MODULES ON EPILEPSY

MODULE VI

Education and Self-Management of Epilepsy

CONTENT

INTRODUCTION

Epilepsy, a complex neurological disorder marked by spontaneous recurrent seizures with unpredictable frequency, significantly affects the health and quality of life (QOL) of people with epilepsy (PWE). It is the fourth most common chronic neurological disorder after migraines, Alzheimer's disease, and Parkinson's disease in terms of 1-year prevalence per 1000 in the general population. In 2015, approximately 1.2% of American adults reported living with epilepsy; 68.5% had seen a neurologist or epilepsy specialist; 93% were taking antiseizure medication (ASM), and only 42.4% of those taking medication were seizure-free in the past year. Epilepsy, especially when uncontrolled, imposes a significant burden on individuals, caregivers, and society due to associated developmental, cognitive, and psychiatric comorbidities; ASM side effects; higher injury and mortality rates; reduced QOL; and increased financial costs. In 2010, neurological disorders accounted for an estimated 3.0% of global disability-adjusted life years (DALYs), with epilepsy contributing a quarter of that burden, making it the second-most burdensome chronic neurological disorder worldwide in terms of DALYs.

SELF-MANAGEMENT

Self-management (SM) education has been shown to improve SM skills, behaviors, and QOL in many chronic diseases, including heart disease, diabetes, asthma, and arthritis. Barlow defines self-management as an individual's ability to manage the symptoms, treatments, physical and psychological consequences, and lifestyle changes inherent in living with a chronic condition. Successful SM requires adequate knowledge of the condition, its treatment, and the skills necessary for SM activities. As with other chronic conditions, the day-to-day management of epilepsy shifts from healthcare professionals to PWE. Effective epilepsy care demands active involvement from PWE in monitoring their health, coping with social (e.g., family/friends, stigma, hobbies), health (e.g., seizure response/tracking, comorbidities like depression/anxiety, sleep, safety, health literacy), employment (e.g., transportation, disability, absenteeism), and economic (e.g., cost of healthcare and medication) challenges. PWE need tools, knowledge, access to relevant information, and the ability to carry out necessary SM tasks to manage their disease.

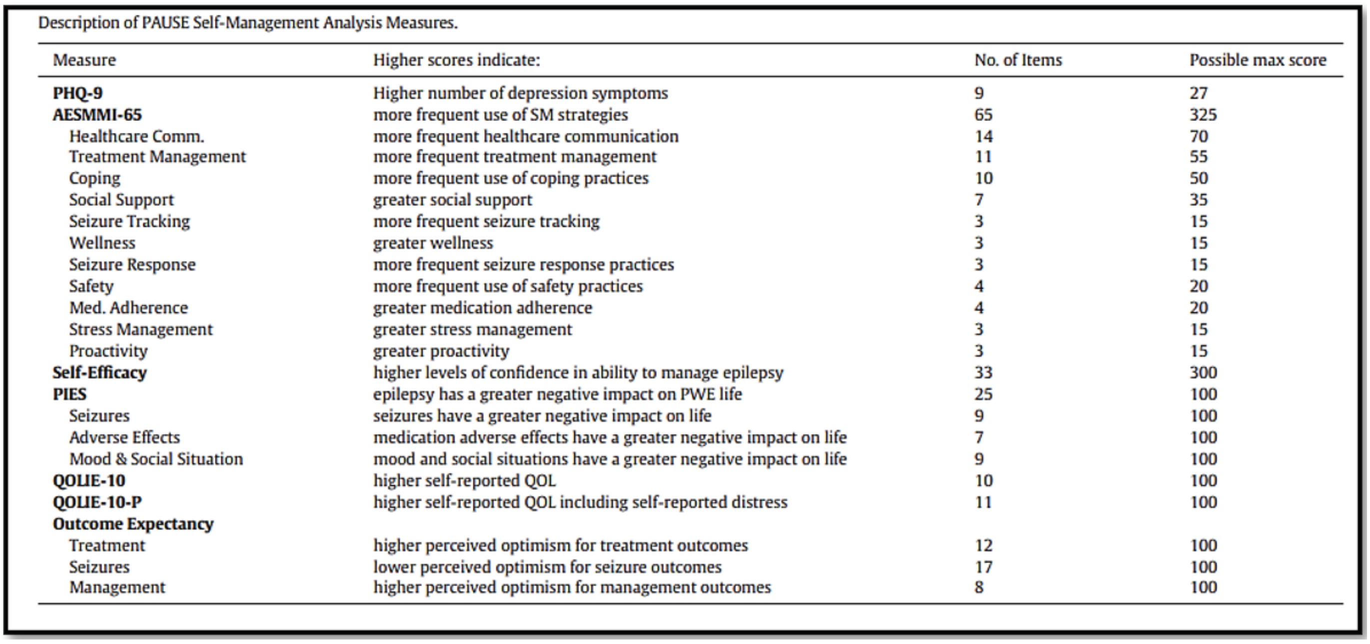
Evidence indicates that many PWE lack adequate knowledge about their disorder and are often not educated about the risks associated with epilepsy, including injury and mortality. Education needs vary among individuals and subgroups of PWE. For example, women may seek information on bone health and the effects of ASM on pregnancy or contraception, while older adults might prioritize fall safety and interactions of ASM with other medications. Studies show that while patients with chronic diseases are willing to receive SM education materials, perceived information overload (i.e., too much or complex information) negatively influences their willingness to use these materials. Patients with low health literacy are particularly susceptible to information overload. The Institute of Medicine recognized SM education gaps for PWE and recommended in its 2012 report, "Epilepsy Across the Spectrum: Promoting Health and Understanding," to improve and expand educational opportunities for PWE and their families, ensuring they have access to accurate, clearly communicated educational materials and information.

Several studies have reported mixed results regarding the efficacy of SM education interventions in improving PWE's knowledge and understanding of epilepsy and QOL. The Modular Service Package Epilepsy study (MOSES) reported significant improvements in ASM tolerability, epilepsy knowledge, coping with epilepsy, and seizure frequency six months after a 2-day SM education program.

The Self-management education for people with poorly controlled epilepsy (SMILE) (UK) study adapted MOSES for use in the United Kingdom but did not find the 2-day course effective in improving QOL or secondary outcome measures (anxiety and depression) after 12 months. While both MOSES and SMILE were randomized control trials (RCTs), MOSES included all adults with epilepsy, whereas SMILE included only adults with chronic epilepsy who had two or more seizures in the previous 12 months.

Another RCT compared the effectiveness of a multicomponent SM intervention consisting of five weekly, 2-hour group sessions followed by a 2-hour group session after three weeks with usual care; they found no difference in measures of self-efficacy but did find improvements in some epilepsy QOL domains and decreases in ASM side effects. Other studies examining the efficacy of in-person, group-based, online, or phone/internet SM interventions, including the Centers for Disease Control and Prevention-supported Managing Epilepsy Well (MEW) network programs, reported improvements in epilepsy SM and QOL.

There is a greater need for patient-centered and individualized education interventions for epilepsy SM that are publicly available, cost-effective, and easily disseminated to clinics or communities, in addition to existing group-based programs, which require permission to use and specialized training. The PAUSE to Learn Your Epilepsy (PAUSE) program, a MEW network collaboration center, was developed and implemented to address the needs of all PWE, particularly those in underserved populations.



Description of PAUSE Self-Management Analysis Measures.

Measure	Higher scores indicate:	No. of Items	Possible max score
PHQ-9	Higher number of depression symptoms	9	27
AESMMI-65	more frequent use of SM strategies	65	325
Healthcare Comm.	more frequent healthcare communication	14	70
Treatment Management	more frequent treatment management	11	55
Coping	more frequent use of coping practices	10	50
Social Support	greater social support	7	35
Seizure Tracking	more frequent seizure tracking	3	15
Wellness	greater wellness	3	15
Seizure Response	more frequent seizure response practices	3	15
Safety	more frequent use of safety practices	4	20
Med. Adherence	greater medication adherence	4	20
Stress Management	greater stress management	3	15
Proactivity	greater proactivity	3	15
Self-Efficacy	higher levels of confidence in ability to manage epilepsy	33	300
PIES	epilepsy has a greater negative impact on PWE life	25	100
Seizures	seizures have a greater negative impact on life	9	100
Adverse Effects	medication adverse effects have a greater negative impact on life	7	100
Mood & Social Situation	mood and social situations have a greater negative impact on life	9	100
QOLIE-10	higher self-reported QOL	10	100
QOLIE-10-P	higher self-reported QOL including self-reported distress	11	100
Outcome Expectancy			
Treatment	higher perceived optimism for treatment outcomes	12	100
Seizures	lower perceived optimism for seizure outcomes	17	100
Management	higher perceived optimism for management outcomes	8	100

This program uses publicly available education information from the Epilepsy Foundation (EF) website, epilepsy.com, linked to a mobile technology-based PAUSE application to provide personalized epilepsy SM lesson plans for PWE. Detailed information about PAUSE, including study design, recruitment, intervention, and assessments, has been published previously. We reported significantly lower epilepsy SM practices and behaviors among PWE from underserved populations compared to all PWE.

This paper aimed to determine whether the PAUSE intervention significantly improves self-efficacy, SM behavior and skills, QOL, personal impact of epilepsy, and epilepsy outcome expectancies over time in adults with epilepsy. Additionally, we assessed whether perceived depression symptoms influence longitudinal changes in SM measures following the PAUSE intervention.

Study Protocol

The study protocol, including recruitment from epilepsy subspecialty clinics and the community for PAUSE, was approved by the University of Illinois at Chicago (UIC) Institutional Review Board.

Study Design

The study was designed to develop and assess the effect of personalized SM education delivered through mobile technology to improve SM practices and behaviors, QOL, personal impact of epilepsy, and epilepsy-related outcome expectations of PWE. Within-subject longitudinal assessments were used to test significant changes in pre- and post-intervention outcome scores and in post-intervention scores over time.

Recruitment

Study participants were recruited between October 2015 and March 2019 via referrals from healthcare providers at the epilepsy specialty clinics at the University of Illinois Hospital and Health System (UIH) or from the Chicago area community via referrals from case managers at the Epilepsy Foundation of Greater Chicago, following human subjects' research approval.

PWE were not selected or referred to PAUSE based on any preexisting measures of epilepsy SM. Study eligibility criteria included PWE aged 18 years and over who speak and understand English, with no severe or unstable medical conditions that would harm or prevent participation. Participants needed to provide consent, be able to read at a minimum eighth-grade level or have a caregiver who could do so, have access to a telephone, and not have undergone or plan to undergo brain surgery for epilepsy in the past six months or the next six months, respectively.

PAUSE APP AND SM LEARNING MODULES

PAUSE Electronic Application

An Android OS-compatible software application for PAUSE was developed and housed on internet-connected tablet devices to provide SM education tailored to the individual needs of adult PWE.

The PAUSE application linked SM education learning modules to publicly available education materials and information from the EF website, epilepsy.com. Tablets were also preprogrammed with video conferencing using a freely available web-conferencing application. A snapshot of the PAUSE study application is shown in Fig. 1.

Self-management Education Learning Modules

Self-management learning modules were assembled with the EF website's associate editor. An individualized educational program was developed for each participant based on the SM learning modules selected by input from both the PWE and their healthcare provider(s) or case manager at study enrollment.

Providers/case managers completed the Epilepsy Self-Management Learning Needs Checklist to indicate which modules should be selected and programmed into the tablet for each individual participant. Participants could include modules that were not selected by their provider(s). The SM learning modules included: Epilepsy New Diagnosis, Managing Seizures/Epilepsy, Impact of Epilepsy, Managing Treatments, Staying Safe, Coping and Living with Epilepsy, and Special Interests (Women's Issues and Information for Seniors)

Study Protocol

8- to 12-week Education Intervention

As each participant was assigned a tailored educational program, there was no set curriculum or timeline for PWE to follow. Participants were encouraged to progress through assigned modules at their own pace, on their own time. All educational programs were designed to be completed within an 8- to 12-week timeframe. Participants received support from an education facilitator via video or telephone conferencing if they chose. Each call was scheduled to last 10–15 minutes; during this time, PWE were encouraged to ask study-related questions, identify important or interesting information, and share their personal experiences living with epilepsy. Facilitators used additional resources to provide relevant information based on conversations, including information on seizure response plans, epilepsy.com forums, EF activities and support groups, and educational resources for family and friends of PWE. Participants returned the tablets upon completing the intervention, and tablets were then reset for the next participant.

Assessments

Study Flow and Data Collection

Fig. 2 illustrates the PAUSE recruitment, intervention, and follow-up study flow. Assessments were conducted using self-reported questionnaires at five time points over 15 months. This analysis focuses on three key time points to evaluate significant changes in outcome scores: enrollment/baseline (T0), post-intervention/follow-up 1 (T1), and second follow-up/follow-up 2 (T2). Of the 112 participants who consented to participate, 91 (81%) received the PAUSE SM education intervention. Among these, 73 (80%) completed and returned at least one follow-up, and 46 (51%) completed and returned at least two follow-up questionnaires.

Participants initially completed the assessment self-reported questionnaire at enrollment during their clinic visit. Due to time constraints (e.g., transportation, diagnostic lab tests, electroencephalogram [EEG]), some participants partially completed the remaining questionnaire at home and mailed it to the study office. All follow-up assessment questionnaires were mailed to participants with prepaid, preaddressed return envelopes. Participants were instructed to complete these questionnaires at each of the four follow-up time points. Follow-up 1 was sent immediately after the SM education intervention completion, often coinciding with tablet return. Follow-up 2 was sent approximately three months after the first follow-up assessment return. The median time to complete each follow-up questionnaire was 17.1 weeks (interquartile range [IQR]: 3.6) for follow-up 1 and 34.8 weeks (IQR: 8.2) for follow-up 2. Participants received $10 as compensation for completing and returning each follow-up questionnaire.

Measures

Sociodemographic and Health Assessments

Baseline sociodemographic and health data were collected using sociodemographic and background health questionnaires, along with the Patient Health Questionnaire (PHQ-9) to assess self-reported symptoms of depression. Additional participant data, such as insurance status, epilepsy type, primary care provider, and the number of current ASM, were obtained from electronic medical records.

EPILEPSY SELF-MANAGEMENT MEASURES

Participants completed the 65-item Adult Epilepsy Self-Management Measurement Instrument (AESMMI-65) to assess the frequency of use of epilepsy SM practices, the 33-item Epilepsy Self-Efficacy Scale to measure self-efficacy of epilepsy SM skills, and the Epilepsy Outcome Expectancy Scale at all time points.

Quality of Life

Quality of life was measured using the QOLIE-10-P instrument, an 11-item survey questionnaire. The first 10 items measure health-related quality of life for adults with epilepsy (referred to as QOLIE-10), where higher scores indicate increased QOL. The last item (11th) of the QOLIE-10-P is a patient-reported distress item used to weight overall QOLIE scores (referred to as QOLIE-10-P). Participants completed QOLIE-10-P questionnaires at all time points. The QOLIE-10-P has been described in previous publications.

Personal Impact of Epilepsy Measure

Participants completed the 25-item Personal Impact of Epilepsy Scale (PIES) questionnaires at all time points. PIES measures the overall negative impact of epilepsy on life. The PIES scores were calculated using the updated PIES Scoring Manual Version 3.0, where higher scores indicate a more negative impact of epilepsy on the life of PWE. The Pearson correlation coefficient (and p-value) between PIES and QOLIE-10 is −0.616 ($p < 0.001$), and between PIES and QOLIE-10-P is −0.661 ($p < 0.001$).

Statistical Analysis

For QOLIE-10 and QOLIE-10-P, total scores were calculated according to the QOLIE Development Group Scoring Manual. If only one QOLIE item was missing, the missing item score was imputed based on the remaining nine items following the scoring manual instructions. If more than one item was missing, the score was invalid and excluded from data analysis. For AESMMI-65, domain-specific and overall scores were calculated according to the AESMMI-65 scoring instructions. Missing values were imputed as described below. If the item value at both T0 and T1 (or T1 and T2) was missing for a participant, it was treated as missing data. If the item value for either T0 or T1 (or T1 or T2) was not missing, the missing item value was imputed from the nonmissing value at the corresponding time point. The percentile value of the nonmissing item among all participant values at that time point was determined, and the missing item value at the corresponding time point was imputed using the same percentile level.

Descriptive Statistics and Regression Analysis

Statistical analysis was performed with STATA 15.0. Descriptive statistics were conducted to examine data distribution, kurtosis, and skewness. Linear regression analysis was utilized to test changes in scores from T0 to T1 (Δ1) with adjustment for T0 scores, and from T1 to T2 (Δ2) with adjustment for T1 scores. The intercept (β0) represents the estimated mean response difference from T0 to T1 (or T1 to T2) if the score at T0 (or T1) was 0, while the slope (β1) coefficient represents the estimated change in the response variable for a 1 unit change in T0 (or T1) score. For all outcomes (Δ1 or Δ2), a positive β1 coefficient indicates that individuals starting with higher scores improve more on average than those starting with lower scores at T0 (or T1). Conversely, a negative β1 coefficient indicates that individuals starting with lower scores improve more on average than those starting with higher scores at T0 (or T1).

Additionally, the effect of moderate to severe depression symptoms (PHQ-9 total score > 9, assessed at study enrollment) and the interaction between moderate-to-severe depression symptoms and T0 scores on Δ1 were evaluated after adjustment for T0 scores. The moderate to severe depression symptoms variable (depression) was categorized as 0 (PHQ-9 score ≤ 9) and 1 (PHQ-9 score > 9). The slope coefficient (β2) represents the effect of depression on the change in scores for response variables, and the slope coefficient (β3) represents the interaction effect between depression and the baseline (T0) response variable score on the change in response variable. Statistical significance was examined with $p < 0.05$.

PAUSE TO LEARN YOUR EPILEPSY SM EDUCATION INTERVENTION

Significant Improvements

Self-Efficacy: The PAUSE intervention significantly improved participants' confidence in managing their epilepsy.

Epilepsy SM Behaviors and Practices: Participants exhibited enhanced self-management behaviors and practices.

Expected Epilepsy Outcomes and Quality of Life (QOL): There was notable improvement in participants' expectations for positive epilepsy outcomes and their overall quality of life.

Personal Impact of Epilepsy: The personal impact of epilepsy on participants' lives was reduced significantly.

Education Components

- Lifestyle: Education on maintaining a healthy lifestyle tailored to individuals with epilepsy.

- Seizure Control: Strategies for effective seizure control were provided.

- Safety: Safety measures and protocols to follow were included.

- Medication Adherence and Compliance: Importance of adhering to medication schedules and compliance with treatment plans.

- Information Management: How to manage and use information relevant to their condition.

Long-Term Effectiveness

- Participants maintained improvements through the second follow-up at about 35 weeks (approximately 8 months).

Scalability and Cost-Effectiveness

- Unlike many current programs deemed labor- and time-intensive by a Cochrane review, PAUSE is scalable and cost-effective.

- It can be quickly and easily implemented in clinics, making it a practical tool for healthcare providers and case managers who lack the time to provide extensive self-management education during every visit.

- PAUSE empowers PWE to manage their unique epilepsy issues independently of environmental barriers and psychological comorbidities.

Patient-Centered Approach

- Providers can identify each patient's self-management education needs in less than 5 minutes during regular clinic visits.

- The PAUSE program allows for equal input from both the patient and the provider on education modules, promoting patient responsibility and ownership of their epilepsy self-management.

Diverse Study Population

- The PAUSE study population accurately represents the racial and ethnic breakdown of underserved areas in Chicago.

- There was a higher proportion of Black participants and slightly fewer Hispanics due to the current English-only offering of PAUSE.

- The study highlights the need for a Spanish-language version of PAUSE to better serve Hispanic communities.

Benefits for Underserved PWE

- Many underserved Chicago residents lack access to care and resources for self-education, such as reliable internet access.

- The COVID-19 pandemic underscored these limitations, with many families lacking computer/Wi-Fi access for remote learning.

- PAUSE provided preprogrammed internet-connected tablets, enabling participants to access personalized epilepsy self-management information at their convenience.

- This innovative approach offers freedom and a sense of ownership over self-management and education.

Comparison with Other Epilepsy SM Interventions

- **Effectiveness**: The PAUSE program effectively provides self-management education during regular clinic visits.

- **Self-Efficacy:** Personalized education led to a significant increase in self-efficacy, especially among those with lower baseline levels.

- **SM Behaviors and Practices**: Participants showed increased frequency in various self-management behaviors, including healthcare communication, treatment management, coping, social support, seizure tracking, wellness, seizure response, safety, medication adherence, stress management, and proactivity.

- **Quality of Life:** Significant increases in QOL measures were observed, indicating improved subjective perceptions of well-being.

- **Personal Impact of Epilepsy:** The Personal Impact of Epilepsy Scale (PIES) scores showed less negative impact of epilepsy following the intervention.

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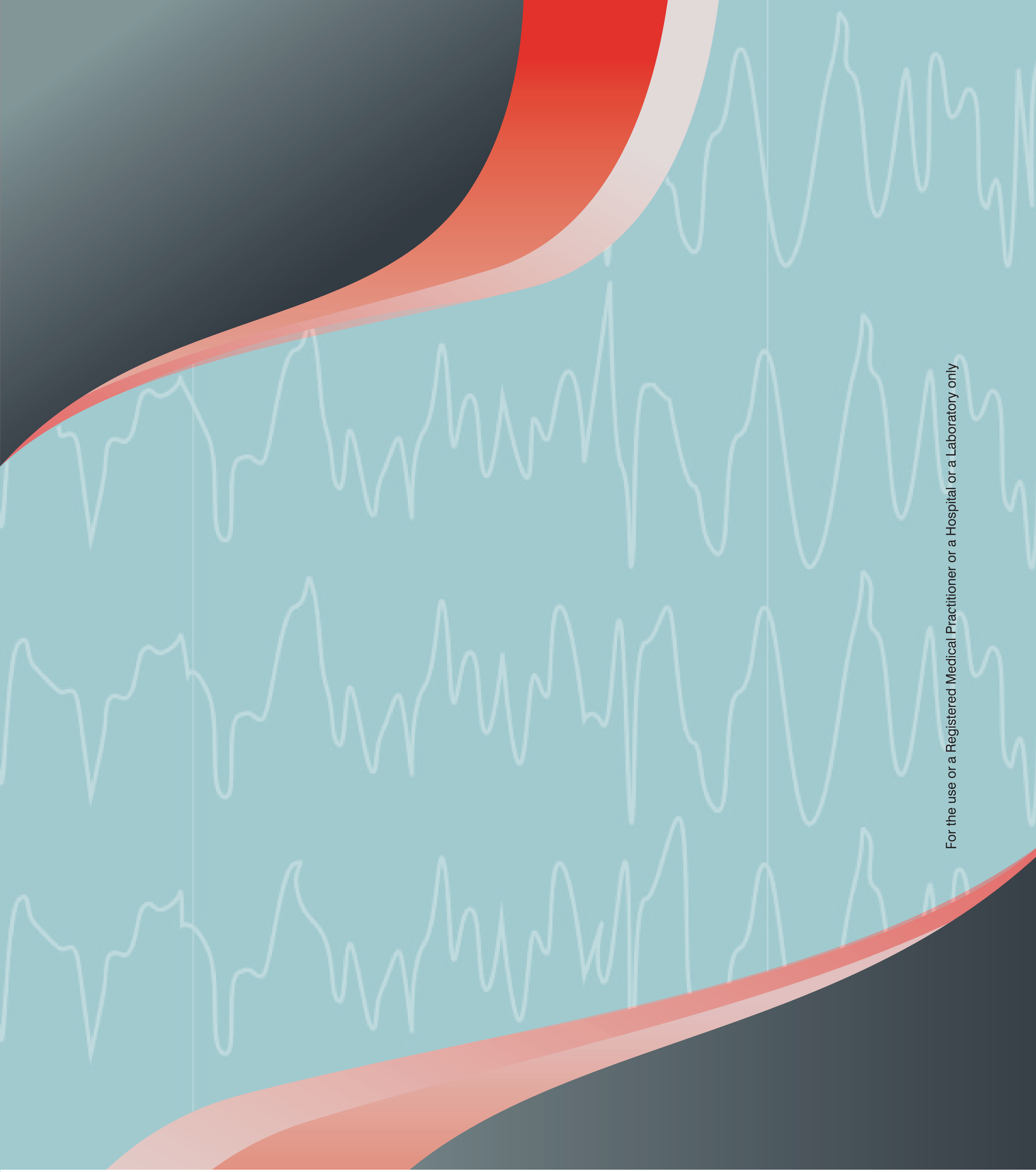

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