surrounded by stigma and prejudice among the general population. [7] Despite, the causes of stigmatization in epilepsy are complex, lack of knowledge about the disease is said to be an important factor in the negative attitudes towards people with epilepsy. [14]

Fisher and colleagues assessed the perceptions and subjective experiences in 1999, showing that nearly a quarter (24%) of 1000 PWE reported element of social stigma in their lives as a result of the disease they had. [15] Another community based survey involving 165 PWE, revealed 42% felt that the general public harbored negative feeling towards PWE and 41% felt that this belief negatively affected them. [16]

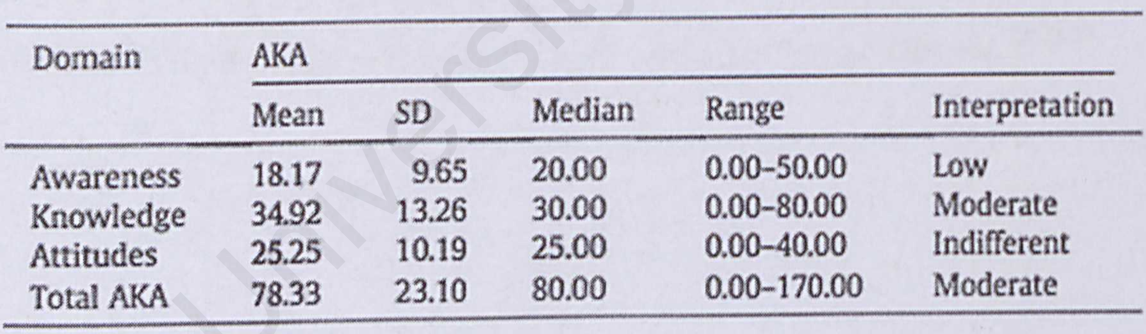
Study on public awareness, knowledge and attitude (AKA) towards epilepsy is useful in decreasing discrimination and stigmatization. [5] By identifying the misunderstandings and misconceptions on epilepsy among the public including parents of CWE, only then can steps be taken to help educate and improve the AKA among the public.

2.2 Awareness, knowledge and attitude of Epilepsy studies in Malaysia

Malaysia like other countries also share the genuine lack of awareness and knowledge, accompanied by false beliefs and negative attitudes towards epilepsy. This is evident in a study done in the East Coast of Peninsular Malaysia, which reported that the levels of epilepsy awareness, knowledge and attitude among rural population was low. [5] To date, there were only two studies on epilepsy awareness, knowledge and attitude in Malaysia, one in Kelantan [5] and the other in Terengganu [8].

Generally, AKA levels in the study population of Terengganu were moderate. Of the domains, Awareness was rated the poorest, Knowledge was moderate and Attitude was indifferent.

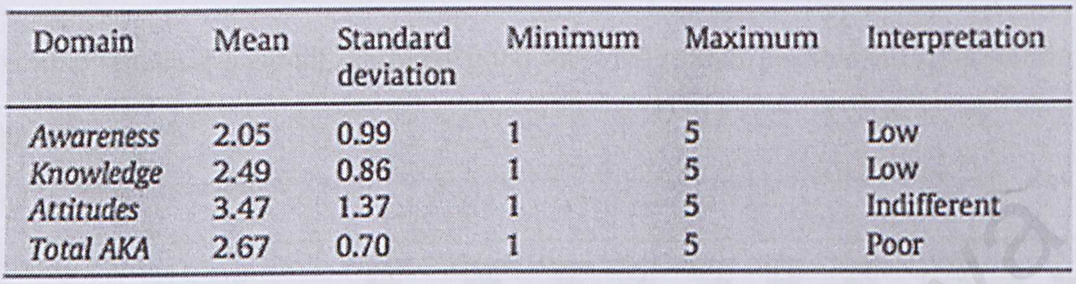
Table 2.1: Awareness, Knowledge, Attitude and AKA scores and interpretation of scores in Terengganu study.



Domain	AKA				
	Mean	SD	Median	Range	Interpretation
Awareness	18.17	9.65	20.00	0.00–50.00	Low
Knowledge	34.92	13.26	30.00	0.00–80.00	Moderate
Attitudes	25.25	10.19	25.00	0.00–40.00	Indifferent
Total AKA	78.33	23.10	80.00	0.00–170.00	Moderate

The study in Kelantan in 2010, revealed AKA level of rural communities in Kelantan was in poor category. Among the tree domains, Attitudes was had the highest mean, followed by Knowledge and lastly Awareness. Based on the mean scores, the Kelantan study population showed low level of awareness and knowledge and sowed in different attitude towards epilepsy.

Table 2.2: Awareness, Knowledge, Attitude scores and interpretation of scores in Kelantan study.

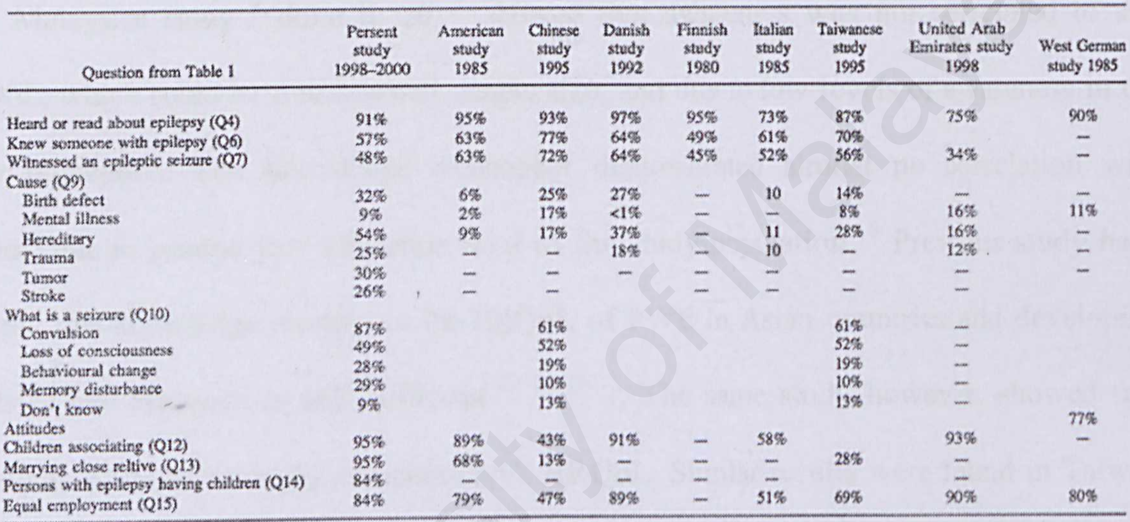


Domain	Mean	Standard deviation	Minimum	Maximum	Interpretation
Awareness	2.05	0.99	1	5	Low
Knowledge	2.49	0.86	1	5	Low
Attitudes	3.47	1.37	1	5	Indifferent
Total AKA	2.67	0.70	1	5	Poor

Comparing both studies, study population in Terengganu [8] were relatively better than the study population in Kelantan [5]. Studies have showed that not only the general public [17-19] had lack of knowledge or negative attitude, specific subgroups like employers [20], students [21], family members [22] and even health care providers [23] themselves demonstrate similar findings. Negative attitude may be resulted as a result of lack of awareness, whereas incorrect knowledge is commonly reported in many Asian countries including Malaysia. [24 25-27]

2.3 Awareness, knowledge and attitude of Epilepsy studies done globally

When we compare Malaysian study population on Epilepsy AKA levels, globally AKA levels were generally reported to be higher except for a study done in Laos in 2007. A study done in Bandung involving general public, showed a high awareness about epilepsy, with 97% of 959 subjects heard about epilepsy. [28] In Iran, a study conducted among mothers with CWE in a teaching hospital, showed good knowledge and positive attitude among Iranian mothers. [9]



Question from Table 1	Persent study 1998–2000	American study 1985	Chinese study 1995	Danish study 1992	Finnish study 1980	Italian study 1985	Taiwanese study 1995	United Arab Emirates study 1998	West German study 1985
Heard or read about epilepsy (Q4)	91%	95%	93%	97%	95%	73%	87%	75%	90%
Knew someone with epilepsy (Q6)	57%	63%	77%	64%	49%	61%	70%		—
Witnessed an epileptic seizure (Q7)	48%	63%	72%	64%	45%	52%	56%	34%	—
Cause (Q9)									
Birth defect	32%	6%	25%	27%	—	10	14%	—	—
Mental illness	9%	2%	17%	<1%	—	—	8%	16%	11%
Hereditary	54%	9%	17%	37%	—	11	28%	16%	—
Trauma	25%	—	—	18%	—	10	—	12%	—
Tumor	30%	—	—	—	—	—	—	—	—
Stroke	26%	—	—		—	—	—	—	
What is a seizure (Q10)									
Convulsion	87%		61%				61%	—	
Loss of consciousness	49%		52%				52%	—	
Behavioural change	28%		19%				19%	—	
Memory disturbance	29%		10%				10%	—	
Don't know	9%		13%				13%	—	
Attitudes									77%
Children associating (Q12)	95%	89%	43%	91%	—	58%		93%	—
Marrying close reltive (Q13)	95%	68%	13%	—	—	—	28%	—	
Persons with epilepsy having children (Q14)	84%	—	—	—	—	—		—	
Equal employment (Q15)	84%	79%	47%	89%	—	51%	69%	90%	80%

Studies: Chinese and Taiwan: M-Y Chung et al., 1995; Italy, West Germany, and USA: Canger and Cornaggia, 1985; U.S.A.: Caveness and Gallup, 1980; Finland: Iivanainen et al., 1980; Denmark: Jensen and Dam, 1992; Australia: Vinson, 1975.

Table 2.3: G. Bryan study comparing with other countries

Based on G. Bryan study 1998-2000, and comparing with other studies in the world, subjects who heard or read about epilepsy range 73% to 97%. Percentage of subjects who witnessed an epileptic seizure range from 34% to 72%. Globally, study population believed in equal employment, percentages ranged 47% to 90%.

Till date, there was a study in Laos done in 2007, indicate that epilepsy knowledge was generally low in Laos population as they had misbeliefs. [6]

2.4 Quality of life of PWE and its association with A, K, A levels

Most often, HRQoL of a PWE is determined mainly by the duration of disease and extend of epilepsy control, it is also affected by non-epileptic parameters like social factors such as social anxiety, employment and stigma. [20 29] Hence to improve HRQoL of PWE, to enhance their level of acceptance into society and reduce stigmatization, it is essential that the general population to improve their awareness, knowledge and also understanding of the impact of epilepsy on HRQoL and inculcate more positive attitude towards PWE. [8]

A Malaysian study [8] done in 2011, showed that awareness was not correlated to any HRQoL, which could be due to small sample size, and due to low levels of awareness in the study population. The knowledge component demonstrated almost no correlation with HRQoL due to general low education level of the study population. [8] Previous study have reported that knowledge relating to the HRQoL of PWE in Asian countries and developing countries like Malaysia is still sufficient [30 24 26] . The same study however, showed that attitude domain was strongly associated with HRQoL. Similar results were found in Taiwan [24]and Turkey [31]. With improved attitude and minimized stigma, PWE would eventually experience better HRQoL. [8]

2.5 IAEEP as an educational tool

Just like epilepsy, other chronic illnesses affect children, such as bronchial asthma and diabetes mellitus. Studies have shown that education programme with regards to the respective disease, helped in providing information to children.

A recent study done in Malaysia on Interactive Animated Epilepsy Education Programme (IAEEP) as an educational tool for CWE. The study showed that it is highly feasible, practical and acceptable among CWE and parents. It is believed that with continuous improvement and modification in keeping with ongoing CWE's needs, it is very likely that this newly-developed education programme could offer an alternate and effective solution to improve awareness, knowledge and cultivate more positive attitudes and hence improving their well-being. [32]

CHAPTER 3: OBJECTIVES

Primary Objectives:

i) To assess the baseline level of epilepsy awareness, knowledge and attitude (AKA) of Malaysian parents of children with epilepsy (CWE).

ii) To assess the effectiveness of Interactive Animated Epilepsy Education Programme (IAEEP) on parents AKA, and whether these effects remained stable over time.

Secondary Objectives:

i) To evaluate possible epilepsy and parenteral characteristics that are associated with baseline level of epilepsy AKA in parents of CWE.

ii) To assess the effects of IAEEP on parent and child epilepsy Health-related quality of life. (HRQoL)

CHAPTER 4: METHODOLOGY

4.1 Patient recruitment

This was a prospective interventional study of all parents of CWE aged 8-18 years old with at least 6 months' duration of epilepsy, minimum reading level of primary school education Year 1 and attending mainstream education. Information of epilepsy was delivered to child and parents of CWE using IAEEP. Parents completed an AKA questionnaire before (TP 1), immediately after (TP 2) and retested 3-6 months (TP 3) after the epilepsy information provision. This study was conducted at 2 tertiary hospitals: Hospital Raja Permaisuri Bainun (HRPB), Ipoh and University Malaya Medical Centre (UMMC) Kuala Lumpur. The parents of the patient were approached and given patient information sheet with verbal explanation. Informed written consent was obtained. A total of 78 subjects were recruited; 29 from UMMC Kuala Lumpur from September 2014 to June 2015 and 49 subjects were from HRPB-Ipoh from June 2015 till March 2017. We analyzed each recruitment centers and together they yielded no significant differences. This study was approved by University Malaya Medical Centre ethic committee (MREC (8) dlm. KKM/NIHSEC/ P14-506) and the Malaysian Ministry of Health ethic committee of National Medical Research Register. (NMRR-14-888-21585)

4.2 Data collection

(i) Standard data performa form was used, obtaining

- Clinical data, baseline demographic and sociodemographic data
- Epilepsy history including seizure frequency, duration, nocturnal seizures, history of status epilepticus

(ii) Awareness, Knowledge and Attitude(AKA) questionnaires

A validated adult Malay AKA epilepsy questionnaire was used. [5] The questionnaire has three major dimensions regarding epilepsy in general are sampled by 20 items; Awareness, Knowledge and Attitude. Each response score ranges from 0 to 10.

The first domain intends to detect Awareness level which contained 5 items with a total score range from 0-50. The scores are interpreted as follows: 0-10 = very low, 11-20 = low, 21-30 = moderate, 31-40 = high and 41-50 = very high.

The second domain determines Knowledge level which contained 8 items with its total score ranging from 0 to 80. The interpretation is as such: 0-16 = very low, 17-32 = low, 33-48 = moderate, 49-65 = high and 66-80 = very high.

The third domain measures Attitude level which is sampled by 4 items. The total score ranges from 0 to 40 and are grouped as follows: 0-9 = very negative, 10-19 = negative, 20-29 = indifferent, 30-39 = positive and 40-49 = very positive.

Finally, the total AKA score is calculated via the summation of all three domain scores to give the General AKA level of all respondents. This General AKA level can range from 0 to 179 divided into categories between 1 = very poor (total: 0-35), 2 = poor (total: 38-71), 3 = moderate (total: 84-107), 4 = good (total: 110-144) and 5 = excellent (147-179) [5].

The questionnaires are given to parents only and at three time points, at first visit; as a baseline AKA before (TP1) and immediately after (TP2) intervention with Interactive Animated Epilepsy Education Programme (IAEEP) and on second visit 3-6 months later (TP3) [8]

i) CHEQOL-25 for HRQOL assessment

CHEQOL-25 is the only epilepsy-specific QOL instrument that is able to measure both child's HRQOL and parent-proxy rating. Both the Malay and Mandarin version have been validated and showed good psychometric properties[33, 34] Either father or mother been reported similar with no significant differences. [35]

The use of the HRQOL questionnaire in Children with Epilepsy (CHEQOL-25) authored by Dr. Gabriel Ronen et al, was made under license from McMaster University, Hamilton, Canada.

The CHEQOL-25 consists of:

Twenty-five items that yield 5 subscales: Interpersonal/Social, Present Worries and Concerns, Intrapersonal/Emotional, Epilepsy Secrecy, Quest for Normality (child only) or Future Worries and Concerns (parent only) [35]

Child self-report (CSR) and parent-proxy report (PPR); with each item scored on a scale of 1–4 and the sum of all items of the subscale will give its total score (scores range between 5 and 20). A higher score reflects a more positive perception in that domain. Hence, a higher total CHEQOL-25 will indicate a better QOL.

(iv) DASS questionnaires

Depression, Anxiety and Stress Scoring(DASS) questionnaire is a quantitative measure, consisting of a set of questions consisting of 21 questions, addressing all three components of mental health. This is used to ascertain whether by using IAEEP to improve AKA, whether it has caused an increased level of depression, anxiety or stress.

(v) IAEEP

The Interactive Animated Epilepsy Education Programme (IAEEP) was pioneered in July 2013 by University Sultan Zainal Abidin (UniSZA) and Hospital Sultanah Nur Zahirah (Neurology and Paediatric departments) in Terengganu, Malaysia [32]. In September 2014, the University Malaya (UM) Paediatric Neurology division further revised and improved the contents of IAEEP. It was used among Malaysian parents and CWE and shown to be easily understandable with a high positive feedback[36]. It is the first interactive and IT-based animated epilepsy programme in Malaysia which requires user participation. The IAEEP can be installed with Windows software on laptops & tablets. It covers 9 topics of epilepsy ("what is epilepsy", "safety tips", "medication", "school", "dealing with epilepsy", "first aid", "teenage years", "good life" and takes about 20 minutes to complete[32].

Usefulness of IAEEP was assessed using 8 feedback questions from parents and child [32].

4.3 Sample size determination

Sample size calculation: Based on previous Malaysian AKA study [5] among adults with awareness mean score of 18 and our objective to potentially increase the score to another category by score increment of 10 points, we will need a sample size of 77 (based on Power=0.8, alpha 5%)

4.4 Statistical analysis

Statistical analyses were performed using Statistical Package for Social Sciences (SPSS) for MAC version v22.0 (SPSS Inc., Chicago, IL., U.S.A.) To determine whether the study of distribution was normal or non-normal, the usage of Kolmogorov- Smirnov test (KS test) was used. If the yielded a p value of less than 0.05, it means that it is not normally distributed, hence a non-parametric test, Wilcoxon Signed Rank Test, was used to compare time points and looking for significant p value ($p<0.05$). If the KS test yielded a p value >0.05, it indicates that data is normally distributed, hence the use of Paired Sample T Test is used to look for significance. Chi square test (Fisher's exact test) is used to look for relation between categorical variables. Pearson linear correlation and Spearman's rho was used to determine strength of association. P value of <0.05 was considered significant.

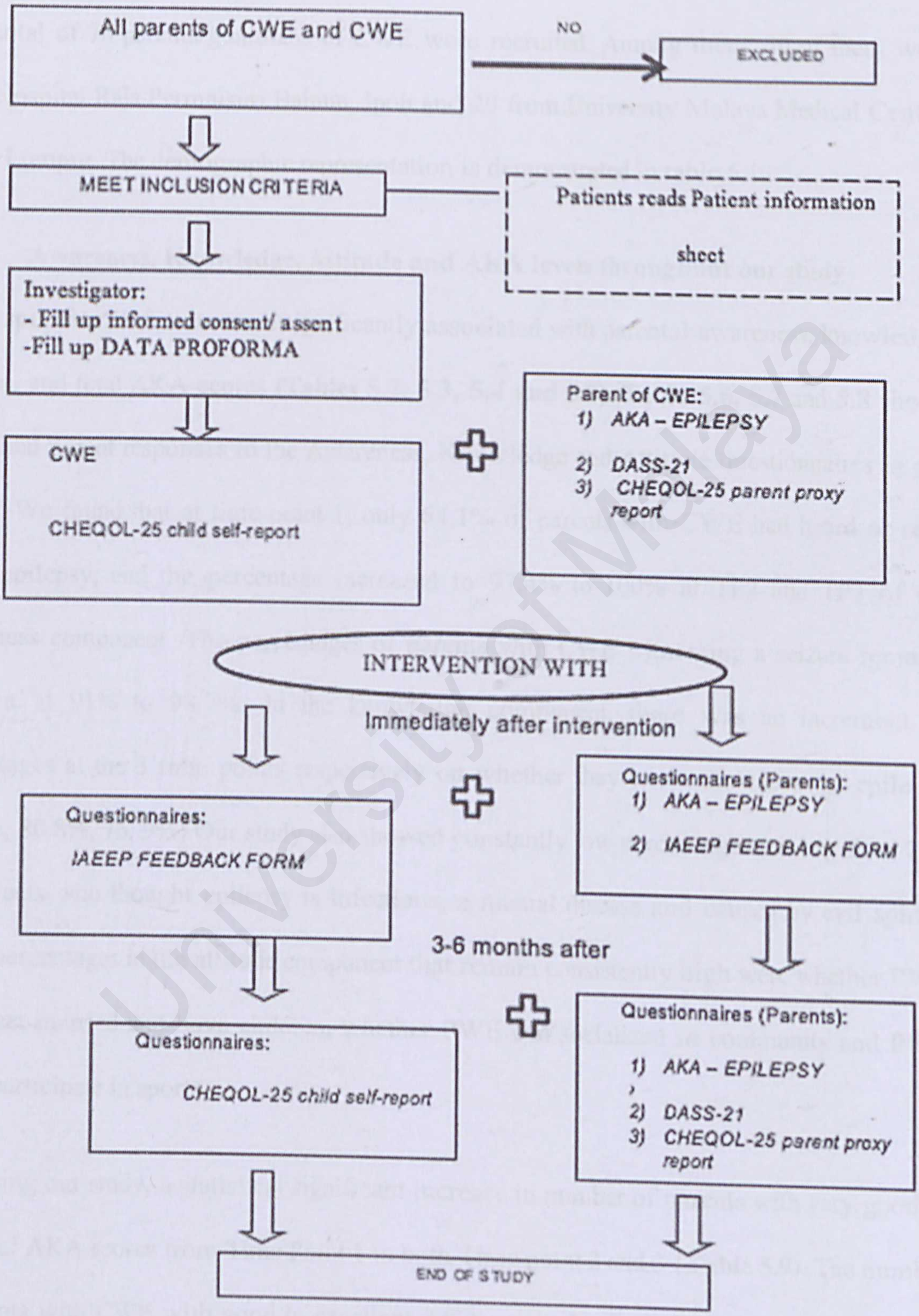


Figure 4.1: Flow chart for our study

CHAPTER 5: RESULTS

5.1 Parents and children characteristics

A total of 78 parents/guardians of CWE were recruited. Among them, 49 of them were from Hospital Raja Permaisuri Bainun, Ipoh and 29 from University Malaya Medical Centre, Kuala Lumpur. The demographic representation is demonstrated in table 5.1.

5.2 Awareness, Knowledge, Attitude and AKA levels throughout our study

No specific risk factors were significantly associated with parental awareness, knowledge, attitude, and total AKA scores **(Tables 5.2, 5.3, 5.4 and 5.5). Table 5.6, 5.7** and 5.**8** shows individual parent responses to the Awareness, Knowledge and Attitude questionnaires in our study. We found that at time point 1, only 64.1% of parents with CWE had heard or read about epilepsy, and the percentage increased to 97.4% to 100% at TP2 and TP3 of the awareness component. The percentages of parents with CWE witnessing a seizure remains constant at 91% to 98.7%. In the knowledge component, there was an increment of percentages at the 3 time points respectively on whether they knew the causes of epilepsy (33.3%, 80.8%, 76. 9%).Our study also showed constantly low percentages (all less than 7%) of subjects who thought epilepsy is infectious, a mental disease and caused by evil spirits. Other percentages in the attitude component that remain consistently high were whether PWE could get married and have children, whether PWE can socialized in community and PWE could participate in sports.

During our study, a statistical significant increase in number of parents with very good to excellent AKA scores from Time Point 1 to both Time point 2 and 3 **(Table 5.9).** The number of parents with CWE with good to excellent AKA scores has increased throughout the time points. **Table 5.10** shows the significant rise in category scores and also median scores in all components of Awareness, Knowledge, Attitude scores along with AKA scores, all showing $p<0.001$.

5.3 CHEQOL levels of parents and CWE throughout out study

Looking into parent's proxy CHEQOL score analysis, it revealed significant improvement in mean scores in Interpersonal/social component ($p=0.020$), and Secrecy ($p=0.039$) component as showed in **Table 5.11.** The other subcategories including Future worries/concern, Intrapersonal/emotional and total CHEQOL scores showed improvement however without non-significant p values ($p >0.05$). **Table 5.13** shows the breakdown of questions asked in Interpersonal/ emotional and future worries/concern, showing there was significant increment in number the questions of whether CWE felt they were treated the equally like other children. ($p=0.014$)

The CWE self-report CHEQOL score analysis, only showed significant improvement in mean scores in Interpersonal/social component ($p=0.020$) and insignificant increment of Intrapersonal/emotional, quest for normality and total CHEQOL scores ($p>0.05$) as shown in **Table 5.12**. Our study also showed significant reduction in mean score of Present worries component ($p=0.021$). **Table 5.14** demonstrates the breakdown of questions asked in Interpersonal/social which yielded no significant increment in each question. However, analyzing the questions asked in Present worries for children, showed that there was a significant increase ($p=0.020$) in children who were worried that would get injured when they had a seizure and significant increment ($p=0.033$) percentage rise in children who think that their parents are worried that they may hurt themselves.

5.4 Correlation between AKA and CHEQOL of parents and CWE.

Analyzing correlation of AKA level score with total CHEQOL score of children at TP3 revealed significant correlation using Pearson Linear correlation, significant at the 0.01 level (2-tailed) as showed in **Figure 1.** Using Spearman Rho Correlation as showed at **Table 5.15,** showed significant correlation of high Awareness, Knowledge, Attitude and total AKA scores with CHEQOL score of children at TP3. In general, all had a strength of moderate correlation. **Figure 2** show there is no significant correlation between total AKA scores of parents with CHEQOL scores of parents at TP3. **Table 5.15** also shows no significant correlation between AKA scores of parents with CHEQOL for children at TP1, CHEQOL for parents of both TP1 and TP3.

5.5 IAEEP feedback

Our study also showed no significant findings of increased emotional distress after intervention with IAEEP. **(Table 5.16)** and all participants showed very positive response towards IAEEP. **(Table 5.17)**

Table 5.1: Demographic representation of our study population

	Participants from HRPB, N=49	Participants from UMMC, N=29	Total participants, N=78	P-value
Gender Male Female	29 (59.1%) 20 (40.8%)	19 (65.5%) 10 (34.5%)	48(61.5%) 30(38.5%)	0.581
Age (years) <10 ≥10	12 (24.5%) 37 (75.5%))	10 (34.5%) 19(65.5%)	22 (28.2%) 56 (71.8%)	0.346
Ethnicity Malay Non-Malay	18 (36.7%) 31(63.3%)	11(37.9%) 18(62.1%)	29 (37.2%) 49 (62.8%)	0.916
Marital status Married Others	47 (95.9%) 2 (4.1%)	29 (100%) 0 (0%)	76 (97.4%) 2 (2.6%)	0.273
School Normal Others	48 (97.9%) 1 (2.1%)	28(96.6%) 1(3.4%)	76 (97.4%) 2 (2.6%)	0.706
Seizure Type Generalised Focal	38 (77.6%) 11 (22.4%)	17 (58.6%) 12 (41.4%)	55 (70.5%) 23 (29.5%)	0.078
Epilepsy Duration (years) < 5 >5	17 (34.7%) 32 (65.3%)	21(72.4%) 8 (27.6%)	38 (48.7%) 40 (51.3%)	0.001
Seizure Frequency High (monthly or more) Low (1-4x/year) or seizure free	10 (20.4%) 39 (79.6%)	11(37.9%) 18(62.1%)	21 (26.9%) 57 (73.1%)	0.094
Nocturnal seizures Yes No	9 (18.4%) 40 (81.6%)	9 (31.0%) 20 (69.0%)	18 (23.1%) 60 (76.9%)	0.202
Household income < RM 4000 >RM 4000	37 (75.5%) 12 (24.5%)	17 (58.6%) 12 (41.4%)	54(69.2%) 24(30.8%)	0.118
Level of education of caregiver Primary Secondary Tertiary	24 (48.9%) 17(34.7%) 8 (16.4%)	0 (0%) 22 (75.9%) 7 (24.1%)	24(30.8%) 39(50.0%) 15(19.2%)	0.000

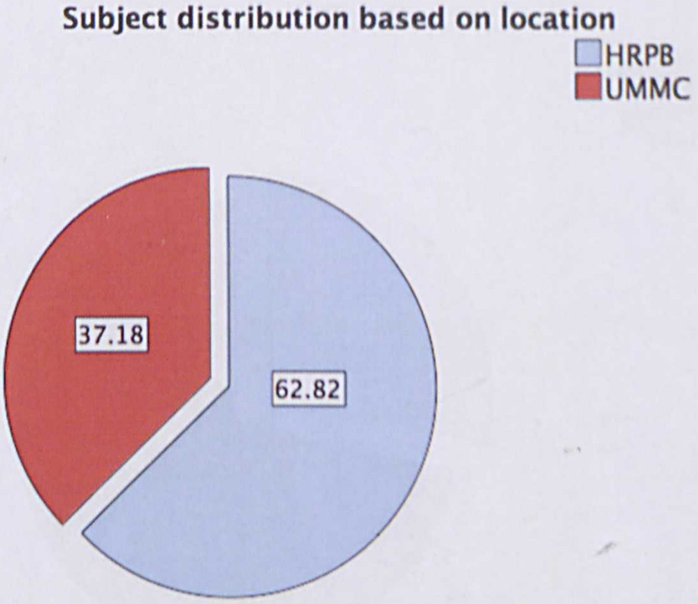


Figure 5.2: Distribution of subjects based on place of recruitment (n=78)

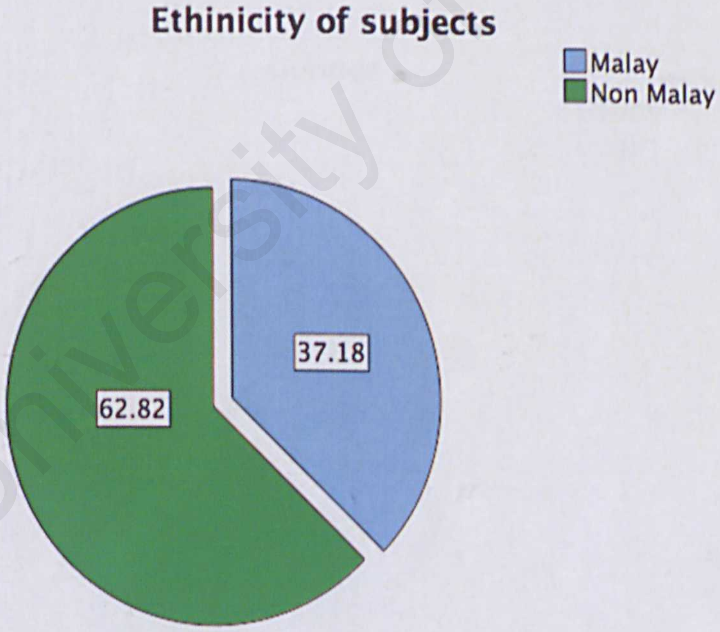


Figure 5.3: Distribution of ethnicities in our study (n=78)

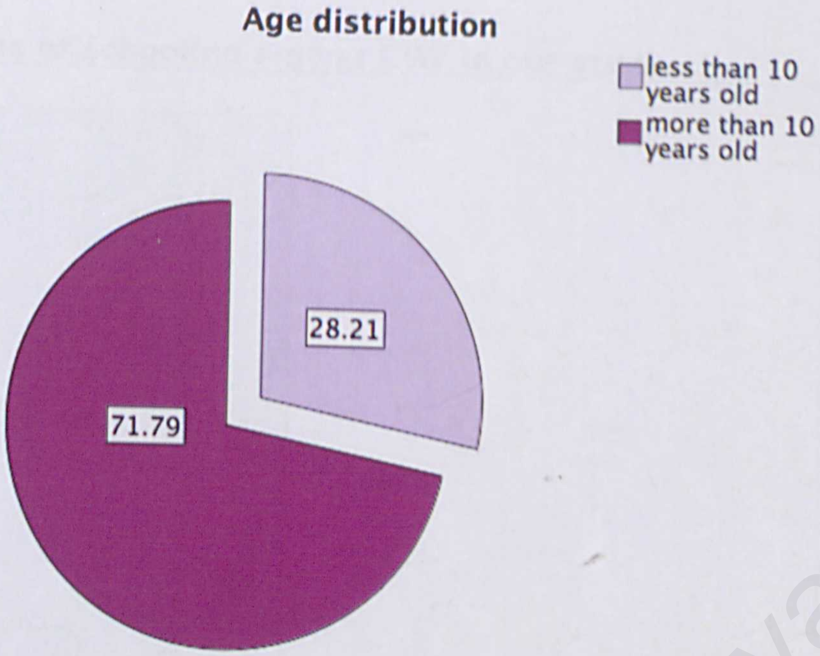


Figure 5.4: Distribution of age groups of our study population (n=78)

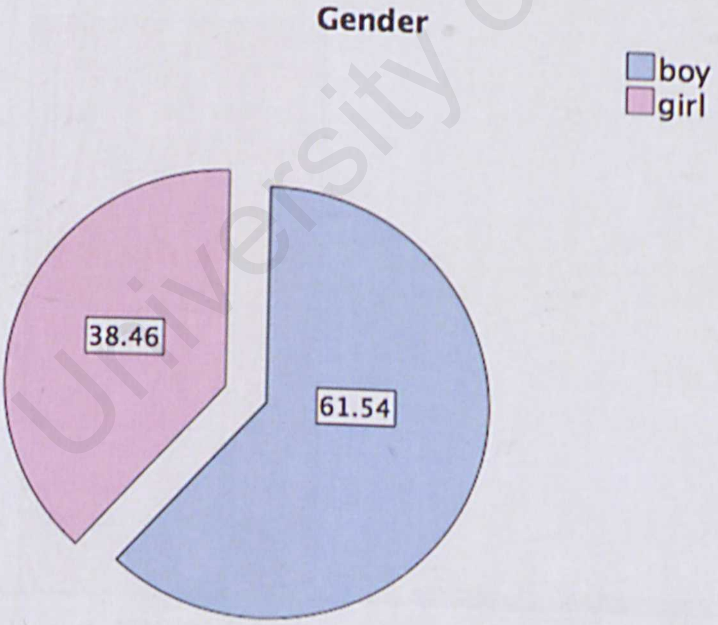


Figure 5.5: Gender distribution in our study (n=78)

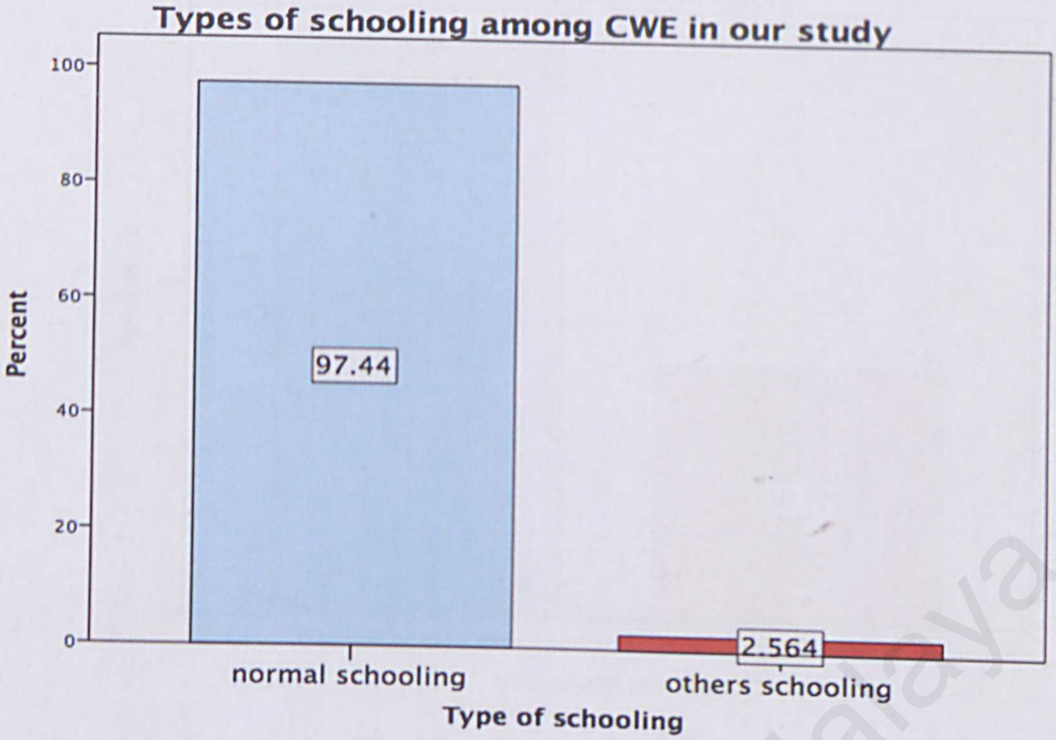


Figure 5.6: Distribution of type of schooling of our CWE (n=78)

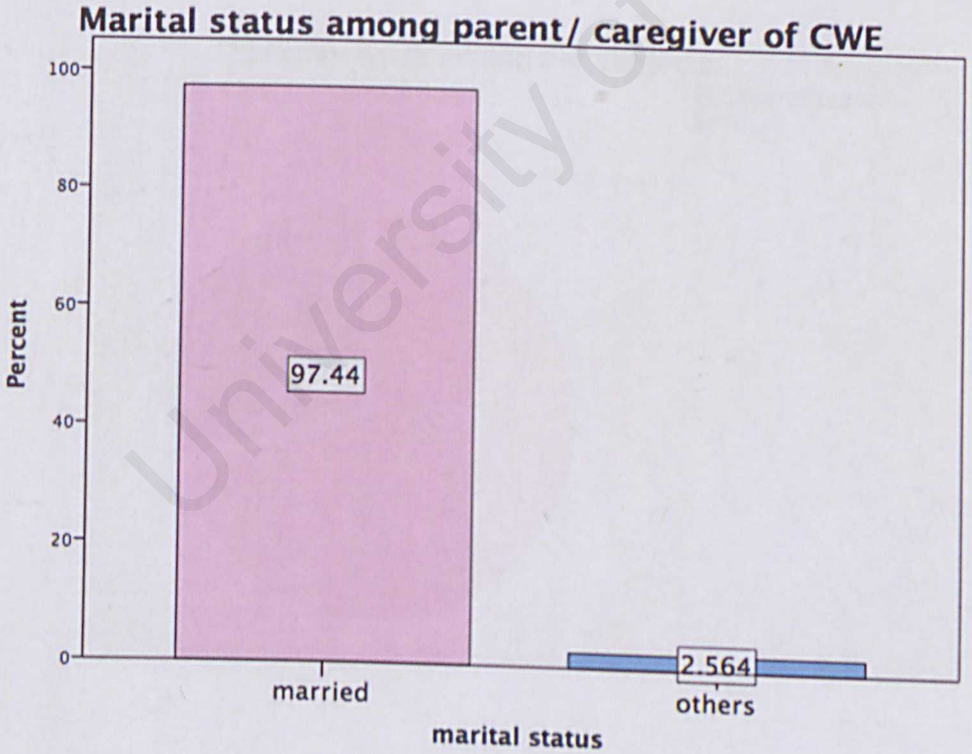


Figure 5.7: Marital status among parents/ caregiver of our study population (n=78)

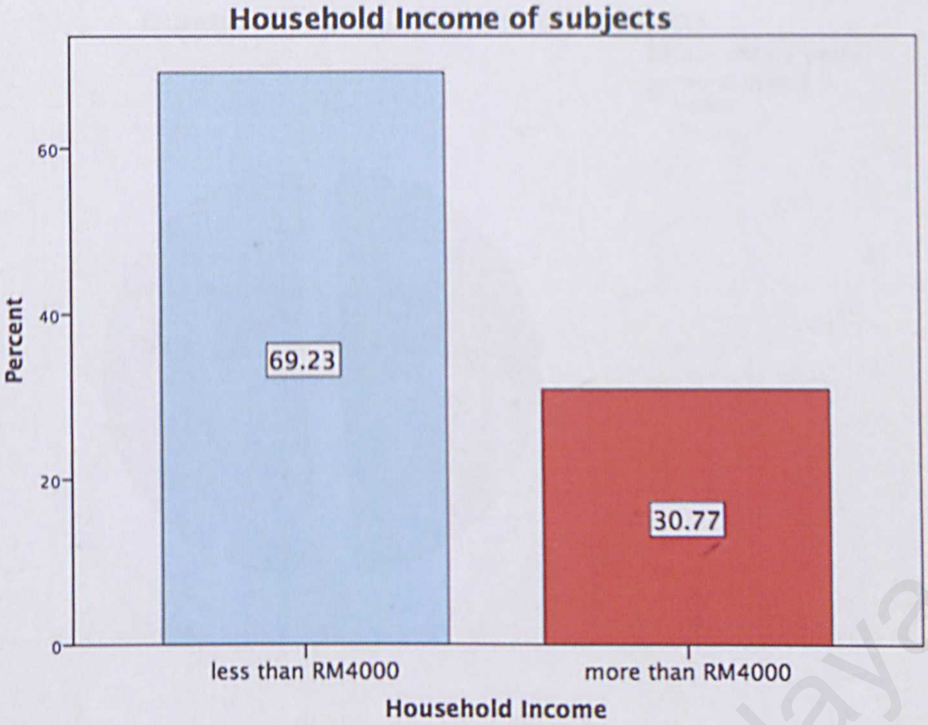


Figure 5.8: Household income of our study population (n=78)

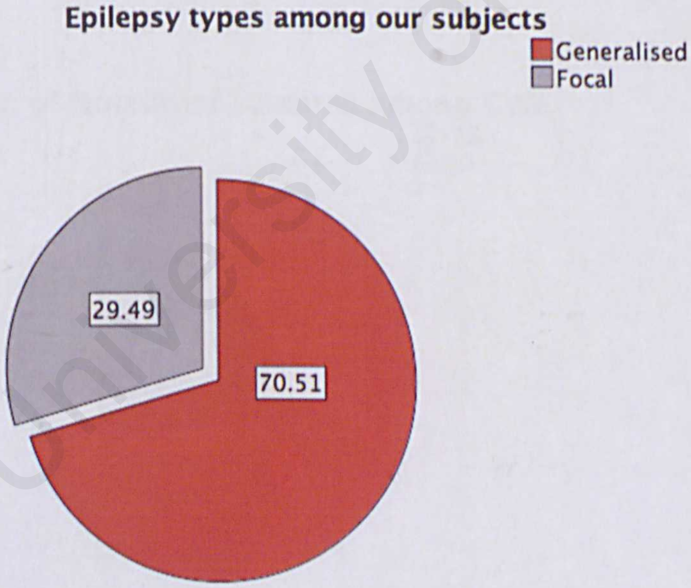


Figure 5.9: Types of epilepsy among our study population (n=78)

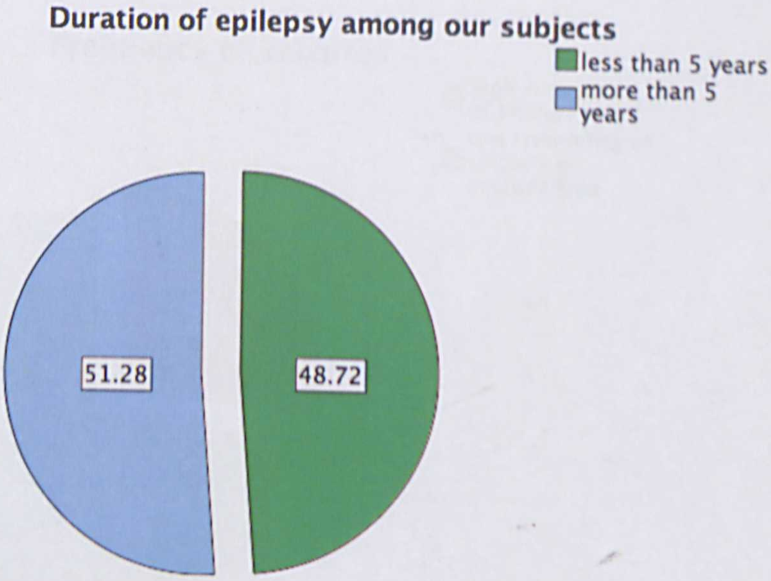


Figure 5.10: Duration of epilepsy among our study population (n=78)

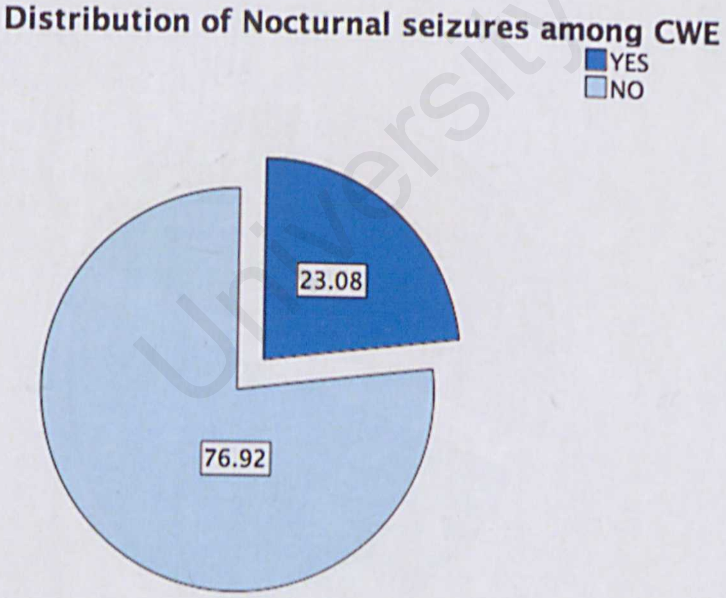


Figure 5.11: percentage of subjects with nocturnal seizures (n=78)

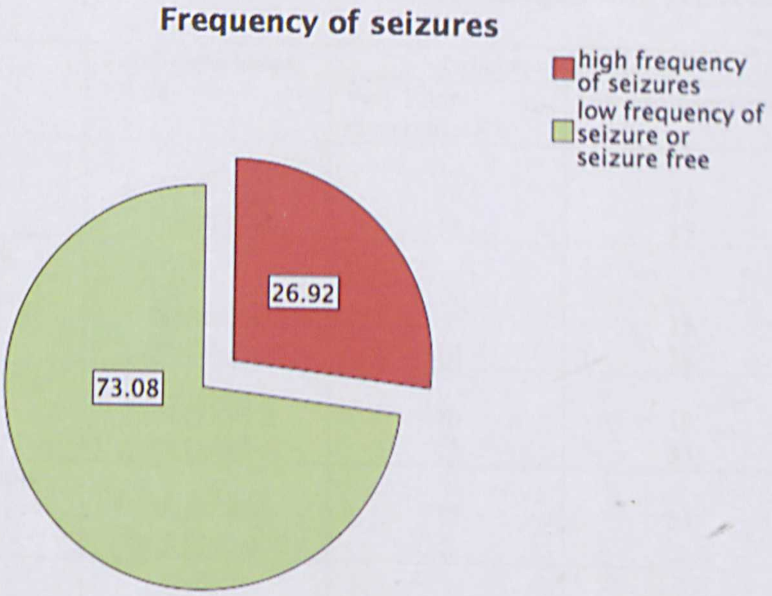


Figure 5.12: Frequency of seizures among our study population (n=78)

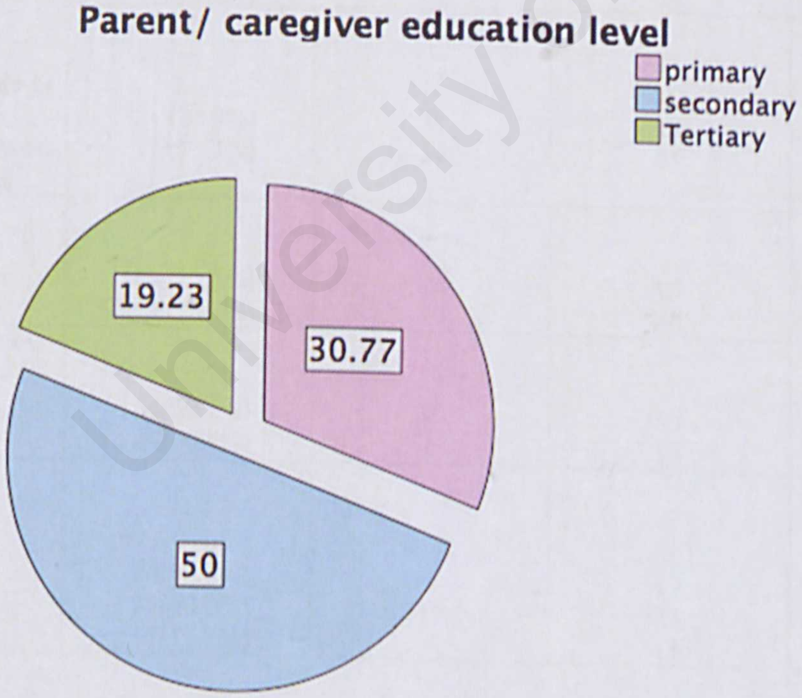


Figure 5.13: Parents/ caregiver education levels

Table 5.2: Risk factor analysis with AKA scores

	Total participants, N=78	Number of participants		P-value
		Very Poor-moderate AKA	Good to excellent AKA	
Gender				
Male	48(61.5%)	14	34	0.493
Female	30(38.5%)	11	19	
Age (years)				
<10	22 (28.2%)	7	15	0.978
≥10	56 (71.8%)	18	38	
Ethnicity				
Malay	29 (37.2%)	10	19	0.723
Non-Malay	49 (62.8%)	15	34	
Marital status				
Married	76 (97.4%)	25	51	0.325
Others	2 (2.6%)	0	2	
School				
Normal	76 (97.4%)	25	51	0.325
Others	2 (2.6%)	0	2	
Seizure Type				
Generalised	55 (70.5%)	16	39	0.386
Focal	23 (29.5%)	9	14	
Epilepsy Duration (years)				
< 5	38 (48.7%)	14	24	0.377
>5	40 (51.3%)	11	29	
Seizure Frequency				
High (monthly or more)	21 (26.9%)	9	12	0.215
Low (1-4x/year) or seizure free	57 (73.1%)	16	41	
Nocturnal seizures				
Yes	18 (23.1%)	5	13	0.658
No	60 (76.9%)	20	40	
Household income				
< RM 4000	54(69.2%)	19	35	0.374
>RM 4000	24(30.8%)	6	18	
Level of education of caregiver				
Primary	24(30.8%)	5	19	0.220
Secondary	39(50.0%)	16	23	
Tertiary	15(19.2%)	4	11	

Table 5.3: Risk factor analysis with Awareness levels

	Total participants, N=78	Number of participants		P-value
		Very low-moderate Awareness	High to very high awareness	
Gender				
Male	48(61.5%)	33	15	0.279
Female	30(38.5%)	17	13	
Age (years)				
<10	22 (28.2%)	14	8	0.957
≥10	56 (71.8%)	36	20	
Ethnicity				
Malay	29 (37.2%)	16	13	0.206
Non-Malay	49 (62.8%)	34	15	
Marital status				
Married	76 (97.4%)	49	27	0.674
Others	2 (2.6%)	1	1	
School				
Normal	76 (97.4%)	48	28	0.284
Others	2 (2.6%)	2	0	
Seizure Type				
Generalised	55 (70.5%)	39	16	0.053
Focal	23 (29.5%)	11	12	
Epilepsy Duration (years)				
< 5	38 (48.7%)	26	12	0.438
>5	40 (51.3%)	24	16	
Seizure Frequency				
High (monthly or more)	21 (26.9%)	14	7	0.774
Low (1-4x/year) or seizure free	57 (73.1%)	36	21	
Nocturnal seizures				
Yes	18 (23.1%)	10	8	0.389
No	60 (76.9%)	40	20	
Household income				
< RM 4000	54(69.2%)	35	19	0.844
>RM 4000	24(30.8%)	15	9	
Level of education of caregiver				
Primary	24(30.8%)	17	7	0.707
Secondary	39(50.0%)	24	15	
Tertiary	15(19.2%)	9	6	

Table 5.4: Risk factor analysis with Knowledge levels

	Total participants, N=78	Number of participants		P-value
		Very low-moderate Knowledge	High to very high Knowledge	
Gender				0.113
Male	48(61.5%)	6	42	
Female	30(38.5%)	8	22	
Age (years)				0.534
<10	22 (28.2%)	3	19	
≥10	56 (71.8%)	11	45	
Ethnicity				0.900
Malay	29 (37.2%)	5	24	
Non-Malay	49 (62.8%)	9	60	
Marital status				0.503
Married	76 (97.4%)	14	62	
Others	2 (2.6%)	0	2	
School				0.503
Normal	76 (97.4%)	14	62	
Others	2 (2.6%)	0	2	
Seizure Type				0.063
Generalised	55 (70.5%)	7	48	
Focal	23 (29.5%)	7	16	
Epilepsy Duration (years)				0.486
< 5	38 (48.7%)	8	30	
>5	40 (51.3%)	6	34	
Seizure Frequency				0.413
High (monthly or more)	21 (26.9%)	5	16	
Low (1-4x/year) or seizure free	57 (73.1%)	9	48	
Nocturnal seizures				0.872
Yes	18 (23.1%)	3	15	
No	60 (76.9%)	11	49	
Household income				0.844
< RM 4000	54(69.2%)	10	44	
>RM 4000	24(30.8%)	4	20	
Level of education of caregiver				0.095
Primary	24(30.8%)	1	23	
Secondary	39(50.0%)	10	29	
Tertiary	15(19.2%)	3	12	

Table 5.5: Risk factor analysis with Attitude levels

	Total participants, N=78	Number of participants		P-value
		Very negative-indifferent attitude	Positive to very positive attitude	
Gender				
Male	48(61.5%)	7	41	0.877
Female	30(38.5%)	4	26	
Age (years)				
<10	22 (28.2%)	5	17	0.170
≥10	56 (71.8%)	6	50	
Ethnicity				
Malay	29 (37.2%)	3	26	0.463
Non-Malay	49 (62.8%)	8	41	
Marital status				
Married	76 (97.4%)	11	65	0.562
Others	2 (2.6%)	0	2	
School				
Normal	76 (97.4%)	11	65	0.562
Others	2 (2.6%)	0	2	
Seizure Type				
Generalised	55 (70.5%)	7	48	0.063
Focal .	23 (29.5%)	4	19	
Epilepsy Duration (years)				
< 5	38 (48.7%)	6	32	0.677
>5	40 (51.3%)	5	35	
Seizure Frequency				
High (monthly or more)	21 (26.9%)	4	17	0.446
Low (1-4x/year) or seizure free	57 (73.1%)	7	50	
Nocturnal seizures				
Yes	18 (23.1%)	3	15	0.722
No	60 (76.9%)	8	52	
Household income				
< RM 4000	54(69.2%)	8	46	0.786
>RM 4000	24(30.8%)	3	21	
Level of education of caregiver				
Primary	24(30.8%)	3	21	0.289
Secondary	39(50.0%)	4	35	
Tertiary	15(19.2%)	4	11	

Table 5.6: Awareness component of AKA questionnaires responses TP1, TP2, TP3 (n=78)

Awareness	TIME POINT 1		TIME POINT 2		P-value	TIME POINT 3		P-value
	Yes (%)	No /Not Sure (%)	Yes (%)	No/ Not Sure (%)	TP1 vs. TP2	Yes (%)	No / Not sure (%)	TP1 vs. TP3
Have you heard or read anything about epilepsy?	50 (64.1)	28 (35.9)	76 (97.4)	2 (2.6)	<0.001	78 (100)	-	<0.001
Have you attended any seminar or lecture about epilepsy?	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?	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?	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?	58 (74.4)	20 (25.6)	64 (82.1)	14 (17.9)	0.014	63 (80.3)	15 (19.2)	0.132

Table 5.7: Knowledge component of AKA questionnaires responses TP1, TP2, TP3 (n=78)

Knowledge	TIME POINT 1		TIME POINT 2		P-value	TIME POINT 3		P-value
	Yes (%)	No/Not sure (%)	Yes (%)	No/Not sure (%)	TP1 vs. TP2	Yes (%)	No/Not sure (%)	TP1 vs. TP3
Do you know what causes epilepsy?	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 can cause death?	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?	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?	53 (67.9)	25 (32.1)	67 (85.9)	11 (14.1)	0.004	69 (88.5)	9 (11.5)	0.026

Knowledge	TIME POINT 1		TIME POINT 2		P-value	TIME POINT 3		P-value
	No/Not sure (%)	Yes (%)	No/Not sure (%)	Yes (%)	TP1 vs. TP2	No/Not sure (%)	Yes (%)	TP1 vs. TP3
Do you think epilepsy is infectious?	78(100)	-	74 (94.9)	4 (5.1)	0.007	78 (100)	-	1.000
Do you think epilepsy is an inherited disease?	54 (69.2)	24 (30.8)	63 (80.8)	15 (19.2)	0.336	69 (88.5)	9 (11.5)	0.314
Do you think epilepsy is a mental disease?	73 (93.6)	5 (6.4)	74 (94.8)	4 (5.1)	0.083	78 (100)	-	0.467
Do you think epilepsy is caused by evil spirits?	77 (98.7)	1 (1.3)	75 (96.2)	3 (3.8)	0.180	77 (98.7)	1 (1.3)	0.206

Table 5.8: Attitude component of AKA questionnaires responses TP1, TP2, TP3 (n=78)

Attitude	TIME POINT 1		TIME POINT 2		P-value	TIME POINT 3		P-value
	Yes (%)	No/ Not sure (%)	Yes (%)	No/Not sure (%)	TP1 vs. TP2	Yes (%)	No/ Not sure (%)	TP1 vs. TP3
Do you think that epilepsy patient can participate in sporting activities?	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 epilepsy patient can drive?	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 epilepsy patient can get married and have family?	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 epilepsy patient can socialise with the community?	78 (100)	-	78 (100)	-	1.000	77 (98.7)	1 (1.3)	0.317

Table 5.9: Comparing AKA scores TP1, TP2 and TP3

	Very poor to moderate AKA (%)	Good to excellent AKA (%)	P-value
Time point 1	25 (32.1)	53 (67.9)	TP1 vs. TP2 <0.001
Time point 2	9 (11.5)	69 (88.5)	
Time point 3	14 (17.9)	64 (82.1)	TP1 vs. TP3 0.016

Table 5.10: Scores and category of Awareness, Knowledge and Attitude (AKA) score comparing all three time points (n=78)

Characteristics	Median (IQR)	Category	Category Interpretation	P-value
Awareness				
Before intervention(TP1)	30.00 (10)	3.00	Moderate	
After intervention (TP2)	50.00 (10)	5.00	Very high	0.000
After intervention (TP3)	50.00 (10)	5.00	Very high	0.000
Knowledge				
Before intervention(TP1)	60.00 (20)	3.75	High	
After intervention (TP2)	80.00 (20)	5.00	Very high	0.000
After intervention (TP3)	80.00 (20)	5.00	Very high	0.000
Attitude				
Before intervention(TP1)	40.00 (10)	5.00	Very positive	
After intervention (TP2)	40.00 (0)	5.00	Very positive	0.000
After intervention (TP3)	40.00 (0)	5.00	Very positive	0.021
AKA levels				
Before intervention(TP1)	130.00 (30)	3.82	Moderate	
After intervention (TP2)	160.00 (30)	4.71	Excellent	0.000
After intervention (TP3)	160.00 (33)	4.71	Excellent	0.000

TP1 – Time point 1 baseline before intervention with IAEEP
TP2- Time point 2 after immediately after intervention with IAEEP
TP3- Time point 3, 3 months after intervention
*Significant p-value (P<0.05)

Table 5.11: CHEQOL Parents comparing all 2 time points (n=78)

Characteristic	Mean	SD	Mean difference	P-value
Interpersonal/ social			0.80	0.020
Time point 1	15.82	3.02		
Time point 3	16.62	2.99		
Present worries			-0.17	0.519
Time point 1	11.95	2.38		
Time point 3	11.78	2.26		
Future worries/ concern			0.24	0.435
Time point 1	12.88	2.67		
Time point 3	13.12	2.84		
Intrapersonal/ Emotional			0.29	0.414
Time point 1	13.74	2.72		
Time point 3	14.03	3.12		
Secrecy			0.56	0.039
Time point 1	13.77	2.12		
Time point 3	14.33	2.13		
Total			1.70	0.071
Time point 1	68.17	8.32		
Time point 3	69.87	9.20		

Table 5.12: CHEQOL Children comparing all 2 time points(n=78)

Characteristic	Mean	SD	Mean difference	P-value
Interpersonal/ social			0.8	0.020
Time point 1	15.46	2.90		
Time point 3	16.26	3.06		
Present worries			-0.78	0.021
Time point 1	12.14	2.53		
Time point 3	11.36	2.16		
Intrapersonal/ Emotional			0.25	0.444
Time point 1	14.33	3.02		
Time point 3	14.58	3.48		
Secrecy			-0.14	0.592
Time point 1	13.64	2.45		
Time point 3	13.78	2.24		
Quest for normality			0.15	0.661
Time point 1	15.23	2.34		
Time point 3	15.38	2.61		
Total			0.55	0.580
Time point 1	70.81	9.75		
Time point 3	71.36	9.24		

Table 5.13: Analysis of significant subcategories of CHEQOL parents

	TP1, n=78 (%)	TP3, n=78 (%)	P-value
Interpersonal/social questionnaire parents (Q1-Q5) p=0.020, increment 1) Some CWE say other children won't play with them. Other CWE say other children always play with them.	11 (14.1) 67 (85.9)	12 (15.4) 66 (84.6)	0.739
2) Some CWE think they cannot do things as well as other children. Other CWE think they can do things as well.	13 (16.6) 65 (83.4)	11 (14.1) 67 (85.9)	0.593
3) Some CWE do not have many friends. Other CWE have many friends.	11 (14.1) 67 (85.9)	7 (9.0) 71 (91.0)	0.206
4) Some CWE feel that they were treated differently as compared to other children. Other CWE feel that they were treated in the same way as other children.	12 (15.4) 66 (84.6)	6 (7.7) 72 (91.0)	*0.014
5) Some CWE often feel bullied by others. Other CWE do not feel that they are bullied by others.	11 (14.1) 67 (85.9)	7 (9.0) 71(91.0)	0.157
Secrecy Questionnaire parents (Q21- Q25) p=0.039, increment 21) Some CWE feel that it's OK to tell other people that they have this illness. Other CWE feel uncomfortable to tell other people that they have this illness.	53 (67.9) 25 (32.1)	60 (77.0) 18 (23.0)	0.108
22) Some CWE worry that their friends will find out that they have epilepsy. Other CWE do not mind if their friends find out about their illness.	21 (26.9) 57 (73.1)	20 (25.6) 58 (74.4)	0.819
23) Some CWE feel embarrassed of being epileptic. Other CWE do not feel embarrassed of being Epileptic.	24 (30.8) 54 (69.2)	20 (25.6) 58 (74.4)	0.248
24) Some CWE worry that their teachers will find out that they have this illness. Other CWE are not worried that their teachers would find out that they have this illness.	13 (16.7) 65 (83.3)	13 (16.7) 65(83.3)	1.000
25) Some CWE worry if no one knows what to do should they have seizures while they are away from home. CWE are not worried if no one knows what to do when they have seizures while they are away from home.	58 (74.4) 20 (25.6)	64 (82.0) 14 (18.0)	0.157

Table 5.14: Analysis of significant subcategories of CHEQOL children

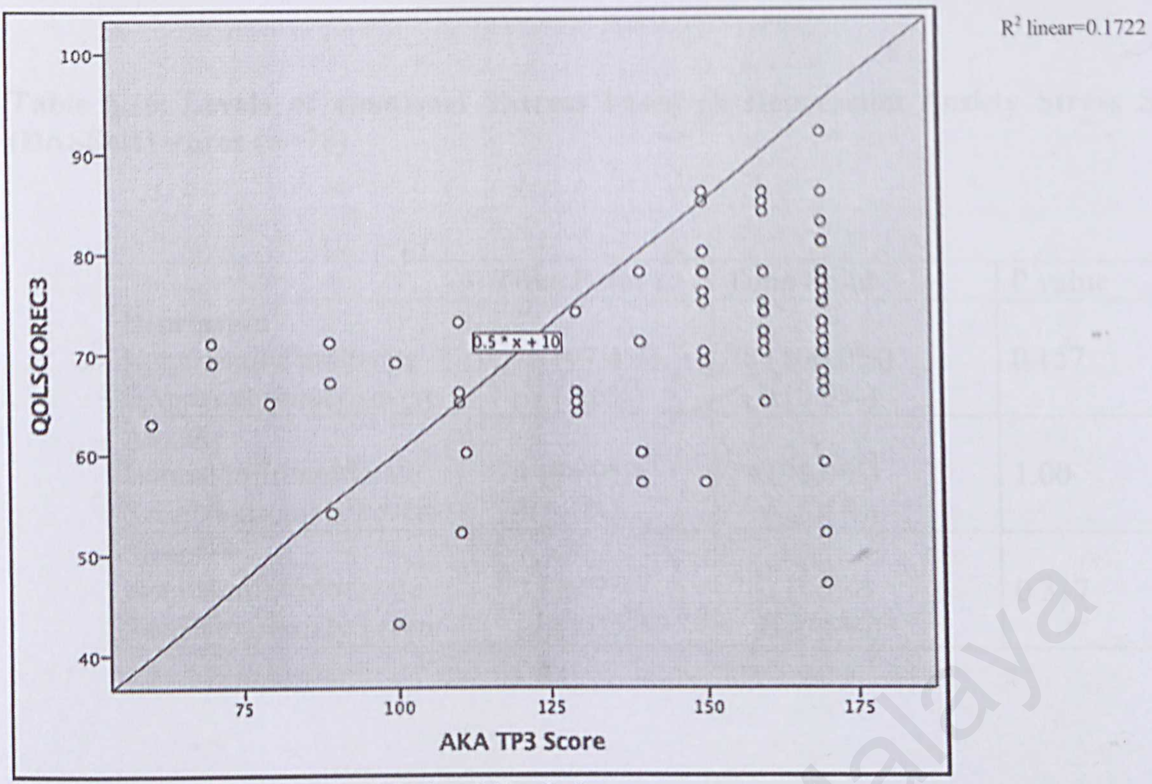
	TP1, n=78 (%)	TP3, n=78 (%)	P-value
<u>Interpersonal/social questionnaire children (Q1-Q5) – p=0.020, increment</u>			
1) Some CWE say other children won't play with them. Other CWE say other children always play with them.	11 (14.1) 67 (85.9)	11 (14.1) 67 (85.9)	1.000
2) Some CWE think they cannot do things as well as other children. Other CWE think they can do things as well.	14 (18.0) 64 (82.0)	15(19.3) 63 (80.7)	0.763
3) Some CWE do not have many friends. Other CWE have many friends.	10 (12.8) 68 (87.2)	11 (14.1) 67 (85.9)	0.739
4) Some CWE feel that they were treated differently as compared to other children. Other CWE feel that they were treated in the same way as other children	13 (16.6) 65 (83.4)	8 (10.3) 70 (89.7)	0.132
5) Some CWE often feel bullied by others. Other CWE do not feel that they are bullied by others.	11 (14.1) 67 (85.9)	8 (10.2) 70 (89.8)	0.366
<u>Present worries Questionnaire children (Q6- Q10) p=0.021, decrement</u>			
6) Some CWE always have to think about their Epilepsy before they do something. Other CWE do not have to think about their Epilepsy before they do something.	52 (66.6) 26 (33.4)	58 (74.3) 20 (25.7)	0.157
7) Some CWE think their parents are worried that they may hurt themselves. Other CWE do not think their parents are worried about them.	63 (80.8) 15 (19.2)	71 (91.0) 7 (9.0)	*0.033
8) Some CWE may not use the computer, play computer games, go camping or do other sport activities. Other CWE may use the computer, play computer games, go camping or do other sport activities.	9 (11.6) 69 (88.4)	15 (19.2) 63 (80.0)	0.157
9) Some children worry about things that might happen if they forget to take their medication. Other children do not worry about things that might happen if they forgot to take their medication.	54 (69.3) 24 (30.7)	60 (76.9) 18 (23.1)	0.201
10) Some children worry that they might get hurt when they experience seizures. Other children are not worried that they might get hurt when they experience seizures.	59 (75.6) 20 (25.6)	64 (82.0) 14 (18.0)	*0.020

Table 5.15: Comparison of Spearman's rho correlation Awareness, Knowledge, Attitude, and AKA scores with total CHEQOL

	Time point 1 rs value (p-value)				Time point 3 rs value (p-value)			
	A	K	A	AKA	A	K	A	AKA
Total CHEQOL score children	-0.097 (0.399)	+0.079 (0.599)	+0.09 (0.436)	+0.172 (0.132)	+0.369* (0.001)	+0.300* (0.008)	+0.304* (0.007)	+0.425* (<0.001)
Total CHEQOL score parents	+0.034 (0.766)	+0.079 (0.493)	+0.047 (0.681)	+0.045 (0.695)	+0.107 (0.352)	+0.130 (0.258)	+0.007 (0.949)	+0.146 (0.203)

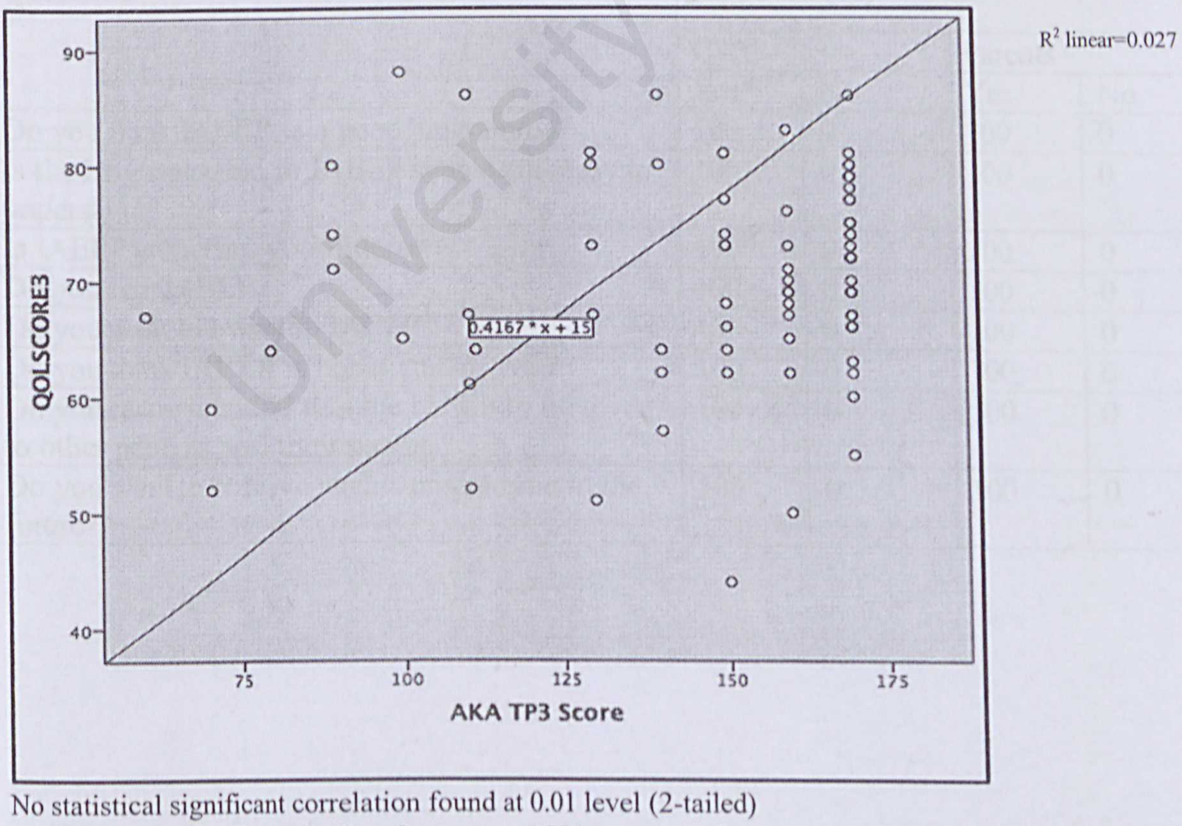
A-awareness, K- knowledge, A- attitude, AKA – awareness knowledge attitude

*Correlation is significant at the 0.01 level (2-tailed)
Positive moderate correlation (rs= 0.3-0.49)



Correlation is significant at the 0.01 level (2-tailed)

Figure 5.14: Correlation between AKA scores of parents at TP3 with CHEQOL scores for children TP3



No statistical significant correlation found at 0.01 level (2-tailed)

Figure 5.15: Correlation between AKA scores of parents at TP3 with CHEQOL score for parents at TP3

Table 5.16: Levels of emotional distress based on Depression Anxiety Stress Scales (DASS-21) scores (n=78)

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

Table 5.17: IAEEP feedback response for current study

Questions	Response (%)			
	CWE		Parents	
	Yes	No	Yes	No
Do you think IAEEP is a good programme?	100	0	100	0
Is the language used in IAEEP simple and easy to understand?	100	0	100	0
Is IAEEP attracting your interest?	100	0	100	0
Do you like IAEEP?	100	0	100	0
Do you want to own the IAEEP?	100	0	100	0
Do you think IAEEP is beneficial for you?	100	0	100	0
Do you recommended that the IAEEP to be given to other patients and their parents?	100	0	100	0
Do you want to receive such a programme in the future?	100	0	100	0

CHAPTER 6: DISCUSSION

Although epilepsy is one of the most prevalent neurological disorder, patients with epilepsy face prejudice among general population due to misconceptions and stigma surrounding epilepsy. [5] Improving public awareness, attitude and knowledge towards epilepsy is a potential step in decreasing discrimination and stigmatization. [5] The study conducted by SW. Neni et al in 2010, involving rural population East Coast Peninsular Malaysia showed a general low awareness, knowledge, attitude and even total AKA scores. Another Malaysian study on AKA and quality of life correlations of the general population in Terengganu, showed a slight improvement in AKA scores compared to Kelantan population in SW. Neni study in 2010. [5] **(Table 6.1)** Our Malaysian parents of CWE yielded a higher baseline AKA when compared with these AKA studies among the Malaysian general population. The possible reason of the differences in baseline scores, could be attributed to the different demographics of population study and also due to the fact that parents of CWE would have a better AKA level when compared to the Malaysian general population at large. Our findings highlight the gap of epilepsy AKA among families with epilepsy and the general population re-emphasizing the need for greater Malaysian public awareness on epilepsy.

What about epilepsy AKA levels in other parts of the world? When comparing percentages of subject who had read or heard of epilepsy with international group population in a review study done by G. Bryan Young et al[37], as shown in **Table 6.4** showed majority (73-95%) of general public from European countries, China, Taiwan and Arab had read or heard about epilepsy (73%). In comparison, our study shows that only 64% of our parents with CWE had read or heard about epilepsy. This is a major concern as our Malaysian parents despite having CWE, 36% of them do not have basic educational knowledge of epilepsy reiterating the need for clinicians to educate them about epilepsy. IAEEP is thus a potential invaluable educational tool for clinicians to use. Our study showed that there was a higher percentage of parents with CWE (91.0%), have seen epileptic attack. When comparing with other general pubic studies worldwide (G. Bryan Young et al), ranging of 34-72%, had witnessed an epileptic attack which were lower compared to our study population. **(Table 6.4)** This is not surprising as our study population involved parents who are caring for CWE, hence likelihood of witnessing an epileptic attack is higher. A study done by Duc Si Tran published in 2007[6], involving Laos family members with CWE, also showed a high percentage, 96.4%, who witness an epileptic attack. **(Table 6.2)**

In 2016, Ali-Asghar Kolahi et al conducted a study with 206 Iranian mothers with CWE [9], when compared to our study showed similar percentage who thought epilepsy was treatable (85-88% agreed) and also whether patients with epilepsy are better not get married (91-93% disagreed) as showed in **Table 6.2**. On the same note, Laos population in Duc-Si Tran study showed 57.8% disagree that PWE are restricted from marriage. **(Table 6.2)** This attributed to local beliefs and also community practices which influence the way of life of people such as marriage restrictions, in comparison to city population with contrasting beliefs.

Local beliefs and taboos still runs deep in some rural communities which regards to epilepsy disease, causing reduction in awareness, knowledge and attitude levels in this communities. In Laos, a study involving families showed that nearly half of the study population involving family with CWE, believed that epilepsy was caused by supernatural forces (42.2%) and about 51.8% believed that epilepsy was contagious. **(Table 6.2)** This indicates that misconception of epilepsy often occurs in rural area where knowledge of epilepsy is limited, and crippled by misbeliefs. [6] In comparison, our study showed less than 2% believed that epilepsy is caused by supernatural forces and that epilepsy was contagious, indicating health related condition were less affected by local beliefs in our community.

One of the attributing factors that causes epilepsy stigmatization is its misconception of it being a psychiatric disorder. A study in Vietnam revealed that 25% of population viewed epilepsy as a mental disorder and according to the law, should be managed by a psychiatrist thus increasing the misconception among the Vietnamese community. [38] In contrast, our study showed only 6.4% believed that epilepsy is a mental disorder. This could be attributed to our health care system, where psychiatric illness and epilepsy are treated in separated departments of a health care center, hence reducing the false believe.

Looking into job employment for PWE, comparing with the data of general public of G. Bryan Young et al study [37], showed higher percentages believe in equal employment for PWE, ranging 79- 90%(Canada, America, Denmark, United Arab Emirates and West German) Our study showed from parental proxy CHEQOL response at TP1 only 48.8% of parents with CWE, believed their CWE would have equal employment. Our percentages are almost comparable with other countries like China, Taiwan and Italy. This indicates that in developed countries, general population believe in equal employment for PWE, indicating that stigmatization is less in these countries compared to developing countries. A recent study done by Wo MC et al in 2016, looked into employability in PWE, showed that only about 64.3% of PWE had a high employability .The study also found that important factors affecting employability included education level, type of epilepsy, self-motivation and family overprotection. [39] Our findings reiterate the importance of improving AKA among parents of CWE to enable parents to adopt a parenting style of less overprotection and consequently enable CWE to be more independent which will allow them to be employable in adulthood.[39]

In our study, when we correlated between AKA levels of parents and Quality of life of parents and Quality of life of children, in general there was a correlation of higher Awareness, Knowledge, Attitude scores and Total AKA scores of parents with higher quality of life of CWE as shown in **figure 5.15** and **Table 5.15** at TP3. When compared to the study done by P.L. Lua, both studies showed that good attitude is associated with better quality of life. These findings were in sync with those of a Turkish study in which the general attitudes of PWE themselves toward epilepsy were more positive and less derogatory. [31] A study carried out in Taiwan also suggested that HRQoL of PWE depends on positive attitudes in addition to access to medical services, assistance from social security, and facilitative government regulations. [24] Consequently, positive alteration of patients' attitudes toward epilepsy may enhance mental health functioning, leading to improvement of self-concept or behavioral problems [40], which have been found to be linked to stigma. Therefore, patients' attitude changes could minimize negative perceptions, allowing stigma to gradually subside. A previous study has also demonstrated that positive attitude is associated with fewer behavior problems and better self-concept in PWE. With improved attitudes and minimized stigma, PWE would eventually experience better HRQoL. [8] A study done on effects of educational programme for Diabetes Mellitus on knowledge, attitude and quality of life in

2016 showed that there was improvement in quality of life and also increased in attitude and knowledge as well.[41]

Our study shows that parental AKA had a relationship to the child's CHEQOL. There are several possible reasons for this. It is possible that an improved parent's AKA will lead to a more positive parenting resulting in an improved child's perception of HRQOL resulting in a higher CHEQOL score. **Table 5.13** and **5.14** show components of CHEQOL for both parents and children which yielded significant results. If we look at Interpersonal/social component for parents there was a significance (p=0.014) in percentage rise in whether parents felt that children were treated equally. On the other hand, CHEQOL for children in Present Worries, showing significant decrement in scores both components of children thinking that their parents are worried about them hurting themselves during a seizure (p=0.033) and also children who are worried about hurting themselves during a seizure (p=0.020). This indicates that clinicians will need to be aware that CWE undergo a period of adjustment when dealing with the information provided for epilepsy. In particular clinicians will need to empower CWE with more information and basic first aid knowledge to minimize and allay any fears that they may in hurting themselves during a seizure.

With regards to IAEEP intervention, our study population shown similar 100% positive outcome compared to previous study done by P.L. Lua et al in 2013 as shown in **Table 6.5.** Being the first interactive and animated epilepsy education programme in Malaysia, the IAEEP was encouragingly very acceptable by all CWE. That was probably because of its unique and attractive features which were successful in engaging CWE during the learning session. The respondents seemed to enjoy the IAEEP and were able to develop self-awareness and instill confidence with their health issue. [32] It was also previously found that more knowledge was gained and retained by using interactive learning methods compared to the conventional ones. [42] Our results reiterate this showing that the educational impact of the IAEEP on the parents AKA remained stable over time after 3-6 months of receiving the IAEEP.

Table 6.1: Comparing current AKA study with AKA study by Selamat et al (2010) [5] and PL Lua et al (2011) [6]

Charasteristic	Current study among parents of CWE				AKA study rural public in Kelantan, Malaysia by Selamat et al (2010)			AKA and QOL study among public in Terengganu, Malaysia by PL Lua (2011)		
	Mean	SD	P	Interpretation	Mean	SD	Interpretation	Mean	SD	Interpretation
Awareness										
Before intervention(TP1)	3.09	1.08	0.00	Moderate	2.05	0.99	Low	N/A	N/A	Low
After intervention (TP2)	4.27	0.96		High						
After intervention (TP3)	4.21	1.02	0.003	High						
Knowledge										
Before intervention(TP1)	3.51	1.05	0.00	High	2.49	0.86	Low	N/A	N/A	Moderate
After intervention (TP2)	4.33	0.95		High						
After intervention (TP3)	4.30	1.08	0.00	High						
Attitude										
Before intervention(TP1)	4.33	1.00	0.00	Positive	3.47	1.37	Indifferent	N/A	N/A	Indifferent
After intervention (TP2)	4.66	0.75		Very positive						
After intervention (TP3)	4.60	0.89	0.00	Very positive						
All										
Before intervention(TP1)	3.59	0.78	0.00	Good	2.67	0.70	Poor	N/A	N/A	Moderate
After intervention (TP2)	4.39	0.74		Good						
After intervention (TP3)	4.34	0.86	0.00	Good						

TP1 – Time point 1 baseline before intervention with IAEEP
TP2- Time point 2 after immediately after intervention with IAEEP
TP3- Time point 3, 3 months after intervention
*Significant p-value (P<0.05) using Paired T test

Table 6.2: Awareness and knowledge of epilepsy comparing current study (n=78) with Kolahi study[9] (n=206) and Duc Si Tran [6] study (n=83)

Questions	Current study TP 1			Ali-Asghar Kolahi study 2016			Duc-Si Tran 2007		
	n (%)			n (%)			n (%)		
	Yes	No	Don't know	Yes	No	Don't know	Yes	No	Don't know
Epilepsy is treatable	69(88.5)	2(2.6)	7(9.0)	176(85.4)	4(2.0)	26(12.6)	N/A	N/A	N/A
Epilepsy is a psychological disorder	5(6.4)	63(80.8)	10(12.8)	22(10.7)	124(60.2)	60(29.1)	N/A	N/A	N/A
Epilepsy is a contagious disease	-	71 (91.0)	7(9.0)	4(1.90)	177(85.9)	25(12.1)	43(51.8)	40(48.2)	-
Patients with epilepsy would better not get married	1(1.3)	73(93.6)	4(5.1)	16 (8.7)	167(91.3)	-	35(42.2)	48(57.8)	-
Epilepsy is an inherited disease	24 (30.8)	32(41.0)	22(28.2)	143(69.4)	14(6.80)	49(23.80)	35(42.2)	48(57.8)	-
Epilepsy is caused by supernatural forces	1 (1.3)	71 (91.0)	6 (7.7)	N/A	N/A	N/A	35(42.2)	48(57.8)	-
Epilepsy is a fatal disease	57 (73.1)	10 (12.8)	11 (14.1)	N/A	N/A	N/A	51(61.4)	32(21.6)	-
Epilepsy is cure by magical/religious practice	-	78 (100)	-	N/A	N/A	N/A	3(3.6)	80(96.4)	-
Epilepsy is cure by traditional medicine	4 (5.1)	74 (94.9)	-	N/A	N/A	N/A	15(18.1)	68(81.9)	-
Has ever seen an epileptic seizure	71 (91.0)	7(9.0)	-	N/A	N/A	N/A	80(96.4)	3(3.6)	-

Table 6.3: Canadian Epilepsy Questionnaire Survey by G. Bryan Young et al (2002) [37]

Question from Table 1	Persent study 1998–2000	American study 1985	Chinese study 1995	Danish study 1992	Finnish study 1980	Italian study 1985	Taiwanese study 1995	United Arab Emirates study 1998	West German study 1985
Heard or read about epilepsy (Q4)	91%	95%	93%	97%	95%	73%	87%	75%	90%
Knew someone with epilepsy (Q6)	57%	63%	77%	64%	49%	61%	70%		—
Witnessed an epileptic seizure (Q7)	48%	63%	72%	64%	45%	52%	56%	34%	—
Cause (Q9)									
Birth defect	32%	6%	25%	27%	—	10	14%	—	—
Mental illness	9%	2%	17%	<1%	—	—	8%	16%	11%
Hereditary	54%	9%	17%	37%	—	11	28%	16%	—
Trauma	25%	—	—	18%	—	10	—	12%	—
Tumor	30%	—	—	—	—	—	—	—	—
Stroke	26%	—	—		—	—	—	—	
What is a seizure (Q10)									
Convulsion	87%		61%				61%	—	
Loss of consciousness	49%		52%				52%	—	
Behavioural change	28%		19%				19%	—	
Memory disturbance	29%		10%				10%	—	
Don't know	9%		13%				13%	—	77%
Attitudes									
Children associating (Q12)	95%	89%	43%	91%	—	58%		93%	—
Marrying close reltive (Q13)	95%	68%	13%	—	—	—	28%	—	
Persons with epilepsy having children (Q14)	84%	—	—	—	—	—		—	
Equal employment (Q15)	84%	79%	47%	89%	—	51%	69%	90%	80%

Studies: Chinese and Taiwan: M-Y Chung et al., 1995; Italy, West Germany, and USA: Canger and Cornaggia, 1985; U.S.A.: Caveness and Gallup, 1980; Finland: Iivanainen et al., 1980; Denmark: Jensen and Dam, 1992; Australia: Vinson, 1975.

Table 6.4: Common questions done in current studies with other studies done (from G. Bryan Young) [37]

Questions	Current study TP1 (n= 78)	Canadian study 2002 (n=191)	American study 1985	Chinese study 1995	Danish study 1992	Finnish study 1980	Italian study 1985	Taiwainese study 1995	United Arab Emirates study 1998	West German study 1985
Heard or read about epilepsy	50 (64.1)	91%	95%	93%	97%	95%	73%	87%	75%	90%
Witness an epileptic seizure	71 (91.0)	48%	63%	72%	64%	45%	52%	56%	34%	-
Epilepsy is mental illness	5 (6.4)	9%	2%	17%	<1%	-	-	8%	16%	11%
Epilepsy is an inherited disease	24 (30.8)	54%	9%	17%	37%	-	11%	28%	16%	-
Should person with epilepsy have children	73 (93.6)	84%	-	-	-	-	-	-	-	-
Person with epilepsy have equal job opportunity	38(48.8)	84%	79%	47%	89%	-	51%	69%	90%	80%

Table 6.5: Comparing current study and PL Lua et al 2013[32] study on IAEEP response

Questions	Current study Response (%)				P.L. Lua et al 2013 Response (%)			
	CWE		Parents		CWE		Parents	
	Yes	No	Yes	No	Yes	No	Yes	No
Do you think IAEEP is a good programme?	100	0	100	0	100	0	100	0
Is the language used in IAEEP simple and easy to understand?	100	0	100	0	100	0	100	0
Is IAEEP attracting your interest?	100	0	100	0	100	0	100	0
Do you like IAEEP?	100	0	100	0	100	0	100	0
Do you want to own the IAEEP?	100	0	100	0	100	0	100	0
Do you think IAEEP is beneficial for you?	100	0	100	0	100	0	100	0
Do you recommended that the IAEEP to be given to other patients and their parents?	100	0	100	0	100	0	100	0
Do you want to receive such a programme in the future?	100	0	100	0	100	0	100	0

CHAPTER 7: CONCLUSION

Clinicians should use the IAEEP as part of the care of Malaysian CWE as IAEEP is an effective IT- based epilepsy educational tool to raise the level AKA among parents with CWE. After IAEEP intervention there was an improvement in both parents and child CHEQOL interpersonal/ social subscale and parent CHEQOL secrecy subscale scores. Our study also showed a positive correlation between parent's AKA and child's total CHEQOL scores. Children who receive the IAEEP show an increase in level of worry, highlighting that CWE should receive ongoing support as they undergo a period of adjustment when dealing with the information provided.

CHAPTER 8: LIMITATIONS AND STRENGTHS

Time point 3 scores were reassessed after 3 months of 2 initial assessment (Time point 1 – baseline, Time point 2 – after IAEEP intervention) The function of Time point 2 is to assess short term effects of IAEEP and the idea of Time point 3 is to assess long term effects of IAEEP. However, Time point 3 is limited also by memories of our subjects, hence it may not reflect on true implication of effect of IAEEP after 3 months of intervention. Our study could have included AKA questionnaires for children as well so that we could study correlation between AKA levels of children with CHEQOL of children. We were unable to assess if the improvement in the CHEQOL of children were attributed directly or by improvement in child's AKA, future studies also include assessment of CWE AKA level. We were not able to find a correlation between parental AKA with parental CHEQOL, however this could be attributed to small sample size of our population. During our evaluation of epilepsy and parental characteristics with baseline level of epilepsy AKA in parents of CWE, we found no significant p values in all characteristics due to small subject number indicating our study was under power to analyze this data.

Our study being the first to in cooperate IAEEP as an educational tool to help improve Awareness, Knowledge and Attitude among Malaysian parents have yielded significant positive results. Based on our study, it was found about 64% of Malaysian parents have read or heard about epilepsy at time point 1, strengthening our notion to educate our Malaysian parents. Our study also has found an association between High AKA levels and children quality of life.

CHAPTER 9: RECOMMENDATION

Provision for epilepsy education to families using IAEEP should form part of care of Malaysian CWE. Families in particular, CWE should receive ongoing support from the clinician following information provision as they undergo period of adjustment when dealing with the information provided.

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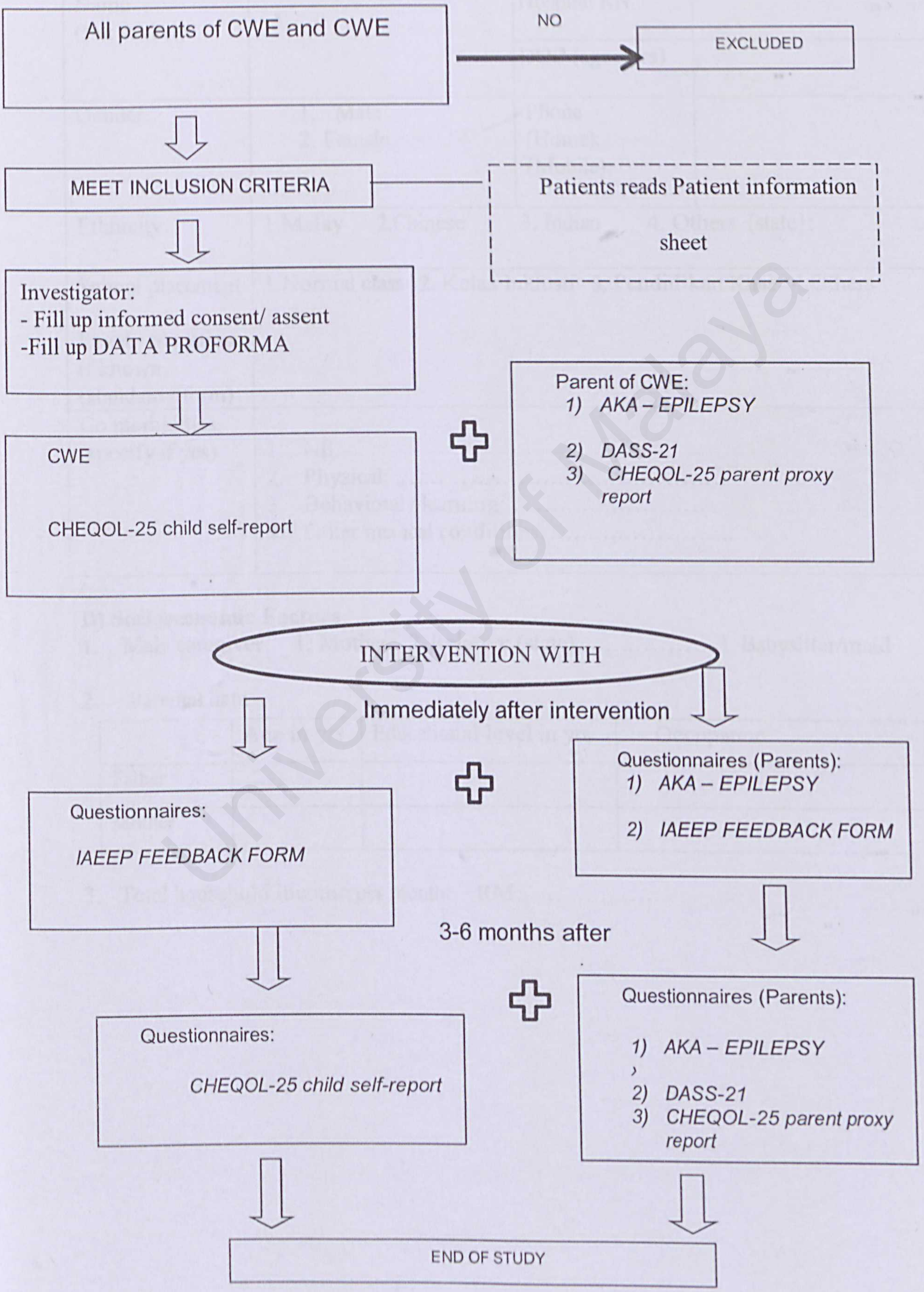
APPENDIX A: WORK FLOW



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APPENDIX B: DATA PERFORMA SHEET

A) Patient Particulars **Subject code:** **Date:**

Name (Put sticker)		Hospital RN	
		DOB (age / yrs)	
Gender	1. Male 2. Female	Phone (Home): (Mobile):	
Ethnicity	1.Malay 2.Chinese 3. Indian 4. Others (state}:		
School placement Level education: if known (standard / form)	1.Normal class 2. Kelas Inklusif 3. Pendidikan Khas 4.Others		
Co morbidities (specify if yes)	1. Nil 2. Physical: …………………………………….. 3. Behavioral / learning: ……………………. 4. Other medical conditions: ……………………..		

B) Socioeconomic Factors

1. Main caregiver 1. Mother 2. Relative (state)……………….3. Babysitter/maid

2. Parental data

	Age in yrs	Educational level in yrs	Occupation
Father			
Mother			

3. Total household income per month: RM……………….

C) Epilepsy background

1. Epilepsy syndrome……………………………………………………………………

2. Type of seizures (if a few types please describe all types):
- Focal (motor, sensory, dyscognitive, autonomic): …………………………………………..........
- Generalised (tonic, tonic-clonic, clonic, absence, myoclonic): ………………….....................

3. Any ongoing nocturnal convulsive seizures: Yes [] No []

- If yes (please state frequency of seizures): ………………………………

4. Age of onset of epilepsy:…………years or …………..months

5. Duration of epilepsy:…………..years…………months
- <6 mths [] - 6 – 12mths [] - 1 – 3yrs [] - 3 – 5 yrs [] - >5yrs []

5. Anti-epileptic drugs (start with current, then previous AED treatment):

AED name	**Date started treatment & duration (months)**	**Any side effects (only for current AEDs)**

6. Seizure frequency over the last 12 months :
- Daily []
- At least once weekly []
- At least once monthly or every other month []
- Maximal of 1-4 times / year []
- Seizure-free []

7. History of convulsive status epilepticus (seizure more than 30mins): Yes / No
- If yes, estimate how many episodes over the past one year: …………….

APPENDIX C: AKA QUESTIONNAIRES (ENGLISH)

QUESTIONNAIRE ON EPILEPSY

We would like to know about your awareness, knowledge and attitude towards epilepsy. Please circle your answer. There is no "right" or "wrong" answer, please respond honestly. Thank you.

(A) Awareness Towards Epilepsy

	Yes	No
1. Have you heard or read anything about "epilepsy"?	1	2
2. Have you attended any seminar or lecture about "epilepsy"?	1	2
3. Have you seen anyone having an "epilepsy attack"?	1	2
4. Have you given any emergency help for "epilepsy"?	1	2
5. Does any of your family member has "epilepsy"?	1	2

(B) Knowledge On Epilepsy

	Yes	No	Not Sure
6. Do you know what causes "epilepsy"?	1	2	3
7. Do you think "epilepsy" is infectious?	1	2	3
8. Do you think "epilepsy" is an inherited disease?	1	2	3
9. Do you think "epilepsy" is a mental disease?	1	2	3
10. Do you think "epilepsy" is caused by evil spirits?	1	2	3
11. Do you think "epilepsy" can cause death?	1	2	3
12. Do you think "epilepsy" is curable?	1	2	3
13. Do you know how to perform an emergency help for "epilepsy"?	1	2	3

(C) Attitude Towards Epilepsy

	Yes	No	Not Sure
14. Do you think that "epilepsy" patient can participate in sporting activitites?	1	2	3
15. Do you think that "epilepsy" patient can drive?	1	2	3
16. Do you think that "epilepsy" patient" can get married and have a family?	1	2	3
17. Do you think that "epilepsy" patient can socialise with the community?	1	2	3

(D) General

18. In your opinion, what is the best treatment for "epilepsy"? (please tick only **ONE** answer)

☐ Modern medicines
☐ Surgery
☐ Traditional therapies (herbs etc.)
☐ Shaman (spells/blessings)
☐ Others. Please state:____________________________

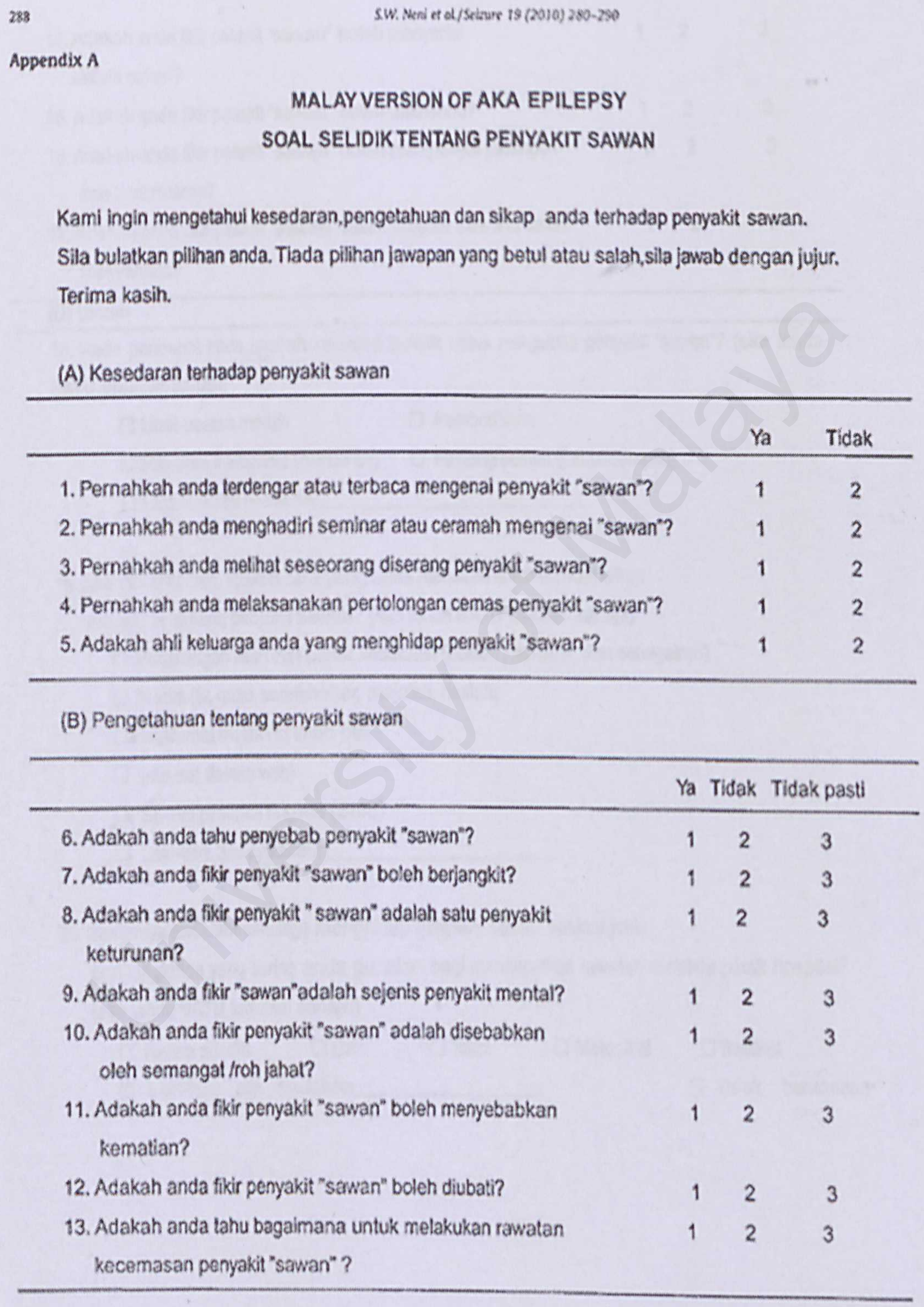
19. If given a choice, what is your preference in obtaining information about epilepsy? (please tick only **ONE** answer)

☐ Verbal explanation from healthcare providers (doctors, nurses etc.)
☐ Media (tv, radio, newspaper, magazines, brochures)
☐ Postal information
☐ Internet (websites)
☐ Short message service (SMS)
☐ Others. Please state:__________________________

20. If you / your family member has epilepsy, what is the mode of transportation which is often used to travel to the hospital for treatment? (please tick only **ONE** answer)

☐ Own car
☐ Bus
☐ Taxi
☐ Motorcycle
☐ Bicycle
☐ Others. Please state ____________________
☐ Not Relevant

APPENDIX D: AKA QUESTIONNAIRES (MALAY)



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

CHEQOL-25 Scale for Parents

Parent's proxy scale: How would my child respond?

Circle only one sentence at each row where your child might choose. Then, place [✓] at the same place if it is true or quite true from the point of view of your children.

	1 Very True for me	2 Quite true for me				3 Quite true for me	4 Very True for me
1.	[ ]	[ ]	Some children with Epilepsy say other children won't play with them.	but	Other children with Epilepsy say other children always play with them.	[ ]	[ ]
2.	[ ]	[ ]	Some children with Epilepsy think they cannot do things as well as other children.	but	Other children with Epilepsy think they can do things as well as other children.	[ ]	[ ]
3.	[ ]	[ ]	Some children with Epilepsy do not have many friends.	but	Other children with Epilepsy have many friends.	[ ]	[ ]
4.	[ ]	[ ]	Some children with Epilepsy feel that they were treated differently as compared to other children.	but	Other children with Epilepsy feel that they were treated in the same way as other children.	[ ]	[ ]
5.	[ ]	[ ]	Some children with Epilepsy often feel bullied by others.	but	Other children with Epilepsy do not feel that they are bullied by others.	[ ]	[ ]
6.	[ ]	[ ]	Some children have to think about their epilepsy before they do something.	but	Other children do not have to think about their epilepsy before they do something.	[ ]	[ ]
7.	[ ]	[ ]	Some children with Epilepsy think their parents worry that they may hurt themselves.	but	Other children with Epilepsy think their parents do not worry about them.	[ ]	[ ]
8.	[ ]	[ ]	Some children with Epilepsy may not use the computer, play computer games, go camping or do other sport activities.	but	Other children with Epilepsy may use the computer, play computer games, go camping or do other sport activities.	[ ]	[ ]
9.	[ ]	[ ]	Some children worry about things that might happen if they forget to take their medication.	but	Other children do not worry about things that might happen if they forget to take their medication.	[ ]	[ ]
10.	[ ]	[ ]	Some children with Epilepsy worry that they might get hurt when they have seizures.	but	Other children with Epilepsy do not worry that they might get hurt when they have seizures.	[ ]	[ ]
11.	[ ]	[ ]	Some children with Epilepsy worry about their future.	but	Other children with Epilepsy are not worried about their future.	[ ]	[ ]
12.	[ ]	[ ]	Some children with Epilepsy are concerned that they might not be able to get into university because of their illness.	but	Other children with Epilepsy are not concern that they cannot get into university because of their illness.	[ ]	[ ]
13.	[ ]	[ ]	Some children with Epilepsy do not know if they can get the job they desire.	but	Other children with Epilepsy feel that they can get the job they desire.	[ ]	[ ]

	1 Very True for me	2 Quite true for me				3 Quite true for me	4 Very True for me
14.	[ ]	[ ]	Some children with Epilepsy do not know if their seizures will be controlled in the future.	but	Other children with Epilepsy believe that their convulsions will be controlled in the future.	[ ]	[ ]
15.	[ ]	[ ]	Some children with Epilepsy think that they would be looked down upon when they grow up.	but	Other children with Epilepsy feel they would not be looked down upon when they grow up.	[ ]	[ ]
16.	[ ]	[ ]	Some children with Epilepsy get angry easily.	but	Other children with Epilepsy do not get angry easily.	[ ]	[ ]
17.	[ ]	[ ]	Some children with Epilepsy have trouble paying attention at school.	but	Other children with Epilepsy are able to pay attention at school.	[ ]	[ ]
18.	[ ]	[ ]	Some children with Epilepsy get angry easily.	but	Other children with Epilepsy do not get angry easily.	[ ]	[ ]
19.	[ ]	[ ]	Some children with Epilepsy have difficulty remembering things they learned at school.	but	Other children with Epilepsy are able to remember things learned at school easily.	[ ]	[ ]
20.	[ ]	[ ]	Some children with Epilepsy feel that they will never recover from this illness.	but	Other children with Epilepsy feel that they will recover from this illness.	[ ]	[ ]
21.	[ ]	[ ]	Some children with Epilepsy feel that it's OK to tell other people that they have this illness	but	Other children with Epilepsy feel uncomfortable to tell other people that they have this illness.	[ ]	[ ]
22.	[ ]	[ ]	Some children worry that their friends will find out that they have epilepsy	but	Other children with Epilepsy do not mind if their friends find out about their illness.	[ ]	[ ]
23.	[ ]	[ ]	Some children with Epilepsy feel embarrassed of being epileptic.	but	Other children with Epilepsy do not feel embarrassed of being Epileptic.	[ ]	[ ]
24	[ ]	[ ]	Some children with Epilepsy worry that their teachers will find out that they have this illness.	but	Other children with Epilepsy are not worried that their teachers would find out that they have this illness.	[ ]	[ ]
25.	[ ]	[ ]	Some children with Epilepsy worry if no one knows what to do should they have seizures while they are away from home.	but	Children with Epilepsy are not worried if no one knows what to do when they have seizures while they are away from home.	[ ]	[ ]

APPENDIX F: CHEQOL QUESTIONNAIRES FOR PARENTS (MALAY)

Skala CHEQOL-25 untuk Ibubapa

Skala Proksi ibubapa: Bagaimanakah anak saya akan menjawab?

Bulatkan hanya satu ayat pada setiap baris dimana anak anda akan pilih, selepas itu tandakan [✓] pada tempat yang sama jika ia benar ataupun agak benar dari sudut pandangan anak anda.

F

	1 Sangat Benar untuk saya	2 Agak benar untuk saya				3 Agak benar untuk saya	4 Sangat Benar untuk saya
1.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi mengatakan kanak-kanak lain tidak mahu bermain bersama mereka.	tetapi	Kanak-kanak lain yang menghidap epilepsi mengatakan kanak-kanak lain selalu bermain bersama mereka.	[ ]	[ ]
2.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi fikir mereka tidak mampu melakukan sesuatu sebaik kanak-kanak yang lain.	tetapi	Kanak-kanak lain yang menghidap epilepsi fikir mereka mampu membuat sesuatu sebaik kanak-kanak yang lain.	[ ]	[ ]
3.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi tidak mempunyai ramai kawan.	tetapi	Kanak-kanak lain yang menghidap epilepsi mempunyai ramai kawan.	[ ]	[ ]
4.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa mereka dilayan dengan cara yang berbeza oleh kanak-kanak yang lain.	tetapi	Kanak-kanak lain yang menghidap epilepsi berasa mereka dilayani dengan cara ynag sama seperti kanak-kanak yang lain.	[ ]	[ ]
5.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa mereka sering dibuli.	tetapi	Kanak-kanak lain yang menghidap epilepsi tidak berasa mereka dibuli.	[ ]	[ ]
6.	[ ]	[ ]	Sesetengah kanak-kanak perlu selalu mengambil kira penyakit epilepsi mereka sebelum mereka melakukan sesuatu.	tetapi	Kanak-kanak lain tidak perlu memikirkan epilepsi mereka sebelum membuat sesuatu.	[ ]	[ ]
7.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa ibubapa mereka risau yang mereka akan mencederakan diri mereka sendiri.	tetapi	Kanak-kanak lain yang menghidap epilepsi berasa ibu bapa mereka tidak risau tentang mereka.	[ ]	[ ]
8.	[ ]	[ ]	Sesetengah kanak-kanak atau remaja yang menghidap Epilepsi mungkin tidak mengguna komputer, tidak main permainan komputer, menyertai perkhemahan atau melakukan aktiviti-aktiviti sukan.	tetapi	Sesetengah kanak-kanak lain yang menghidap epilepsi mungkin boleh mengguna komputer, main permainan komputer, menyertai perkhemahan atau melakukan aktiviti-aktiviti sukan.	[ ]	[ ]
9.	[ ]	[ ]	Sesetengah kanak-kanak bimbang tentang perkara yang mungkin berlaku kepada mereka sekiranya mereka terlupa mengambil ubat.	tetapi	Kanak-kanak yang lain tidak bimbang tentang apa yang mungkin berlaku jika mereka terlupa mengambil ubat.	[ ]	[ ]
10.	[ ]	[ ]	Sesetengah kanak-kanak bimbang mereka akan tercedera ketika sawan.	tetapi	Kanak-kanak lain yang menghidap epilepsi tidak bimbang mereka akan tercedera ketika sawan.	[ ]	[ ]
11.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi risau akan masa depan mereka.	tetapi	Kanak-kanak lain yang menghidap epilepsi tidak risau akan masa depan mereka.	[ ]	[ ]

	1 Sangat Benar untuk saya	2 Agak benar untuk saya				3 Agak benar untuk saya	4 Sangat Benar untuk saya
12.	[ ]	[ ]	Sesetengah kanak- berasa bimbang mereka tidak dapat masuk ke universiti kerana menghidapi penyakit ini.	tetapi	Kanak-kanak lain tidak bimbang sekiranya mereka tidak dapat masuk ke universiti kerana mereka ada epilepsi.	[ ]	[ ]
13.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi tidak pasti jika mereka akan dapat mencapai kerjaya yang diinginkan.	tetapi	Kanak-kanak lain yang menghidap epilepsi berasa mereka dapat mencapai kerjaya yang diinginkan .	[ ]	[ ]
14.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi tidak pasti jika sawan mereka akan dapat dikawal pada masa depan.	tetapi	Kanak-kanak lain yang menghidap epilepsi percaya sawan mereka dapat dikawal pada masa depan.	[ ]	[ ]
15.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa mereka akan dipandang rendah apabila mereka dewasa.	tetapi	Kanak-kanak lain yang menghidap epilepsi berasa mereka tidak akan dipandang rendah apabila mereka dewasa.	[ ]	[ ]
16.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi lebih mudah berasa susah hati.	tetapi	Kanak-kanak lain yang menghidap epilepsi tidak mudah susah hati.	[ ]	[ ]
17.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi mempunyai masalah untuk menumpukan perhatian di sekolah.	tetapi	Kanak-kanak lain yang menghidap epilepsi boleh menumpukan perhatian di sekolah.	[ ]	[ ]
18.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi cepat naik marah.	tetapi	Kanak-kanak lain yang menghidap epilepsi tidak mudah naik marah.	[ ]	[ ]
19.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi mempunyai masalah untuk mengingati apa yang mereka pelajari di sekolah.	tetapi	Kanak-kanak lain yang menghidap epilepsi boleh mengingati perkara yang dipelajari di sekolah dengan mudah.	[ ]	[ ]
20.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa mereka tidak akan sembuh dari penyakit mereka.	tetapi	Kanak-kanak lain yang menghidap epilepsi berasa mereka akan sembuh dari penyakit mereka.	[ ]	[ ]
21.	[ ]	[ ]	Sesetengah kanak-kanak berasa OK untuk memberitahu orang lain tentang penyakit epilepsi mereka.	tetapi	Kanak-kanak lain yang menghidap epilepsi tidak selesa memberitahu orang lain tentang penyakit mereka.	[ ]	[ ]
22.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi bimbang kawan mereka akan mendapat tahu t mereka ada epilepsi.	tetapi	Kanak-kanak lain tidak kisah sekiranya kawan-kawan mereka mendapat tahu yang mereka ada epilepsi	[ ]	[ ]
23.	[ ]	[ ]	Sesetengah kanak-kanak berasa malu kerana mereka ada epilepsi.	tetapi	Kanak-kanak lain tidak berasa malu kerana mereka ada epilepsi	[ ]	[ ]
24	[ ]	[ ]	Sesetengah kanak-kanak bimbang guru mereka akan mendapat tahu mereka ada epilepsi.	tetapi	Kanak-kanak lain tidak bimbang sekiranya guru mereka mendapat tahu mereka ada epilepsi.	[ ]	[ ]
25.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi bimbang sekiranya tiada orang yang tahu apa yang perlu dilakukan ketika mereka mengalami sawan di luar rumah.	tetapi	Kanak-kanak lain yang menghidap epilepsi tidak bimbang sekiranya tiada orang yang tahu apa yang perlu dilakukan ketika mereka mengalami sawan di luar rumah.	[ ]	[ ]

CHEQOL-25 Scale for Children with Epilepsy

Children self report scale: What are most like me?

Circle only one sentence at each row that fits you the most. Then, place a [✓] at the same place if it is true or quite true for you.

	1 Very True for me	2 Quite true for me				3 Quite true for me	4 Very True for me
1.	[ ]	[ ]	Some children with Epilepsy say other children won't play with them.	but	Other children with Epilepsy say other children always play with them.	[ ]	[ ]
2.	[ ]	[ ]	Some children with Epilepsy think they cannot do things as good as other children.	but	Other children with Epilepsy think they can do things as good as other children.	[ ]	[ ]
3.	[ ]	[ ]	Some children with Epilepsy do not have many friends.	but	Other children with Epilepsy have many friends.	[ ]	[ ]
4.	[ ]	[ ]	Some children with Epilepsy feel that they are treated differently by other children.	but	Other children with Epilepsy feel that they are treated the same as other children.	[ ]	[ ]
5.	[ ]	[ ]	Some children with Epilepsy feel like they are bullied by others.	but	Other children with Epilepsy do not feel that they are bullied by others.	[ ]	[ ]
6.	[ ]	[ ]	Some children always have to think about their Epilepsy before they do something.	but	Other children do not have to think about their Epilepsy before they do something.	[ ]	[ ]
7.	[ ]	[ ]	Some children with Epilepsy think their parents are worried that they may hurt themselves.	but	Other children with Epilepsy do not think their parents are worried about them.	[ ]	[ ]
8.	[ ]	[ ]	Some children/adolescents with Epilepsy may not use the computer, play computer games, go camping or do other sport activities.	but	Other children/adolescents with Epilepsy may use the computer, play computer games, go camping or do other sport activities.	[ ]	[ ]
9.	[ ]	[ ]	Some children worry about things that might happen if they forget to take their medication.	but	Other children do not worry about things that might happen if they forgot to take their medication.	[ ]	[ ]
10.	[ ]	[ ]	Some children worry that they might get hurt when they experience seizures.	but	Other children are not worried that they might get hurt when they experience seizures.	[ ]	[ ]
11.	[ ]	[ ]	Some children with Epilepsy get upset easily.	but	Other children with Epilepsy do not get upset easily.	[ ]	[ ]
12.	[ ]	[ ]	Some children with Epilepsy have trouble paying attention at school.	but	Other children with Epilepsy can pay attention at school.	[ ]	[ ]

	1 Very True for me	2 Quite true for me				3 Quite true for me	4 Very True for me
13.	[ ]	[ ]	Some children with Epilepsy get angry easily.	but	Other children with Epilepsy do not get angry easily.	[ ]	[ ]
14.	[ ]	[ ]	Some children with Epilepsy have difficulty remembering things learned in school.	but	Other children with Epilepsy can remember things learned in school easily.	[ ]	[ ]
15.	[ ]	[ ]	Some children feel they need to take seizure medication for the rest of their life.	but	Other children feel that they could stop taking their seizure medication soon.	[ ]	[ ]
16.	[ ]	[ ]	Some children feel OK telling other people about their Epilepsy.	but	Other children feel uncomfortable telling other people about their Epilepsy.	[ ]	[ ]
17.	[ ]	[ ]	Some children are afraid that their friends will find out that they have Epilepsy.	but	Other children do not mind if their friends know about their Epilepsy.	[ ]	[ ]
18.	[ ]	[ ]	Some children with Epilepsy feel safe when they are away from home.	but	Other children with Epilepsy do not feel safe when they are away from home.	[ ]	[ ]
19.	[ ]	[ ]	Some children feel embarrassed to have Epilepsy.	but	Other children do not feel embarrassed to have Epilepsy.	[ ]	[ ]
20.	[ ]	[ ]	Some children with Epilepsy feel that their friends are a bit afraid of them.	but	Other children with Epilepsy feel that their friends are not afraid of them.	[ ]	[ ]
21.	[ ]	[ ]	Some children with Epilepsy are treated the same way as their brothers and sisters.	but	Other children with Epilepsy are treated differently than their brothers and sisters.	[ ]	[ ]
22.	[ ]	[ ]	Some children live normally even though they have seizures.	but	Other children are not able to live normally because they have seizures.	[ ]	[ ]
23.	[ ]	[ ]	Some children with Epilepsy feel that their teachers treat them the same way as the other children at school.	but	Other children with Epilepsy feel that their teachers treat them differently from the other children at school.	[ ]	[ ]
24	[ ]	[ ]	Some children do not let their Epilepsy slow them down.	but	Other children let their Epilepsy slow them down.	[ ]	[ ]
25.	[ ]	[ ]	Some children with Epilepsy feel comfortable at school.	but	Other children with Epilepsy feel uneasy at school.	[ ]	[ ]

APPENDIX H: CHEQOL QUESTIONNAIRES FOR CHILDREN (MALAY)

Skala CHEQOL-25 untuk Kanak-kanak yang menghidap Epilepsi

Skala laporan kendiri kanak-kanak: Apakah yang paling seperti saya?

Bulatkan hanya satu ayat pada setiap baris yang paling serupa dengan anda, selepas itu tandakan [✓] pada tempat yang sama jika ia sangat benar ataupun agak benar untuk kamu.

	1 Sangat Benar untuk saya	2 Agak benar untuk saya				3 Agak benar untuk saya	4 Sangat Benar untuk saya
1.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi mengatakan kanak-kanak lain tidak mahu bermain bersama mereka.	tetapi	Kanak-kanak lain yang menghidap Epilepsi mengatakan kanak-kanak lain selalu bermain bersama mereka.	[ ]	[ ]
2.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi fikir mereka tidak dapat melakukan sesuatu sebaik kanak-kanak yang lain.	tetapi	Kanak-kanak lain yang menghidap Epilepsi fikir mereka mampu membuat sesuatu sebaik kanak-kanak yang lain.	[ ]	[ ]
3.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi tidak mempunyai ramai kawan.	tetapi	Kanak-kanak lain yang menghidap Epilepsi mempunyai ramai kawan.	[ ]	[ ]
4.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa mereka dilayan dengan cara yang berbeza oleh kanak-kanak yang lain.	tetapi	Kanak-kanak lain yang menghidap Epilepsi berasa mereka dilayani denagn cara yang sama seperti kanak-kanak yang lain.	[ ]	[ ]
5.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa mereka dibuli.	tetapi	Kanak-kanak lain yang menghidap Epilepsi tidak berasa mereka dibuli.	[ ]	[ ]
6.	[ ]	[ ]	Sesetengah kanak-kanak perlu selalu mengambilkira penyakit epilepsi mereka sebelum mereka melakukan sesuatu.	tetapi	Kanak-kanak lain tidak perlu memikirkan epilepsi mereka sebelum membuat sesuatu.	[ ]	[ ]
7.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa ibubapa mereka risau yang mereka akan mencederakan diri mereka sendiri.	tetapi	Kanak-kanak lain yang menghidap Epilepsi berasa ibubapa mereka tidak risau tentang mereka.	[ ]	[ ]
8.	[ ]	[ ]	Sesetengah kanak-kanak atau remaja yang menghidap Epilepsi mungkin tidak mengguna komputer, tidak main permainan komputer, menyertai perkhemahan atau melakukan aktiviti-aktiviti sukan.	tetapi	Sesetengah kanak-kanak lain yang menghidap Epilepsi mungkin boleh mengguna komputer, main permainan komputer, menyertai perkhemahan atau melakukan aktiviti-aktiviti sukan.	[ ]	[ ]
9.	[ ]	[ ]	Sesetengah kanak-kanak bimbang tentang perkara yang mungkin berlaku kepada mereka sekiranya mereka terlupa mengambil ubat.	tetapi	Kanak-kanak lain tidak bimbang tentang apa yang mungkin berlaku jika mereka terlupa mengambil ubat.	[ ]	[ ]
10.	[ ]	[ ]	Sesetengah kanak-kanak bimbang mereka akan tercedera ketika sawan.	tetapi	Kanak-kanal lain tidak bimbang mereka akan tercedera ketika sawan.	[ ]	[ ]

	1 Sangat Benar untuk saya	2 Agak benar untuk saya				3 Agak benar untuk saya	4 Sangat Benar untuk saya
11.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi mudah berasa susah hati.	tetapi	Kanak-kanak lain yang menghidap Epilepsi tidak mudah berasa susah hati.	[ ]	[ ]
12.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi mempunyai masalah untuk menumpukan perhatian di sekolah.	tetapi	Kanak-kanak lain yang menghidap Epilepsi boleh menumpukan perhatian di sekolah.	[ ]	[ ]
13.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi cepat naik marah.	tetapi	Kanak-kanak lain yang menghidap Epilepsi tidak mudah naik marah.	[ ]	[ ]
14.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi mempunyai masalah untuk mengingati apa yang mereka pelajari di sekolah.	tetapi	Kanak-kanak lain yang menghidap Epilepsi boleh mengingati apa yang mereka pelajari di sekolah dengan mudah.	[ ]	[ ]
15.	[ ]	[ ]	Sesetengah kanak-kanak fikir mereka perlu mengambil ubat sawan seumur hidup mereka.	tetapi	Kanak-kanak lain fikir mereka boleh berhenti mengambil ubat sawan tidak berapa lama lagi.	[ ]	[ ]
16.	[ ]	[ ]	Sesetengah kanak-kanak berasa OK untuk memberitahu orang lain tentang penyakit epilepsi mereka.	tetapi	Kanak-kanak lain berasa tidak selesa memberitahu orang lain tentang penyakit epilepsi mereka.	[ ]	[ ]
17.	[ ]	[ ]	Sesetengah kanak-kanak bimbang kawan-kawan mereka akan mendapat tahu mereka ada Epilepsi	tetapi	Kanak-kanak lain tidak kisah jika kawan-kawan mereka mendapat tahu mereka ada Epilepsi.	[ ]	[ ]
18.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa selamat berada jauh dari rumah.	tetapi	Kanak-kanak lain tidak berasa selamat berada jauh dari rumah.	[ ]	[ ]
19.	[ ]	[ ]	Sesetengah kanak-kanak berasa malu kerana mereka ada Epilepsi.	tetapi	Kanak-kanak lain yang menghidap Epilepsi tidak berasa malu mereka ada Epilepsi.	[ ]	[ ]
20.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa kawan-kawan mereka agak takut akan mereka.	tetapi	Kanak-kanak lain yang menghidap Epilepsi berasa kawan-kawan mereka tidak takut akan mereka.	[ ]	[ ]
21.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi dilayan sama seperti adik-beradik mereka.	tetapi	Kanak-kanak lain yang menghidap Epilepsi dilayani dengan cara yang berlainan daripada adik-beradik mereka.	[ ]	[ ]
22.	[ ]	[ ]	Sesetengah kanak-kanak menjalani kehidupan secara normal walaupun mereka menghidap sawan.	tetapi	Kanak-kanak lain tidak dapat menjalani kehidupan secara normal kerana mereka menghidap sawan.	[ ]	[ ]
23.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa guru mereka melayani mereka sama seperti kanak-kanak yang lain di sekolah.	tetapi	Kanak-kanak lain yang menghidap Epilepsi berasa guru mereka melayani mereka dengan cara yang berbeza daripada kanak-kanak yang lain di sekolah.	[ ]	[ ]
24	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap tidak membiarkan Epilepsi memperlahankan kemajuan mereka.	tetapi	Kanak-kanak lain membiarkan penyakit Epilepsi memperlahankan kemajuan mereka.	[ ]	[ ]
25.	[ ]	[ ]	Sesetengah kanak-kanak yang menghidap Epilepsi berasa selesa semasa di sekolah.	tetapi	Kanak-kanak lain yang menghidap Epilepsi berasa gelisah semasa di sekolah.	[ ]	[ ]

APPENDIX I: IAEEP FEEDBACK FORM (ENGLISH)

Evaluation form for Interactive Animated Epilepsy Education Programme (IAEEP)

Patient's Name:

DOB:

Date:

Person making the evaluation: Patient / Parent

	Yes	No
1. Do you think the IAEEP is a good programme?	1	2
2. Is the language used in the IAEEP simple and easy to understand?	1	2
3. Does the IAEEP attract your interest?	1	2
4. Do you like the IAEEP?	1	2
5. Do you think the IAEEP is beneficial to you?	1	2
6. Would you recommend the IAEEP to be given to other patients and their parents?	1	2
7. Do you want to receive such a programme in the future?	1	2

APPENDIX J: IAEEP FEEDBACK FORM (MALAY)

Penilaian Program Pembelajaran Animasi Interaktif Epilepsi (IAEEP)

Nama Pesakit:

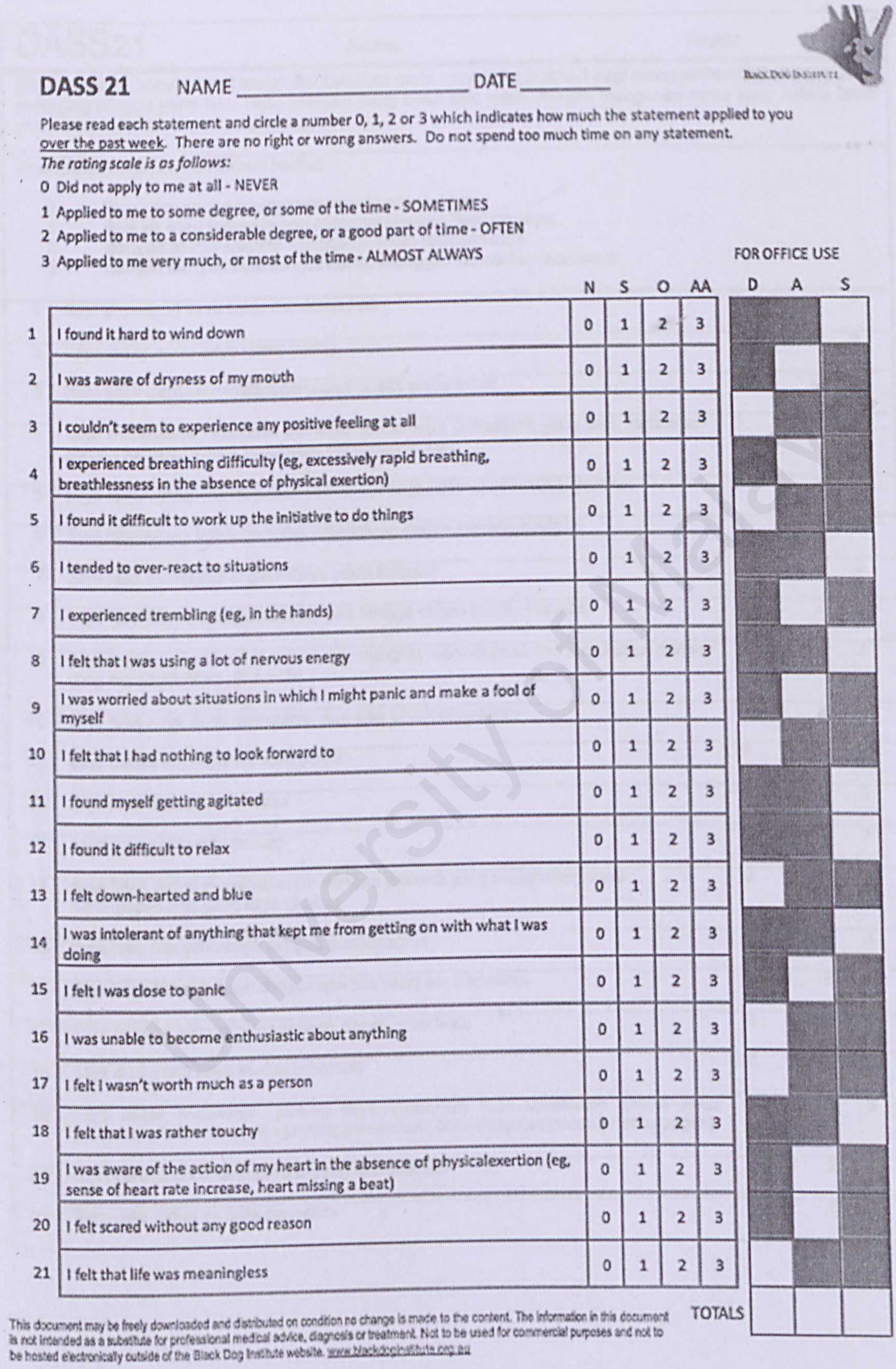
Tarikh Lahir:

Tarikh:

Individu yang melakukan penilaian: Pesakit / Ibubapa

	Ya	Tidak
1. Adakah anda merasakan program IAEEP adalah bagus ?	1	2
2. Adakah bahasa yang digunakan dalam program IAEEP senang dan mudah difahami ?	1	2
3. Adakah program IAEEP berjaya menarik minat anda?	1	2
4. Adakah anda berminat dengan program IAEEP?	1	2
5. Adakah anda merasakan program IAEEP ini berfaedah kepada anda?	1	2
6. Adakah anda mencadangkan program IAEEP ini patut diberikan /di kongsikan dengan pesakit dan ibubapa yang lain?	1	2
7. Adakah anda ingin menerima program seperti ini pada masa akan datang?	1	2

APPENDIX K: DASS-21 QUESSTIONNAIRE (ENGLISH)



DASS 21 NAME ________________________ DATE __________

BLACK DOG INSTITUTE

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you <u>over the past week</u>. There are no right or wrong answers. Do not spend too much time on any statement.

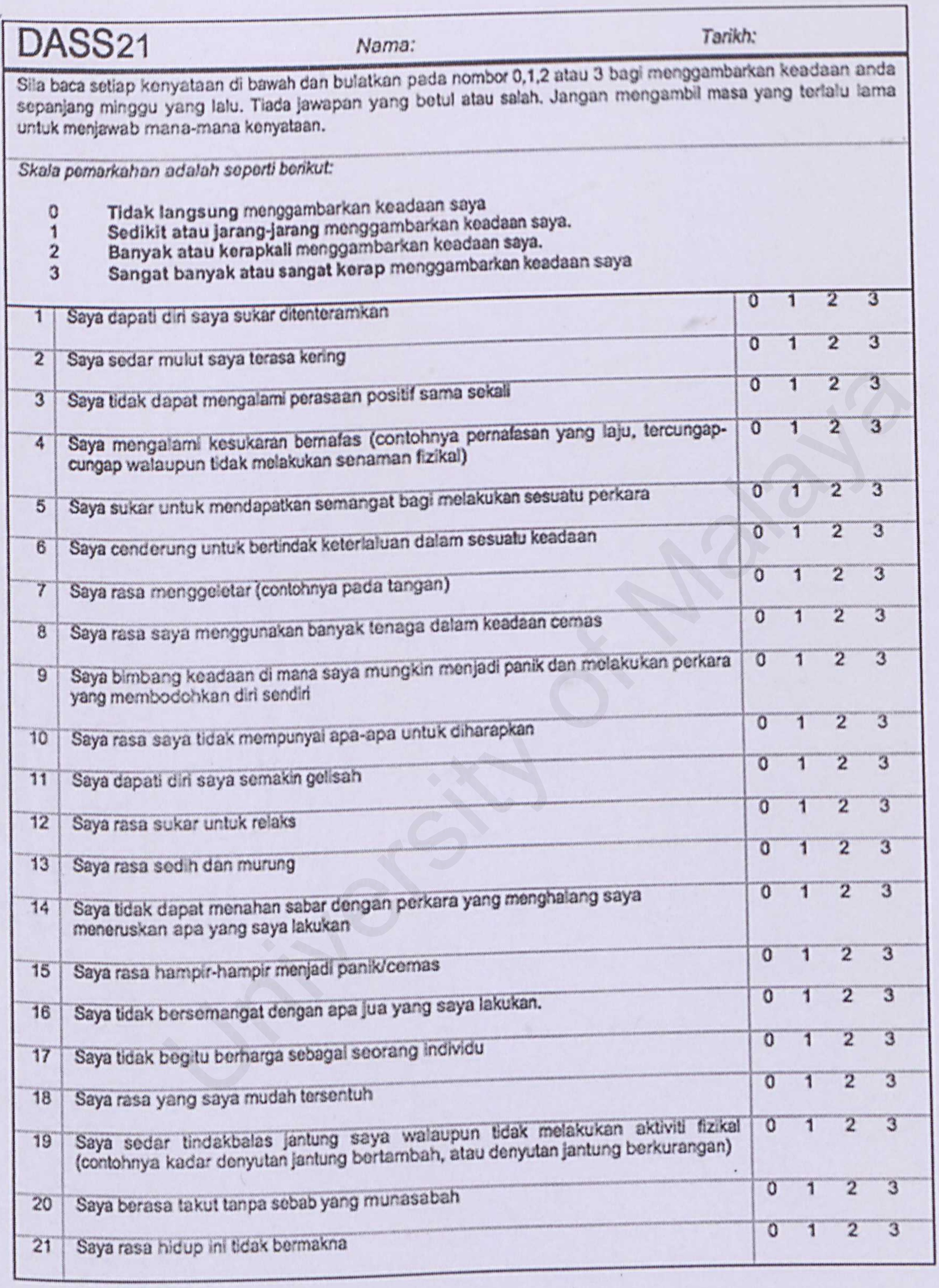
The rating scale is as follows:

0 Did not apply to me at all - NEVER
1 Applied to me to some degree, or some of the time - SOMETIMES
2 Applied to me to a considerable degree, or a good part of time - OFTEN
3 Applied to me very much, or most of the time - ALMOST ALWAYS

FOR OFFICE USE

		N	S	O	AA	D	A	S
1	I found it hard to wind down	0	1	2	3	▨	▨	
2	I was aware of dryness of my mouth	0	1	2	3	▨		▨
3	I couldn't seem to experience any positive feeling at all	0	1	2	3		▨	▨
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3	▨		▨
5	I found it difficult to work up the initiative to do things	0	1	2	3		▨	▨
6	I tended to over-react to situations	0	1	2	3	▨	▨	
7	I experienced trembling (eg, in the hands)	0	1	2	3	▨		▨
8	I felt that I was using a lot of nervous energy	0	1	2	3	▨	▨	
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3	▨		▨
10	I felt that I had nothing to look forward to	0	1	2	3		▨	▨
11	I found myself getting agitated	0	1	2	3	▨	▨	
12	I found it difficult to relax	0	1	2	3	▨	▨	
13	I felt down-hearted and blue	0	1	2	3		▨	▨
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3	▨	▨	
15	I felt I was close to panic	0	1	2	3	▨		▨
16	I was unable to become enthusiastic about anything	0	1	2	3		▨	▨
17	I felt I wasn't worth much as a person	0	1	2	3		▨	▨
18	I felt that I was rather touchy	0	1	2	3	▨	▨	
19	I was aware of the action of my heart in the absence of physicalexertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3	▨		▨
20	I felt scared without any good reason	0	1	2	3	▨		▨
21	I felt that life was meaningless	0	1	2	3		▨	▨
					TOTALS			

APPENDIX L: DASS-21 QUESTIONNAIRES (MALAY)



DASS21 *Nama:* *Tarikh:*

Sila baca setiap kenyataan di bawah dan bulatkan pada nombor 0,1,2 atau 3 bagi menggambarkan keadaan anda sepanjang minggu yang lalu. Tiada jawapan yang betul atau salah. Jangan mengambil masa yang terlalu lama untuk menjawab mana-mana kenyataan.

Skala pemarkahan adalah seperti berikut:

0 **Tidak langsung** menggambarkan keadaan saya
1 **Sedikit atau jarang-jarang** menggambarkan keadaan saya.
2 **Banyak atau kerapkali** menggambarkan keadaan saya.
3 **Sangat banyak atau sangat kerap** menggambarkan keadaan saya

1	Saya dapati diri saya sukar ditenteramkan	0	1	2	3
2	Saya sedar mulut saya terasa kering	0	1	2	3
3	Saya tidak dapat mengalami perasaan positif sama sekali	0	1	2	3
4	Saya mengalami kesukaran bernafas (contohnya pernafasan yang laju, tercungap-cungap walaupun tidak melakukan senaman fizikal)	0	1	2	3
5	Saya sukar untuk mendapatkan semangat bagi melakukan sesuatu perkara	0	1	2	3
6	Saya cenderung untuk bertindak keterlaluan dalam sesuatu keadaan	0	1	2	3
7	Saya rasa menggeletar (contohnya pada tangan)	0	1	2	3
8	Saya rasa saya menggunakan banyak tenaga dalam keadaan cemas	0	1	2	3
9	Saya bimbang keadaan di mana saya mungkin menjadi panik dan melakukan perkara yang membodohkan diri sendiri	0	1	2	3
10	Saya rasa saya tidak mempunyai apa-apa untuk diharapkan	0	1	2	3
11	Saya dapati diri saya semakin gelisah	0	1	2	3
12	Saya rasa sukar untuk relaks	0	1	2	3
13	Saya rasa sedih dan murung	0	1	2	3
14	Saya tidak dapat menahan sabar dengan perkara yang menghalang saya meneruskan apa yang saya lakukan	0	1	2	3
15	Saya rasa hampir-hampir menjadi panik/cemas	0	1	2	3
16	Saya tidak bersemangat dengan apa jua yang saya lakukan.	0	1	2	3
17	Saya tidak begitu berharga sebagai seorang individu	0	1	2	3
18	Saya rasa yang saya mudah tersentuh	0	1	2	3
19	Saya sedar tindakbalas jantung saya walaupun tidak melakukan aktiviti fizikal (contohnya kadar denyutan jantung bertambah, atau denyutan jantung berkurangan)	0	1	2	3
20	Saya berasa takut tanpa sebab yang munasabah	0	1	2	3
21	Saya rasa hidup ini tidak bermakna	0	1	2	3