Malaysian Journal of Pharmaceutical Sciences
Vol. 18, No. 2, 1–14 (2020)

IMPACT OF AN EPILEPSY EDUCATIONAL PROGRAMME ON COPING MECHANISM, ATTITUDE, KNOWLEDGE AND AWARENESS: A RURAL SABAH EXPERIENCE

SIVARAJ RAMAN[1,3*], CHUN WAI CHANG[1], JIN EE HENG[1] AND SEE WAN WONG[2]
[1]Pharmacy Department, Hospital Keningau, Keningau, Sabah, Malaysia
[2]Pharmacy Department, Hospital Tenom, Tenom, Sabah, Malaysia
[3]Discipline of Social and Administrative Pharmacy, School of Pharmaceutical Sciences, Universiti Sains Malaysia, Pulau Pinang, Malaysia

To cite this article: SIVARAJ RAMAN, CHUN WAI CHANG, JIN EE HENG & SEE WAN WONG (2020) Impact of an epilepsy educational programme on coping mechanism, attitude, knowledge and awareness: A rural Sabah experience, *Malaysian Journal of Pharmaceutical Sciences*, 18(2): 1–14, https://doi.org/10.21315/mjps2020.18.2.1
To link to this article: https://doi.org/10.21315/mjps2020.18.2.1

Epilepsy is a disabling disease which has not been adequately emphasised as a public health concern. Patients are often left in the dark about their disease, affecting their ability to cope and live a normal life. This study aimed to explore and evaluate the effects of a structured epilepsy education programme (EEP) on awareness, knowledge and attitude (AKA) and coping mechanism of patients. Recruited participants were required to complete the modified Malay AKA epilepsy questionnaire and Malay brief coping orientation to problem experienced (Brief COPE)-27. Upon completion, they received a structured EEP conducted by trained personnel using validated materials. Participants were then followed up for a period of 6 months and reassessed at 1, 3 and 6 months to measure any changes in their AKA and coping mechanisms. Twenty-two participants were successfully recruited. Total AKA score of participants showed a significant increase (mean score difference = 16.3, p = 0.021, 95% CI: 3.0, 28.1) at 6 months post-EEP. This improvement was mostly contributed by the increase in both knowledge and attitude scores. Religion was the most preferred coping mechanism (82.5%), followed by instrumental support, emotional support, active coping and acceptance at 75.0%, respectively. Only three domains showed significant differences after the educational programme: planning: 62.5% versus 77.5%, p = 0.026; denial: 57.5% versus 37.5%, p = 0.004; venting: 62.5% versus 52.5%, p = 0.004. The EEP was effective in improving attitude and knowledge while bringing about changes in coping skills of patients over a period of time. Educational programmes should be part of epilepsy standard of care, especially as they are inexpensive and brief yet impactful.

Keywords: Epilepsy, Education, Awareness, Knowledge, Attitude, Coping skills

---

[*]Corresponding author: surge_raj@yahoo.com

INTRODUCTION

It is estimated about 70 million of the world population have epilepsy (Singh and Trevick 2016). The prevalence is believed to be higher in developing and resource poor countries, especially among ethnic minorities, people of lower socioeconomic status and people living in rural areas (Mac *et al*. 2007; Theodore *et al*. 2006). Although epilepsy is common and disabling, it has not been adequately emphasised as a public health concern. On the contrary, patients continue to be stigmatised and at large remains in dark about the disease.

More and more studies have identified knowledge and education as key aspects in success of care and treatment. In epilepsy for example, knowledge on disease, diagnosis, precipitants, side effects and management are deemed vital in becoming better partners in patient-centred care. Numerous studies have demonstrated that quite often patients with epilepsy (PWE) neither have a good understanding of their conditions nor improve periodically throughout the treatment. Clinically this is important as patient groups with limited knowledge are at a higher risk of seizure complications (Beghi 2005; Fisher *et al*. 2000; Poole *et al*. 2000).

Awareness is often the first step in ensuring patients and carers are being well-informed. This is mainly projected by a sense of perception and a concern about the epilepsy. Although awareness tends to be general and lacks the in-depth characterisation, it can still be harnessed to help people to acquire their necessary capacities while reducing both internalised and external stigma (England *et al*. 2012).

Coping mechanism, on the other hand, are strategies employed by patients to adapt to living with their ailment. While coping methods are often individualised, a right approach allows patients to make appropriate psychosocial adjustment in view of their limitations. A local study conducted among the population in Kuala Terengganu, for example, showed PWE often opted for coping strategies such as religion and instrumental support to cope with their condition (Neni *et al*. 2010). Identification of such strategies can assist in improving patients' quality of life and development of psychosocial counselling tools (Lua, Neni and Samira 2012).

It was congruently shown in numerous studies that awareness, knowledge and attitude (AKA) levels were associated with the coping strategies adopted. Improvements in AKA was postulated to help PWE employ more positive coping mechanisms. These studies often recommend that AKA and coping strategies to be incorporated into interventions and epilepsy care (Neni and Lua 2011). Still, it is yet to be characterised whether such interventions are able to successfully influence changes in both aspects over a period of time.

Health education programmes have been established to cater for the unmet information and psychosocial needs of PWE and their carer. These programmes are often implemented via various platforms such as media, verbal advice to written information. Unfortunately, only a limited number of such programmes are well evaluated, validated or accessible for general public and patient (Bradley, Lindsay and Fleeman 2016; Helgeson *et al*. 1990; Liu *et al*. 2003; Wang *et al*. 2009).

One of the most established and investigated programme is the Modular Service Package Epilepsy (MOSES) programme. The educational programme has been implemented in many epilepsy centres in Germany, Austria and Switzerland. A randomised controlled study among 22 centres demonstrated a significant improvement in knowledge, coping ability, seizure outcome and side effects tolerability (May and Pfäfflin 2002). Similarly, a nurse-led epilepsy education programme in Norway also showed comparable changes. There was improvement in patients' satisfaction and process of care, albeit no changes in other outcomes such as seizure frequency and severity (Helde *et al*. 2005; Meads, Bradley and Burls 2001).

At present, only two epilepsy education programme (EEPs) have been investigated in Malaysia, with emphasis on feasibilities and short term changes in AKA (Lua and Neni 2012; Lua *et al*. 2013). However, in order to evaluate the impact of such education programme, we now need to further explore the sustainability of improvements in AKA and whether it is translated to changes in coping mechanisms over time. Thus, this study aimed to provide an insight into AKA and coping strategies of patients in rural Sabah and measure the effectiveness of a structured programme to bring about these changes.

METHODS

This was a prospective study conducted among PWE for a period of 2 years. We recruited participants from the specialist clinic pharmacy of Hospital Keningau and outpatient pharmacy of Hospital Tenom. Hospital Keningau is a secondary referral hospital for central rural zone of Sabah, Malaysia with Hospital Tenom being one of the district hospitals within the cluster.

The inclusion criteria for the study was set as PWE aged 18 years old and above, able to either understand, read, speak or write in Malay language, capable of answering the questions in either written form or by interview. Patients with diagnosed psychological disorders, not able to communicate effectively or not able to collect next supply of medications personally were excluded from the study. This was because responses were to be collected consistently throughout routine medication collections from the outpatient pharmacy for 6 months.

The sample size was calculated to detect a mean AKA score difference of 15 between pre-post pairs, while assuming the standard deviation of the difference to be 20. Based on level of confidence of 95% and power of 80%, the calculated sample size was 17 respondents. Participants were recruited by convenience sampling via pharmacists encounter for a period of three months.

All participants were briefed about the study, particulars needed, instruments used and the study requirements. We obtained written consent from all participants and asked them to complete the instruments according to the following order: Participant Demographic Form, modified Malay AKA epilepsy questionnaire and Malay Brief Coping Orientation to Problem Experienced (COPE)-27 (Neni *et al*. 2010; Neni and Lua 2011).

After completion of the questionnaires, we conducted a pharmacist-led epilepsy education programme in a counselling room. Each session took on average about 30–40 minutes depending on participants understanding. They were also briefed to follow up with the investigators for the next 6 months. All participants were required to complete the modified Malay AKA Epilepsy questionnaire 1, 3 and 6 months after and Malay Brief COPE-27, 1 month after the education programme. While participants were not stopped from participating in any activities related to their epilepsy or gaining new information, they were requested to inform the investigators during the follow-up sessions.

Epilepsy Education Programme

In view of a lack of availability of epilepsy educational materials in rural settings and Malaysia as a whole, a locally structured programme was initiated to fill these gaps and supplement available care. Our EEP was based on the interactive MOSES programme design. Due to access limitations to healthcare facilities in rural area, the two-day programme was compressed to a single session with provision of written materials and epilepsy diary. EEP was pharmacists led with collaboration and referrals from both the medical and therapeutic drug monitoring teams.

Prior to implementation of EEP, all the modules were evaluated for relevance and importance by two medical specialists. Several amendments were made to simplify and individualise the contents to rural Sabah context. This was followed by readability and comprehension assessment of the modules and accompanying written guides in Malay language by five epilepsy patients. Certain medical terms were further simplified and additional keywords were added to the interviewer guide to assist in standardised explanation.

Each EEP session was carried out by trained pharmacists to ensure consistent and timely implementation. The programme consisted of four major modules, which were: About Epilepsy, Causes, Treatment and Living with Epilepsy (Table 1). Treatment and Living with Epilepsy modules were further divided into several subtopics and selected based on patient characteristics and needs. Upon completion of a session, patients were provided a written guide containing similar information for reference. An epilepsy diary was also provided to remind patients of their follow-up assessment appointments.

Table 1: Modules and subtopics of epilepsy education programme.

1. About Epilepsy	2. Causes
3. Treatment Importance of medications Side effects	4. Living with Epilepsy Driving Sports & activities Pregnancy Emergency management

Instruments

Malay AKA Epilepsy is a validated questionnaire used in a study by Neni *et al.* (2010) for evaluation in rural communities in East Coast region of Peninsular Malaysia towards epilepsy. The questionnaire consists of three domains: awareness (5 items), knowledge (8 items) and attitudes (4 items). The awareness domain measures the familiarity towards epilepsy, while the knowledge domain evaluates the specific attributes of the disease. Concurrently, the attitude domain takes upon the perspective of subjects on whether PWE would be able to participate positively as part of the community. Each response has a score range of 0–10. The scores for both awareness and knowledge domain can further be grouped and interpreted into 5 levels: very low, low, moderate, high and very high. Attitude scores can also be grouped and interpreted into 5 levels: very negative, negative, indifferent, positive and very positive.

A total AKA score can be generated via the summation of all three domain scores to give the overall AKA level of all respondents. The score ranges from 0–170 with the interpretation of total AKA level: 0–33 = very poor, 34–67 = poor, 68–101 = moderate, 102–135 = good and 136–170 = excellent. This instrument could either be self or interviewer administered.

Malay Brief COPE-27 was used to evaluate the coping mechanisms of the participants in the study (Neni and Lua 2011). This validated Malay version is based on the original Brief COPE, consisting of 27 items assessing 14 different domains (Ab Rahman 2005). The 14 dimensions of coping consists of self-distraction, active-coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame. Each response was scored on a Likert scale ranging from 1–4, with higher score reflecting higher rate of opting for the activities.

Statistical Analysis

We used IBM SPSS Statistics for Windows, version 18.0 (IBM Corp., Armonk, N.Y., USA) to analyse the data. The changes in AKA were analysed using paired *t*-test while changes in coping mechanisms were analysed using Wilcoxon-signed-ranks test. Spearman's rank correlation test was used to analyse the correlation between AKA and coping mechanisms.

Ethical Approval

The study obtained ethical approval from the National Institute of Health (NIH) and Medical Research and Ethics Committee (MREC) (NMRR-12-847-13039).

RESULTS

Twenty-one participants were recruited from specialist clinic pharmacy of Hospital Keningau and one participant from outpatient pharmacy of Hospital Tenom, Sabah. Out of the 22, 14 participants successfully completed the 6-month follow up study period. The socio-demographic characteristics are shown in Table 2. Respondents characteristics varied in terms of both age and duration of epilepsy. The median duration of epilepsy was 11 years while ranging from 1–46 years. All 22 of the respondents recruited had generalised tonic-clonic seizure. There were more males and most participants were staying with spouse or family. All participants had a faith in religion, with Christianity forming more than half of the number.

Table 2: Socio-demographic characteristics of participants (*n* = 22).

Variables	**Median**	**Min, max**
Age (years)	33	18, 59
Duration of epilepsy (years)	11	1, 46
	n	**%**
Gender		
Male	15	68.2
Female	7	31.8
Living arrangement		
Alone	2	9.1
With spouse / family	20	90.9

(*continued on next page*)

Table 2: (*continued*)

	n	**%**
Education level		
Tertiary	6	27.3
Secondary	13	59.1
Primary	3	13.6
Religion		
Islam	8	36.4
Christian	14	63.6
Ethnicity		
Dusun	13	59.1
Murut	5	22.7
Malay	2	9.1
Chinese	1	4.5
Brunei	1	4.5

While the environment was not controlled, no participants reported that they had participated in any other internal or external education programme during the 6 months period and this also corresponded with the hospital programme activity lists. Total AKA score of participants showed a significant increase (mean score difference = 16.3, *p* = 0.021, 95% CI: 3.0, 28.1) at 6 months post-EEP. This improvement was mostly contributed by the increase in both Knowledge (mean score difference = 8.9, *p* = 0.009, 95% CI: 2.9, 14.9) and Attitude scores (mean score difference = 5.6, *p* = 0.040, 95% CI: 0.3, 10.8). However, in terms of clinical improvement, only attitude level showed an improvement from 'indifferent' to 'positive' while Knowledge level remained 'high' throughout the study. Awareness level was 'low' and not affected by the programme. The total AKA level nevertheless showed a positive change, from 'moderate' to 'good' after the intervention. Figure 1 shows that these changes are sustained at least for a period of 6 months.

The result of the Malay Brief COPE-27 is shown in Figure 2. Among all the coping mechanisms, religion was the most popular (82.5%), followed by instrumental support, emotional support, active coping and acceptance (75.0%). Substance Use was the least preferred coping skills (32.5%). After 1 month of education programme, only three coping skills showed significant differences. Planning showed an increase in preference (62.5% versus 77.5%; *p* = 0.026) while denial and Venting showed a decreasing trend (57.5% versus 37.5%; *p* = 0.04 and 62.5% versus 52.5%; *p* = 0.04, respectively).

In terms of correlation between AKA and coping mechanisms, only knowledge showed significant correlations with five of the coping strategies. Knowledge was negatively correlated with Active Coping while being positively correlated with emotional support, instrumental support, humour and acceptance (Table 3).

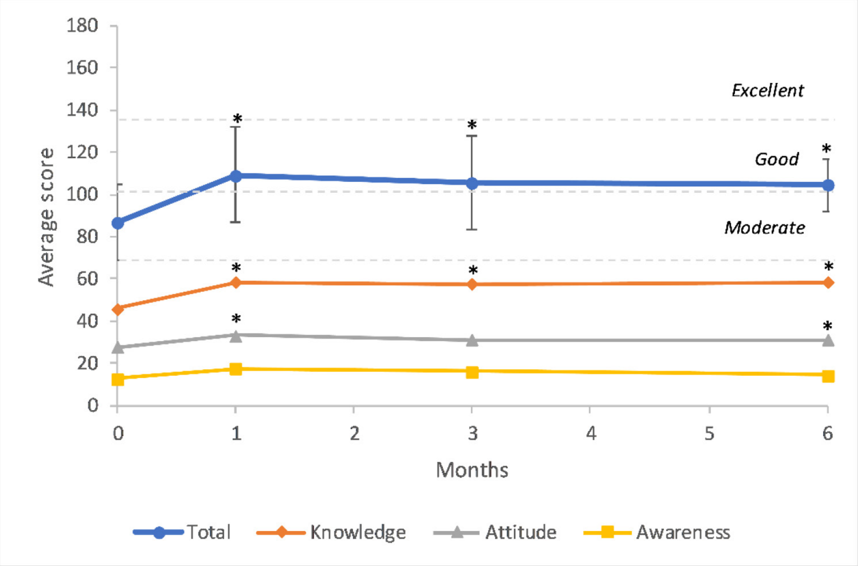

Figure 1: Total AKA scores of patients over a period of 6 months (*$p < 0.05$, based on paired *t*-test). Dotted lines represent the cut-off range for categorising the levels of total AKA scores.

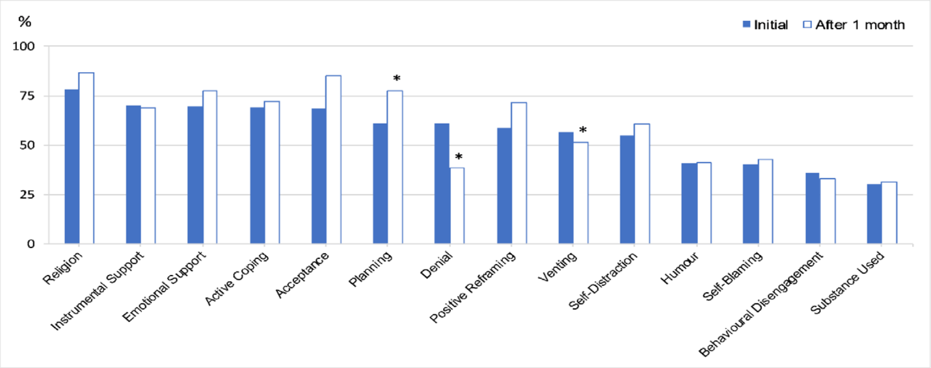

Figure 2: Coping mechanism of 22 patients with epilepsy before and after 1 month of EEP (*$p < 0.05$, based on Wilcoxon-signed-ranks test). Each bar represents the average preference towards specific coping strategies in percentage.

Table 3: Correlation between AKA and coping mechanism.

Coping mechanisms	**AKA**		
	Awareness (r_s)	**Knowledge (r_s)**	**Attitude (r_s)**
Self-distraction	+0.164	–0.303	+0.021
Active coping	–0.140	**–0.553***	–0.127
Denial	–0.528	+0.018	–0.367
Substance use	+0.143	–0.501	+0.081
Emotional support	–0.284	**+0.620***	–0.420
Instrumental support	–0.161	**+0.644***	–0.466
Behavioural disengagement	–0.413	–0.102	+0.460
Venting	–0.073	+0.121	+0.002
Positive reframing	–0.392	+0.156	+0.313
Planning	–0.426	+0.317	+0.063
Humour	+0.178	**+0.577***	–0.240
Acceptance	+0.010	**+0.560***	–0.172
Religion	–0.073	+0.380	+0.024
Self-blame	–0.110	+0.040	+0.321

Note: r_s= Correlation coefficient based on Spearman's rank correlation test (*$p < 0.05$).

DISCUSSION

This study provided a preliminary insight to the gaps in awareness, knowledge and attitude of PWE in rural Sabah. Even though based on total AKA score, respondents were categorised as being 'moderate', their baseline knowledge on epilepsy was 'high'. This was in contrary to a majority of studies carried out locally and around the world (Gourie-Devi, Singh and Bala 2010; Kiwanuka and Anyango Olyet 2018; Long *et al*. 2000). Studies in rural areas of East Coast Peninsular Malaysia for example showed PWE generally had a low level of knowledge (Neni *et al*. 2010; Rathor *et al*. 2017). Besides some common misconceptions on epilepsy, our patients largely had a good understanding of the disease. This may have been formed by good healthcare support services and communication with healthcare professionals. Based on our findings, some of the areas with misconceptions that can be further improved are on causes of epilepsy and emergency management of seizures.

The change in Attitude from 'indifferent' to 'positive' after the educational programme might be influenced by the gain in knowledge on management of epilepsy. Several interventional studies showed similar trends of improvement in attitudes occurring with improvements in knowledge (Lim *et al*. 2013; Wang *et al.* 2009). Although significantly associated, only certain aspects of knowledge were shown to influence better attitudes in these studies. Knowing information such as epilepsy can be treated effectively, being non-contagious and nature of seizures were some of the parts consistently associated with better attitudes towards epilepsy and can be incorporated during consultations or in educational programmes (Kim *et al*. 2003; Lim *et al*. 2013).

The constantly low level of awareness might have been due to lack of specificity of the items in the domain towards PWE. This is because the questions were directed more towards awareness of general public rather than the PWE themselves (Ab Rahman 2005). For example, questions such as "Have you seen a seizure?", "Do you have family members with epilepsy?", and "Have you carried out emergency assistance during seizure?" are not suitable to gauge the level of awareness of PWE. Patients tend to have better understanding or information seeking behaviour compared to disease naïve public. Furthermore, EEP was not able to modify these aspects of awareness as they are solely based on individual exposures rather than intrinsic cognisance. Thus, a more patient-specific questionnaire may be needed in future to measure changes in awareness.

The improvement in knowledge was in similar pattern to education programmes like MOSES, albeit the latter being carried out for a longer period of time and involving more resources such as manuals, trainers and therapeutic aids (May and Pfäfflin 2002). Furthermore, the improvement was shown to be retained over a period of at least 6 months. High information retention can be partly attributed by the modular structure of the programme and complemented with written materials. A parallel study in general practice care showed a structured counselling was critical for information recall by PWE (Rajpura and Sethi 2004).

Choice and Changes in Coping Mechanisms

From our study, the most frequently practised coping strategy, Religion was unaffected by the education programme. It can be concluded that knowledge does not interfere with established patients' beliefs. All the participants were either Muslims or Christians. Both religions teach about the concept of acceptance, where the disease process for example is seen as a test from God (Neni and Lua 2011).

Besides religion, four other coping skills that were equally highly preferred were instrumental support, emotional support, acceptance and active coping. Similar trend was also seen in a study among PWE in Kuala Terengganu (Neni and Lua 2011). The need for support arises because most PWE are taken care by family members due to the unpredictable nature of seizures. Acceptance and Active Coping, on the other hand, are closely associated with psychosocial aspect of trying to fit into family or society (Paschal *et al*. 2007). These are further supported by local cultural norms that regard the family as the most important social group, especially in a more rural community. The lack of changes in preference after the EEP reflects either these skills were not affected by improvement in knowledge and awareness or changes could not be seen as they are highly preferred.

Planning skills, which involves finding strategies for improving the current situation became more preferred after the intervention. Certain changes occur from acquisition of new information regarding their condition which allowed them to make informed choices regarding their well-being. For example, information about avoidance of seizure triggers and lifestyle modifications from the education programme might guide patients to proactively develop strategies to deal with their condition. On the other hand, the decrease in denial and venting might have been contributed by the change in behaviour, as they have learnt to accept their condition (Hagemann *et al.* 2016).

AKA dan Coping Mechanisms

Understanding the correlation between AKA and coping mechanisms among PWE may assist healthcare professionals to develop shorter interventional programmes with greater impact. Our study showed that only the Knowledge domain is significantly correlated with domains from coping skills.

Knowledge and Active Coping were shown to be negatively correlated. This means that higher knowledge level corresponds to lower willingness to actively cope with the disease. This might be due to understanding of the disease process which is seen as natural and thus, does not need any active interventions or solutions. Patients at this level often have learned to 'accept' and live with their condition. Such a pattern is consistent with the improvement in Acceptance score as knowledge level increases.

Knowledge was positively correlated with Acceptance*,* Instrumental Support and Emotional Support. These were also the preferred coping skills by many in our rural setting. Instrumental Support is seeking others for solutions and advices while Emotional Support is the availability of support system from those around. This relationship could have been contributed by alleviation of stigma, discriminations and low self-esteem of the patients (Saengpattrachai *et al*. 2010). The knowledge obtained could assist the patients to understand their conditions better. This is often followed by enhanced awareness on their needs and increased vigilance, leading to greater help seeking behaviour (Lau *et al*. 2001; Neni and Lua 2011).

Both Instrumental and Emotional Supports are also vital as PWE are often debilitated by the stigmas closely associated with them. This is repeatedly reinforced by false perceptions such as epilepsy being caused by 'spirits' and it being 'contagious', as seen from our study (Ab Rahman 2005). Such views further cause them to shy away from professional help or family support, causing the isolation to deepen. From the perspective of a healthcare professional, an educational programme such as this can be used as a tool to engage patients for a better management of the symptoms and improvement in quality of life (Lua and Neni 2011; Lua, Neni and Samira 2012).

Knowledge and Humour were also positively correlated. The knowledge gained might place the patients in a better position to explain, or in this instance, humour and joke about the condition as a positive adaptive exercise (Couldridge, Kendall and March 2001; Neni and Lua 2011). Fascinatingly, humour was one of the least preferred coping skills. Patients in a more rural setting might be uncomfortable to take their conditions lightly or joke about it. Thus, even though knowledge was shown to correlate significantly with Humour, the impact of it as a crucial coping skill is still negligible in our setting.

Limitations and Future Research

As with other studies in this setting, caution should be practised while generalising or extrapolating our results to a larger population. This is mostly due to the limited sample size caused by the constraints of time and human resources to carry out such a novel programme. Even though the sample obtained was lesser than the initial calculated number, it was still powered to detect the differences in the larger than estimated changes in AKA scores. However, the smaller sample coupled with large heterogeneity associated with clinical condition and socio-demographic factors may limit the generalisability of the findings. This study highlights the diverse epilepsy population spectrum and the benefits measured may act as a gauge of effectiveness of the educational programme in the real world.

This study was designed in an observational exploratory approach due to uncertainties on changes in coping skills in PWE from the education programme. While improving the feasibility of study conduct in a resource-limited rural area, this approach may have discounted the effect of factors such as healthcare contact, constant support and reaffirmation of behaviours. These factors can only be distinguished from the educational programme if the study can be conducted as a randomised controlled trial. We hope that with our findings, it will now be possible to have a more accurate sample size estimations and to justify the exploration of education programmes via such a strategy.

Impact of the education programme on clinical outcomes such as seizure severity, frequencies, and seizure-related injuries will be more of a value as they represent the ideal indication of treatment success in a hospital setting. This was unable to be analysed due to the variation in the seizure nature and participants socio-demographic factors. Thus, further studies in these areas with a larger population may elucidate the clinical benefits of knowledge-guided behavioural influences. Nevertheless, improvements in coping skills should not be discounted regardless of clinical outcomes as they are a vital component of psychosocial adjustment and quality of life indicator.

CONCLUSION

The study clearly indicated the needs of patients for education regarding epilepsy. Changes in AKA were shown to affect how patients adapt to their conditions. Our EEP was effective in improving certain aspects of attitude and knowledge while bringing about changes in coping with epilepsy in daily life. Educational programmes such as this is recommended to be a standard care in epilepsy care, especially as they are inexpensive and brief yet impactful. Focus should also be redirected to devise programmes that tackle both knowledge and coping skills of patients for a more sustainable outcome in terms of epilepsy management and quality of life.

ACKNOWLEDGEMENTS

We would like to thank Dr. Ridwan Hashim and Mrs. Vivila Bubuyan of Hospital Keningau, Sabah for consistently supporting and assisting in completion of this study. We would also like to extend our deepest gratitude to Prof. Lua Pei Lin and Dr. Neni Widiasmoro Selamat for sharing their questionnaire and constructive inputs on the analysis.

The authors would also like to thank the Director General of Health, Ministry of Health Malaysia for his permission to publish this paper.

REFERENCES

AB RAHMAN, A. F. (2005) Awareness and knowledge of epilepsy among students in a Malaysian university, *Seizure: European Journal of Epilepsy,* 14(8): 593–596. https://doi.org/10.1016/j.seizure.2005.09.005

BEGHI, E. (2005) Injuries in patients with epilepsy, *The Lancet Neurology,* 4(2): 71–72. https://doi.org/10.1016/S1474-4422(05)00971-3

BRADLEY, P. M., LINDSAY, B. & FLEEMAN, N. (2016) Care delivery and self management strategies for adults with epilepsy, *Cochrane Database of Systematic Reviews,* (2): Art No. CD006244. https://doi.org/10.1002/14651858.CD006244.pub3

COULDRIDGE, L., KENDALL, S. & MARCH, A. (2001) A systematic overview decade of research. The information and counselling needs of people with epilepsy, *Seizure,* 10(8): 605–614. https://doi.org/10.1053/seiz.2001.0652

ENGLAND, M. J., LIVERMAN, C. T., SCHULTZ, A. M. & STRAWBRIDGE, L. M. (2012) Epilepsy across the spectrum. Promoting health and understanding: A summary of the Institute of Medicine report, *Epilepsy & Behavior,* 25(2): 266–276. https://doi.org/10.17226/13379

FISHER, R. S., VICKREY, B. G., GIBSON, P., HERMANN, B., PENOVICH, P., SCHERER, A., et al. (2000) The impact of epilepsy from the patient's perspective II: Views about therapy and health care, *Epilepsy Research,* 41(1): 53–62. https://doi.org/10.1016/S0920-1211(00)00128-5

GOURIE-DEVI, M., SINGH, V. & BALA, K. (2010) Knowledge, attitude and practices among patients of epilepsy attending tertiary hospital in Delhi, India and a review of Indian studies, *Neurology Asia,* 15(3): 225–232.

HAGEMANN, A., PFÄFFLIN, M., NUSSBECK, F. W. & MAY, T. W. (2016) The efficacy of an educational program for parents of children with epilepsy (FAMOSES): Results of a controlled multicenter evaluation study, *Epilepsy & Behavior,* 64: 143–151. https://doi.org/10.1016/j.yebeh.2016.09.027

HELDE, G., BOVIM, G., BRÅTHEN, G. & BRODTKORB, E. (2005) A structured, nurse-led intervention program improves quality of life in patients with epilepsy: A randomized, controlled trial, *Epilepsy & Behavior,* 7(3): 451–457. https://doi.org/10.1016/j.yebeh.2005.06.008

HELGESON, D. C., MITTAN, R., TAN, S. Y. & CHAYASIRISOBHON, S. (1990) Sepulveda epilepsy education: The efficacy of a psychoeducational treatment program in treating medical and psychosocial aspects of epilepsy, *Epilepsia,* 31(1): 75–82. https://doi.org/10.1111/j.1528-1157.1990.tb05363.x

KIM, M.-K., KIM, I.-K., KIM, B.-C., CHO, K.-H., KIM, S.-J. & MOON, J.-D. (2003) Positive trends of public attitudes toward epilepsy after public education campaign among rural korean residents, *Journal of Korean Medical Science,* 18(2): 248. https://doi.org/10.3346/jkms.2003.18.2.248

KIWANUKA, F. & ANYANGO OLYET, C. (2018) Knowledge, attitude, and beliefs on epilepsy among adults in Erute South, Lira District, Uganda, *Epilepsia Open,* 3(2): 264–269. https://doi.org/10.1002/epi4.12223

LAU, V. W., LEE, T. M., NG, P. K. & WONG, V. C. (2001) Psychosocial adjustment of people with epilepsy in Hong Kong, *Epilepsia,* 42(9): 1169–1175. https://doi.org/10.1046/j.1528-1157.2001.06101.x

LIM, K. S., WO, M., CHEN, M., AHMAD, S. B. & TAN, C. T. (2013) Only certain aspects of knowledge have impact on attitudes toward epilepsy, *Neurology Asia,* 18(4): 361–368.

LIU, L., YIU, C.-H., YEN, D.-J., CHOU, M.-H. & LIN, M.-F. (2003) Medication education for patients with epilepsy in Taiwan, *Seizure,* 12(7): 473–477. https://doi.org/10.1016/S1059-1311(03)00006-2

LONG, L., REEVES, A. L., MOORE, J. L., ROACH, J. & PICKERING, C. T. (2000) An assessment of epilepsy patients' knowledge of their disorder, *Epilepsia,* 41(6): 727–731. https://doi.org/10.1111/j.1528-1157.2000.tb00235.x

LUA, P. L. & NENI, W. S. (2011) Awareness, knowledge, and attitudes with respect to epilepsy: An investigation in relation to health-related quality of life within a Malaysian setting, *Epilepsy & Behavior,* 21(3): 248–254. https://doi.org/10.1016/j.yebeh.2011.03.039

LUA, P. L. & NENI, W. S. (2012) Feasibility and acceptability of mobile epilepsy educational system (MEES) for people with epilepsy in Malaysia, *Telemedicine and e-Health,* 18(10): 777–784. https://doi.org/10.1089/tmj.2012.0047

LUA, P. L., NENI, W. S., LEE, J. K. F. & ABD AZIZ, Z. (2013) The interactive animated epilepsy education programme (IAEEP): How feasible, acceptable and practical is the technology to children? *Technology and Health Care,* 21(6): 547–556. https://doi.org/10.3233/THC-130758

LUA, P. L., NENI, W. S. & SAMIRA, T. N. (2012) Coping with epilepsy: How do they influence: Health-related quality of life (HRQoL), *Int J Psychosoc Rehabil,* 16(1): 17–32.

MAC, T. L., TRAN, D.-S., QUET, F., ODERMATT, P., PREUX, P.-M. & TAN, C. T. (2007) Epidemiology, aetiology, and clinical management of epilepsy in Asia: A systematic review, *The Lancet Neurology,* 6(6): 533–543. https://doi.org/10.1016/S1474-4422(07)70127-8

MAY, T. W., & PFÄFFLIN, M. (2002) The efficacy of an educational treatment program for patients with epilepsy (MOSES): Results of a controlled, randomized study, *Epilepsia,* 43(5): 539–549. https://doi.org/10.1046/j.1528-1157.2002.23801.x

MEADS, C., BRADLEY, P. & BURLS, A. (2001). *The effectiveness of specific epilepsy services*. (Birmingham: Department of Public Health and Epidemiology, University of Birmingham).

NENI, S. W., LATIF, A. Z. A., WONG, S. Y. & LUA, P. L. (2010) Awareness, knowledge and attitudes towards epilepsy among rural populations in East Coast Peninsular Malaysia: A preliminary exploration, *Seizure,* 19(5): 280–290. https://doi.org/10.1016/j.seizure.2010.04.006

NENI, S. W., & LUA, P. L. (2011) Relationships between awareness, knowledge, attitudes and coping mechanisms in epilepsy, *ASEAN J Psychiatry,* 12(2): 131–142.

PASCHAL, A. M., HAWLEY, S. R., ROMAIN, T. S., LIOW, K., MOLGAARD, C. A., SLY, J. et al. (2007) Epilepsy patients' perceptions about stigma, education, and awareness: Preliminary responses based on a community participatory approach, *Epilepsy & Behavior,* 11(3): 329–337. https://doi.org/10.1016/j.yebeh.2007.06.007

POOLE, K., MORAN, N., BELL, G., SOLOMON, J., KENDALL, S., MCCARTHY, M. et al. (2000) Patients' perspectives on services for epilepsy: A survey of patient satisfaction, preferences and information provision in 2394 people with epilepsy, *Seizure,* 9(8): 551–558. https://doi.org/10.1053/seiz.2000.0450

RAJPURA, A. & SETHI, S. (2004) Evidence-based standards of care for adults with epilepsy—a literature review, *Seizure,* 13(1): 45–54. https://doi.org/10.1016/S1059-1311(03)00074-8

RATHOR, M. Y., SHAHAR, M. A., OMAR, A. M. B., SHAH, A. S., HASMONI, M. H., DRAMAN, C. R. et al. (2017) Assessment of knowledge, attitude and practices of epilepsy patients towards their illness and treatment in a tertiary care hospital in Kuantan Pahang Malaysia, *Bangladesh Journal of Medical Science,* 16(4): 545–553. https://doi.org/10.3329/bjms.v16i4.33610

SAENGPATTRACHAI, M., SRINUALTA, D., LORLERTRATNA, N., PRADERMDUZZADEEPORN, E. & POONPOL, F. (2010) Public familiarity with, knowledge of, and predictors of negative attitudes toward epilepsy in Thailand, *Epilepsy & Behavior,* 17(4): 497–505. https://doi.org/10.1016/j.yebeh.2010.01.164

SINGH, A. & TREVICK, S. (2016) The epidemiology of global epilepsy, *Neurologic Clinics,* 34(4): 837–847. https://doi.org/10.1016/j.ncl.2016.06.015

THEODORE, W. H., SPENCER, S. S., WIEBE, S., LANGFITT, J. T., ALI, A., SHAFER, P. O. et al. (2006) Epilepsy in North America: A report prepared under the auspices of the global campaign against epilepsy, the International Bureau for Epilepsy, the International League Against Epilepsy, and the World Health Organization, *Epilepsia,* 47(10): 1700–1722. https://doi.org/10.1111/j.1528-1167.2006.00633.x

WANG, W., ZHAO, D., WU, J., WANG, T., DAI, X., MA, G. et al. (2009) Changes in knowledge, attitude, and practice of people with epilepsy and their families after an intervention in rural China, *Epilepsy & Behavior,* 16(1): 76–79. https://doi.org/10.1016/j.yebeh.2009.06.027