

IBE Briefing Document: Published Research papers

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Dear readers,

As promised here is our 2nd briefing document on recently published research which we hope will be of interest to the IBE Membership. Key topics will continue to 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 in epilepsy: facilitators and barriers

Barriers and facilitators to implementation of epilepsy self-management programs: a systematic review using qualitative evidence synthesis. Lewinski et al Hu et al., *Systematic reviews* 2020

Background

Self-management is critical for individuals with epilepsy in order to maintain optimal physical, cognitive, and emotional health. Implementing and adopting a self-management program requires considering many factors at the person, program, and systems levels. The authors conducted a systematic review of qualitative and mixed-methods studies to identify facilitators and barriers that impact implementation and adoption of self-management programs for adults with epilepsy.

Methods

We used established systematic review methodologies for qualitative and mixed-methods studies. We included studies addressing facilitators (i.e., factors that aided) or barriers (i.e., factors that impeded) to implementation and adoption of self-management interventions for adults with epilepsy. We conducted a narrative thematic synthesis to identify facilitators and barriers.

Results

The literature search identified 2700 citations; 13 studies met eligibility criteria. Our synthesis identified five themes that categorize facilitators and barriers to successful implementation epilepsy self-management: (1)relevance, intervention content that facilitates acquisition of self-management skills; (2) personalization, intervention components that account for the individual's social, physical, and environmental characteristics; (3) intervention components, components and dosing of the intervention; (4) technology considerations, considerations that account for individual's use, familiarity with, and ownership of technology; and (5) clinician interventionist, role and preparation of the individual who leads intervention. We identified facilitators in 11 of the 13 studies and barriers in 11 of the 13 studies and classified these by social-ecological level (i.e., patient/caregiver, program, site/system).

Conclusions

Identification of facilitators and barriers at multiple levels provides insight into disease-specific factors that influence implementation and adoption of self-management programs for individuals with epilepsy. Our findings indicate that involving individuals with epilepsy and their caregivers in intervention development, and then tailoring intervention content during the intervention, can help ensure the content is relevant to intervention participants. Our findings also indicate the role of the clinician (i.e., the individual who provides self-management education) is important to intervention implementation, and key issues with clinicians were identified as barriers and opportunities for improvement. Overall, our findings have practical value for those seeking to implement and adopt self-management interventions for epilepsy and other chronic illnesses.

Editors comments

There is unlikely to be a situation where we have enough resources to provide self-management programmes for all those who would benefit from them. It will be important for the IBE and its member countries to identify programmes that are going to work for them.

Epilepsy self-management during a pandemic: Experiences of people with epilepsy

Epilepsy & Behavior – June 2020

The purpose of this descriptive study was to, from the perspective of adult people with epilepsy (PWE) and caregivers of PWE, explore the effects of the current pandemic and resulting societal changes on epilepsy self-management. Ninety-four respondents completed a mixed-methods quantitative and qualitative survey focused on their epilepsy self-management experiences during the coronavirus disease-19 (COVID-19) pandemic.

Respondents noted significant disruption in epilepsy self-management. Lack of ability to obtain medications or see epilepsy providers, as well as increased stress, social isolation, and changes in routine were all reported as troublesome, and more than one-third of the sample reported an increase in seizure frequency since the onset of the pandemic. Suggestions are given regarding how to support PWE during future COVID-19 outbreaks and to better prepare PWE and their caregivers for any life-altering events, such as a pandemic, with robust self-management skills that will allow them to maintain the highest level of function possible.

Editors comments

It is clear from the published literature to date that Covid-19 has created unique problems for people with epilepsy and their families. The ILAE and IBE have set up a number of initiatives to help cope with this crisis and they can be accessed through their websites. .

Stigma reduction interventions for epilepsy: A systematized literature review

Epilepsy and Behaviour August 2020

Epilepsy is a disease that is stigmatized globally. Several studies have introduced sensitization efforts to reduce stigma towards people with epilepsy (PWE) in various settings. Although sensitization efforts have shown some evidence of improved attitudes towards epilepsy, progress has been limited. This systematized literature review summarizes the existing literature concerning interventions that reduce stigma towards PWE. By conducting an overview of existing interventions, we aimed to consolidate knowledge and outcomes of existing efforts as well as highlight gaps and directions for future interventions.

Methods

We searched MEDLINE (via PubMed) and Embase for English-language studies published between January 1, 1970 and November 15, 2017 that focused on stigma reduction strategies for PWE in any global setting. Studies were included if they described a stigma reduction intervention for epilepsy. Studies were excluded if they were reviews, editorials, conference proceedings, abstracts, or did not discuss a stigma reduction intervention. We thematically grouped studies based on type(s) of intervention(s) addressed and summarized interventions, outcome measures, and results for each study included in the review.

Results

Of the 1975 initial citations, 32 studies met our inclusion criteria. Interventions clustered into four broad categories including public awareness interventions, policy-based interventions, school-based interventions, and interventions that targeted PWE themselves as well as their caregivers and peers. Efficacy of these interventions as reported by the authors was mixed. Many studies did not use validated outcome measures to assess stigma.

Conclusions

Although intervention efforts have been made towards epilepsy stigma reduction at many levels, stigma towards and discrimination against PWE prevail worldwide. About 75% of the studies included in this review were conducted in high-income countries (HICs) despite the disproportional need in low- and middle-income countries (LMICs). Furthermore, robust outcome measures to assess efficacy in stigma reduction for interventions are lacking, calling into question the validity of reported outcomes for both positive and null findings. Therefore, more work is needed in both developing effective stigma reduction strategies, especially in LMICs, and validating tools to measure their efficacy.

Editors Comments

This study is important in that it highlights that more efforts are needed to reduce stigma in both developed and developing countries.

Barriers to biomedical care for people with epilepsy in Uganda: A cross-sectional study

Epilepsy and Behaviour September 2020

Epilepsy, a neurological disorder with effective biomedical treatment, remains largely untreated in Uganda. Potential reasons for this treatment gap (TG) include limited access to trained providers and clinics, social stigmata of seizures, cultural beliefs, or lack of public understanding of epilepsy as a treatable condition. The current study aimed to formally evaluate barriers faced by people with epilepsy (PWE) in Uganda when seeking biomedical care.

Methods

In a cross-sectional study, 435 participants drawn from a community prevalence study were enrolled. We included participants reporting a history of recurrent seizures suggestive of epilepsy, who completed a survey about barriers to obtaining care for their symptoms. Principal axis factor analysis (PFA) using a promax rotation was conducted for data reduction. Frequencies of barrier factors were compared across those who did not seek care for epilepsy (n = 228), those who sought care from biomedical facilities (n = 166), and those who sought care from a traditional or pastoral healer (n = 41).

Results

The PFA yielded a five-factor solution: 1) logistical and actual costs; 2) treatment effectiveness; 3) influence of the opinion of others; 4) doctors' care; and 5) contextual factors impacting decision-making. Variables related to logistical and actual costs were most endorsed. Comparison of groups by care sought did not reveal a difference in endorsement of factors, with the exception that those who sought biomedical care were more likely to endorse factors related to doctors' care compared with those that sought care from traditional or pastoral healers ($P = .005$).

Conclusions

People with repetitive seizures in Uganda report several barriers to obtaining biomedical care in Uganda, with those related to practical and actual costs endorsed the most. It is imperative that interventions developed to reduce the TG in Uganda consider these practical issues to improve access to effective epilepsy care.

Editors Comments

The importance of this study is that while the IBE may not be able to address the issues of trained providers and clinics, we should be able to assist in addressing the social stigmata of seizures, cultural beliefs, or lack of public understanding of epilepsy as a treatable condition.

The information needs of parents of children with early-onset epilepsy: A systematic review –

Epilepsy & Behavior – November 2020

Objective

Early-onset epilepsy has broad physical and psychosocial impacts, and parents have a wide variety of information needs. This systematic review set out to assess 1) whether parents of children with early-onset epilepsy have unmet information needs and 2) their preferences regarding information content and style of information delivery.

Methods

We searched Medline, Embase, PsychInfo, and CINAHL using keywords relating to information needs, information resources, and preferences for information delivery. We limited the search to parent populations and included all peer-reviewed publications published in English after the year 2005.

Results

Eleven studies met our inclusion criteria. Parents reported a clear need for understandable, realistic, and focused information, highlighting a particular need for content about comorbidities and emotional support. Parents reported limited availability of detailed information resources on early-onset epilepsy, which compromised their ability to access appropriate healthcare services. Unmet information needs were associated with greater levels of stress, poorer psychosocial outcomes, and lower satisfaction with healthcare services.

Significance

The results highlight the importance of detailed epilepsy information for families. Healthcare professionals should be aware of the impact of a lack of epilepsy information on family wellbeing. Multipronged and tailored interventions targeting the information needs of families are warranted.

Editors Comments

There have been many studies highlighting informational educational needs of people with epilepsy and their families This study is important because it draws our attention to the needs of children with newly diagnosed epilepsy and their parents.

An intensive education program for caregivers ameliorates anxiety, depression, and quality of life in patients with drug-resistant temporal lobe epilepsy and mesial temporal sclerosis who underwent cortico-amygdalohippocampectomy

Brazilian Journal of Medical and Biological Research – July 2020

Purpose

This study aimed to investigate the effect of a caregiver intensive education program (CIEP) on anxiety, depression, and quality of life (QOL) in patients with drug-resistant temporal lobe epilepsy and mesial temporal sclerosis (TLE-MTS) who underwent cortico-amygdalohippocampectomy (CAH).

Methods

Ninety patients with drug-resistant TLE-MTS who underwent CAH and their caregivers were recruited and randomly allocated to the CIEP group or control group as 1:1 ratio. Caregivers received the CIEP program or routine guidance/education (control group). Anxiety/depression and QOL in patients at month (M)0, M1, M3, and M6 were assessed by the Hospital Anxiety and Depression Scale (HADS) scale and the QOL in Epilepsy Inventory-31 (QOLIE-31), respectively. Treatment efficacy at M6 was assessed by Engel classification.

Results

The HADS-anxiety score at M3 ($P=0.049$) and M6 ($P=0.028$), HADS-anxiety score change (M6-M0) ($P=0.001$), percentage of anxiety patients at M6 ($P=0.025$), and anxiety severity at M6 ($P=0.011$) were all decreased in the CIEP group compared with the control group. The HADS-depression score at M6 ($P=0.033$) and HADS-depression score change (M6-M0) ($P=0.022$) were reduced, while percentage of depression patients at M6 ($P=0.099$) and depression severity at M6 ($P=0.553$) showed no difference in the CIEP group compared with the control group. The QOLIE-31 score at M6 ($P=0.043$) and QOLIE-31 score change (M6-M0) ($P=0.010$) were both elevated in the CIEP group compared with the control group.

Conclusion

In conclusion, CIEP for caregivers contributed to the recovery of anxiety and depression as well as the improvement of QOL in patients with drug-resistant TLE-MTS who underwent CAH.

Editors comments

This study is important in that it credits the importance of families in helping people with epilepsy who have undergone surgery to adjust after the procedure and highlights the need to educate families about the impact of epilepsy surgery.

The effects of a brief memory enhancement course on individuals with epilepsy –

Epilepsy & Behavior – November 2020

Purpose

The purpose of the study was to determine whether a brief memory enhancement course in persons with epilepsy (PWE) can improve cognitive abilities, quality of life, self-management, and seizure severity.

Methods

Thirty-nine PWE completed a 1-hour memory enhancement course. This was preceded by a baseline/preintervention assessment (BA/PRE), followed by postintervention assessment (POST) at 1 & 1/2 to 3 months, and a delayed postintervention assessment evaluation (DPOST) at 4 & 1/2 to 6 months after course completion. In order to assess for retesting bias, an additional 30 PWE underwent a separate BA and PRE.

Results

There was significant improvement on the Patient-Reported Outcomes Patient Information System version 2.0 Cognitive Function Abilities Subset and the Epilepsy Self-Management Scale (ESMS) on both POST and DPOST when compared with BA/PRE. Retesting bias did not occur. On ESMS subscale evaluation, significant improvement occurred on the Lifestyle Management subscale. There was no improvement in quality of life and seizure severity. There was good patient acceptability for the memory program.

Conclusion

A brief memory enhancement course results in sustained improvement in cognitive functioning and self-management of PWE.

Editors comments

The cognitive consequences of epilepsy are often misunderstood and neglected by both researchers and clinicians. This study is important in that it provides a simple programme that could be of assistance to people with epilepsy and their families.

Technological Innovations

There are a number of publications that have specifically documented the development of tools and services that can be administered through the internet that we thought the readers might find interesting: While we do not have the space to discuss these in detail, we thought that the readership could at least have access to them

Bridging the gap in epilepsy care: A single-center experience of 3700 outpatient tele-epilepsy visits – Brief Communication, *Epilepsia* – July 2020

The development of an epilepsy electronic patient portal: Facilitating both patient empowerment and remote clinician-patient interaction in a post-COVID-19 world – full-length original article, *Epilepsia* – July 2020

Bridging the healthcare gap: Building the case for epilepsy virtual clinics in the current healthcare environment – review, *Epilepsy & Behavior* – July 2020

Counseling of people with epilepsy via telemedicine: Experiences at a German tertiary epilepsy center during the COVID-19 pandemic – full length article, *Epilepsy & Behavior* – August 2020

Editors

We have again provided the readership 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