

Dear readers,

As promised following our recent announcement here is our first briefing document on recently published research which we hope will be of interest to the IBE Membership.

Key topics will include :

- Self-management including education and knowledge; and the application of self-help strategies.
- Stigma interventions aimed at both people with epilepsy and the public.
- Discrimination against people with epilepsy in different life areas (eg. healthcare, education, occupation, insurance)
- Educational and occupational initiatives targeted at different sections of the public.
- Specific interventions for the comorbidities of epilepsy [anxiety, depression, low self-esteem].
- The application of mobile health apps, telemedicine and social media in these areas (self-management, stigma and discrimination, education and assessment for psychiatric comorbidities).

*Self- management
of epilepsy*

Self-Management in epilepsy

Effect of intensive self-management education on seizure frequency and quality of life in epilepsy patients with prodromes or precipitating factors. Hu et al., *Seizure: European Journal of Epilepsy*, 05 March 2020

Purpose

To explore the impact of an intensive self-management education strategy on seizure frequency and quality of life in patients with epileptic seizures with prodromes or precipitating factors. The intensive self-management education included monthly education sessions on prodromes and precipitating factors aiming to help patients to adopt self-management strategies.

Methods

Adult patients with epilepsy (PWE) able to identify prodromes or precipitating factors of their seizures were randomly assigned to an intensive education group (IEG) (n = 45) or a regular education group (REG) (n = 47). All patients received a single face-to-face self-management education session at the time of enrollment. Both groups of patients received monthly telephone follow-up for 1 year. PWE in the IEG received intensive education during each follow-up call. Primary outcomes were seizure frequency, quality

of life (Quality of life in epilepsy-31 inventory scores, QOLIE 31), and drug adherence (Morisky medication adherence scale, MMAS).

Results

At the end of the 1-year follow-up period, seizure frequency in the IEG was significantly lower than at baseline ($p < 0.001$), but not in the REG ($p = 0.085$). Quality of life had improved significantly in the IEG ($p < 0.001$), but not in the REG ($p = 0.073$). Drug adherence was better in the IEG than in the REG ($p = 0.003$), and there were fewer accidental injuries in the IEG than the REG ($p = 0.031$).

Conclusions

In PWE aware of seizure prodromes or precipitating factors, intensive self-management education may reduce seizure frequency, improve quality of life, increase adherence with antiepileptic medication and reduce accidental injuries caused by seizures.

Editors comments

It will be important to have available proven intervention programmes that can be adapted and rolled out

Children with epilepsy and the Ketogenic diet

Use of Ketogenic diets in infants with epilepsy

Use of ketogenic diet therapy in infants with epilepsy: A systematic review and meta-analysis.

Lyons et al., *Epilepsia*, 26 May 2020

Purpose

Ketogenic diet therapy (KDT) is a group of high-fat, low-carbohydrate diets used as an effective treatment option for children and adults with drug-resistant epilepsy. There is limited research on the efficacy of KDT in infants, where there is the highest incidence of onset of the epilepsy. The authors aimed to systematically review studies that have reported on response to KDT in infants with epilepsy

Methods

Thirty-three studies met inclusion criteria and were included in the final analysis, with a total of 534 infants with efficacy data. Two studies were randomized controlled trials, and the remainder were uncontrolled cohort studies.

Results

All studies were categorized as low quality. Meta-analyses of uncontrolled studies estimate 59% of infants achieved $\geq 50\%$ seizure reduction and 33% of infants achieved seizure freedom. Retention rates ranged from 84% at 3 months to 27% at 24 months. The most commonly reported side effects were dyslipidemia (12%), vomiting (6%), constipation (74%), gastroesophageal reflux (64%), and diarrhea (4%).

Conclusions

This review indicates that KDT is safe and tolerable and that it can be an effective treatment option for infants with drug-resistant epilepsy. However, there are few studies focusing on infants treated with KDT, and high-quality evidence is lacking.

Editors Comments

This study is important in that it highlights the role of KDT in the management of chronic epilepsy in infants and the need for better evidence.

Public Attitudes Toward Epilepsy (PATE) Study

Public Attitudes Toward Epilepsy in East Malaysia

Attitudes toward epilepsy in East Malaysia using the Public Attitudes Toward Epilepsy (PATE) scale. Chia et al., *Epilepsy & Behavior*, 05 June 2020

Purpose

Public Attitudes Toward Epilepsy (PATE) scale was developed by Lim et al. in 2012 (*Epilepsy & Behavior* 2012) aimed to explore the attitudes in two domains. General domain explores the general attitudes toward epilepsy without personal involvement, whereas personal domain requires the participant to consider personal commitment, such as dating, marriage, and employment.

Methods

This scale was translated to many languages and applied in different populations for direct comparison. East Malaysia comprises of 2 out of 13 states of Malaysia (Sabah and Sarawak) and the Federal Territory of Labuan, located on the island of Borneo, adjacent to Brunei and Kalimantan, a state of Indonesia. A large proportion of its population is made up of the indigenous ethnic groups such as Iban and Bidayuh in Sarawak and Kadazan-Dusun in Sabah.

Results

A total of 360 respondents (41.7% Kadazan-Dusun, 30.6% Bidayuh, and 24.7% Iban) aged 34.6 ± 12.6 years completed the questionnaire. They were predominantly females and had lower education level and income compared with the West Malaysians. The Sabah population had significantly lower mean scores (better attitudes) than those in Sarawak, in both personal and general domains ($p < .001$). As compared with West Malaysia, the mean score in the personal domain was significantly lower in Sabah, while Sarawak had significantly higher scores in general domain ($p < .001$). Subanalysis showed that the Sabah population had better attitudes toward marriage and employment in PWE than the West Malaysians, whereas Sarawak had poorer attitudes toward education and social contact in PWE

Conclusions

The attitudes toward epilepsy were different among the indigenous populations in Sabah and Sarawak, and from the West Malaysians, which could be attributable to their sociocultural differences

Editors Comments

The importance of this study is that it highlights differences in attitudes across countries such that in any programme of attitude change, cultural differences will need to be considered.

Discrimination and Stigma study

Agreement of Palestinian nursing students with recommendations to eliminate epilepsy stigma and change perception of the general public about epilepsy: A cross-sectional study

Agreement of Palestinian nursing students with recommendations to eliminate epilepsy stigma and change perception of the general public about epilepsy: A cross-sectional study. Shawahna, *Epilepsy & Behavior*, 18 May 2020

Purpose

This study was conducted to assess the degree of agreement of Palestinian nursing students with recommendations and key messages to eliminate/reduce epilepsy stigma and change perception of the general public about epilepsy and people with epilepsy (PWE).

Methods

A cross-sectional observational study was conducted among undergraduate nursing students. The study tool was a questionnaire with 24 items which collected the sociodemographic and academic characteristics of the participants (6 items) and agreements with 18 recommendations and key messages to eliminate/reduce epilepsy stigma.

Results

A total of 342 nursing students completed the questionnaire with a response rate of 68.4%. The participants agreed with the 6 recommendations to inform media, improve awareness, and educate the general public on epilepsy (agreement rates: 87.7% to 92.4%), 4 recommendations to coordinate efforts to improve awareness and educate the general public on epilepsy and PWE (agreement rates: 89.8% to 93.0%), and 8 key messages to eliminate/reduce epilepsy stigma (agreement rates: 70.2% to 93.9%). In

general, female students tended to express significantly higher levels of agreement with the recommendations and key messages (p -value < 0.05).

Conclusion

Results of the present study highlighted the importance of involving nurses and future nurses in eliminating/reducing epilepsy stigma and changing perception of the general public about epilepsy and PWE. Further studies are to be conducted to investigate if these recommendations and messages can eliminate or significantly reduce epilepsy stigma and change perception of the general public about epilepsy and PWE.

Editors Comments

Any programme for reducing stigma in epilepsy is likely to be multi-faceted and treating clinical staff do have a significant role in reducing the impact of epilepsy and its treatment.

Public perception and attitudes towards epilepsy

Public perception and attitude towards people living with epilepsy in Nigeria

Public perception and attitude towards people living with epilepsy in Nigeria. Adewumi et al., *Epilepsy & Behavior*, 24 March 2020

Purpose

This study aimed to assess the community knowledge, awareness, and attitude towards people living with epilepsy (PLWE) in Lagos, Nigeria. This was to provide background information for formulating evidence-based campaign and intervention to reduce stigma and improve health-related quality of life amongst PLWE and their families.

Methods

Adult respondents ($n = 1614$) selected via multistage probability sampling completed a set of questionnaires. A case vignette was used to depict epilepsy. The respondents' knowledge of, familiarity with, perceived cause, and preferred treatment option for epilepsy were assessed. Their attitude towards people's attitude was measured with Attitudes and Beliefs about Living with Epilepsy (ABLE) scale.

Results

While a total of 1258 (67.6%) could correctly name the illness as epilepsy, only 945 (58.5%) had witnessed an epileptic seizure episode before. The most endorsed causes of epilepsy were brain injury/infection (75.8%), evil spirit/witchcraft (73.0%), God's will (70.0%), and infection by contact (64.9%). Only 67.6%

believe that epilepsy is treatable, and 42.5% preferred treatment by spiritualist. Generally, there was a positive attitude to PLWE; however, there were serious risk and safety concerns. The factors associated with negative attitude towards PLWE include male gender (adjusted odds ratio [AOR]: 2.44, 95% confidence interval [CI]: 1.98–3.00), lower educational status (AOR: 1.69, 95% CI: 1.32–2.16), poor knowledge of epilepsy (AOR: 1.74, 95% CI: 1.36–2.22), poor familiarity with epilepsy (AOR: 1.65, 95% CI: 1.14–2.42), and endorsement of supernatural causes of epilepsy (AOR: 1.59, 95% CI: 1.28–1.97).

Conclusion

Closing the treatment gap for epilepsy in Nigeria and other sub-Saharan Africa countries will involve steps to change the misconception of the Nigerian populace as regards the causes of epilepsy and help seeking pathway. There is need for nationwide educational programs for epilepsy that consider cognitive and affective processes and also involve all the major stakeholders like primary care workers, community leaders, and spiritual and traditional leaders.

Editors comments

Addressing public attitudes towards peoples with epilepsy has always been at the forefront of the IBE alongside interventions to reducing the stigma of the condition.

Editors

We have provided the reader with a small number of articles that we feel may be of interest to members of the IBE. We hope that the readers will find them relevant. We have provided The IBE office with the full articles for further information.

If you wish to bring to our attention any other papers that we should bring to the attention of the IBE members please do not hesitate to contact us by [emailing the IBE Office](#).

We are grateful to the support of Lee Rusowicz in assisting with the production of this research brief.

With Best Wishes,

Professor Gus A Baker and Professor Kheng Seang