# 5th African Epilepsy Congress

16-18 May 2025 | Lusaka, Zambia

## Oral Presentations

## In-Person Poster Presentations

# Oral Presentations

**Platform Session** **14:15 – 15:45**
**Saturday, 17 May** **Room 1**

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## Comorbidities, symptoms, and medical procedure histories in functional seizure patients from two public and private hospital settings

G Vilyte[1,2], J Butler[3], V Ives-Deliperi[4], C Pretorius[1] [1]Stellenbosch University, Department of Psychology, Faculty of Arts and Social Sciences, Stellenbosch, South Africa, [2]Stellenbosch University, Division of Epidemiology and Biostatistics, Department of Global Health, Faculty of Medicine and Health Sciences, Cape Town, South Africa, [3]Stellenbosch University, Division of Neurology, Department of Medicine, Faculty of Medicine and Health Sciences, Stellenbosch, South Africa, [4]University of Cape Town, Neuroscience Institute, Faculty of Health Sciences, Cape Town, South Africa

**Purpose**: Functional seizures (FS) may manifest differently across socioeconomic contexts, yet this area remains underexplored. Comorbidities can be pivotal in triggering and sustaining FS, making their recognition important for tailoring effective treatment. This study describes and contrasts the medical and psychiatric comorbidities, injuries, somatic and cognitive symptoms, and medical procedures reported by FS patients at two private and public epilepsy monitoring units in Cape Town, South Africa.
**Method**: This retrospective case-control study analysed data from patients with video-EEG-confirmed FS, excluding those with coexisting epilepsy. Information on comorbidities, symptoms, and medical procedure histories was obtained from digital patient records including all available records through to 2022. Descriptive statistics and bivariate analyses using chi-square, Fisher's exact, and Wilcoxon rank-sum tests were used. Logistic regression identified factors associated with public hospital status, adjusting for sex, age, and comorbidity reporting.
**Results**: The study included 372 patients: 305 from a private hospital and 67 from a public hospital. Public hospital patients were more likely to report intellectual disability (aOR=15.58, 95% CI [1.80, 134.95]), circulatory system disease (aOR=2.63, 95% CI [1.02, 6.78]), and gait disturbances (aOR=8.52, 95% CI [1.96, 37.08]). Conversely, they had lower odds of reporting infectious or parasitic diseases (aOR=0.31, 95% CI [0.11, 0.87]), respiratory system conditions (aOR=0.23, 95% CI [0.06, 0.82]), and prior medical procedures (aOR=0.32, 95% CI [0.16, 0.63]).
**Conclusion**: This study highlights differences and similarities in the medical profiles of FS patients from diverse socioeconomic settings. These findings underscore the need to consider contextual factors in the diagnosis and management of FS.

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## Call for action - no epilepsy care without mental health care

T Fischl[1] [1]Israel Stroke Centre, Tel Aviv, Israel

Effective epilepsy care goes beyond seizure control. It requires a comprehensive approach that addresses the full range of neuropsychiatric, cognitive, and psychosocial multimorbidities. Mental health symptoms—often seizure-related or medication-induced—are frequently overlooked or misdiagnosed. When left untreated, they are associated with poorer quality of life, reduced seizure control, heightened medication side effects, poor adherence, increased risk of injury and even premature mortality.

In sub-Saharan Africa, the risk of mental health morbidity in individuals with epilepsy is compounded by limited access to both epilepsy and mental health services and medications. Moreover, the most common causes of epilepsy in the region—cerebral infections, perinatal injury, and traumatic head injury—are themselves associated with significant neuropsychiatric multimorbidities. However, region-specific data remain scarce and are urgently needed to inform mental health screening and guide the development of interventions tailored to epilepsy care in very low-resource settings.

This presentation calls for the urgent integration of mental health into epilepsy care, tailored to local realities. A community-led approach, coordinated across health, education, and government systems, is essential to reduce suffering and disability, close the treatment gap, and relieve the cumulative economic burden. Mental health care is neither a luxury nor an afterthought, rather a fundamental component of effective and equitable epilepsy care worldwide.

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## Initiating epilepsy surgery program in Tanta University, Egypt: Preliminary Results and lessons learnt from first 30 cases

AF Saleh[1] [1]Tanta University, Tanta, Egypt

**Purpose**: to study factors affecting postoperative seizure freedom and how to overcome obstacles in establishing an epilepsy surgery center in a limited resources country.

**Method**: 30 Drug resistant epilepsy patients were operated in Tanta University Neurosurgery department between January 2020 and April 2023.,

All the patients were followed for at least 1 year.

For preoperative assessment MRI Brain HARNESS protocol and long-term EEG were the only two investigations used in all cases, while video EEG, PET scan were used only in some cases as indicated, neither SPECT nor invasive EEG were used in any case because of unavailability.

**Results**: 3/30 (10%) cases with generalized epilepsy were operated for corpus callosotomy, while 15/30 (50%) cases were operated for temporal lobe resections and other 12/30 (40%) extra temporal resections. Postoperative complete seizure freedom outcome of Engel Class I was achieved in 73 % of our patients. Few minor and temporary post-operative complications occurred with no mortality or permanent morbidity observed in our series.

**Conclusion**: Epilepsy surgery is very effective, safe and feasible solution that should be offered and strongly recommended for drug resistant epilepsy patients even in limited resource centers.

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## Prevalence of epilepsy in Ghana: A population-based study in the Shai Osudoku and Ningo-Prampram districts: A three-stage approach

EK Darkwa[1], S Asiamah[1], C Sottie[2], A Godi[3], F Atuguba[4], A Akpalu[5], JH Cross[6], JW Sander[7], A Sen[8], CR Newton[8], P Adjei[5] [1]Dodowa Health Research Centre, Ghana Health Service, University of Ghana, Accra, Ghana, [2]Ghana Health Service, Accra, Ghana, [3]University of Ghana, Accra, Ghana, [4]Dodowa Health Research Centre, Ghana Health Service, Accra, Ghana, [5]University of Ghana Medical School, Korle Bu Teaching Hospital, Korle Bu, Accra, Ghana, [6]UCL Great Ormond Street NIHR BRC Institute of Child Health, London, United Kingdom, [7]UCL Queen Square Institute of

Neurology, London, United Kingdom, [8]Oxford Epilepsy Research Group, Nuffield Department of Clinical Neurosciences, Oxford, United Kingdom

**Purpose**: To estimate the prevalence of epilepsy using a comprehensive, multi-stage screening process to improve case detection and provide data for public health planning.
**Method**: We performed a three-stage population-based cross-sectional study of residents within a demographic surveillance system in the Shai-Osudoku and Ningo Prampram Districts of Accra, Ghana. Stage 1 involved administering a validated epilepsy screening questionnaire in English, Asante Twi, and Dangme to household representatives to identify possible cases. Positive cases advanced to Stage 2, where a detailed 10-item questionnaire was administered to reduce false positives. Suspected cases underwent clinical assessments, including electroencephalography (EEG) and neurologist-confirmed diagnoses in Stage 3. Due to attrition at each successive stage, the respective sampling weights and sensitivity were used to adjust for the overall prevalence. Data collection utilized the KoboCollect app, with analysis in Stata/SE 17.
**Results**: From April to December 2023, 65,178 individuals were screened (54.75% females, 45.25% males), with a median age of 24 years (IQR: 13–40). The crude prevalence of suspected epilepsy in Stage 1 was 9.5 per 1000 people, slightly higher in males (10.5 per 1000) than females (8.6 per 1000; p = 0.014). Stage 2 identified 466 suspected cases (85.82%), while Stage 3 confirmed 434 cases (94.3%). The adjusted prevalence of epilepsy was 8.41 per 1000 people (95% CI: 2.73–14.10), with a diagnostic gap of 65.7%. Generalized convulsive seizures were the most common (69.13%).
**Conclusion**: These findings highlight a substantial epilepsy burden with a huge diagnostic gap and underscore the need for better diagnostic systems to enhance timely treatment.

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## Perception of non-neurosurgical health professionals towards the role of neurological surgery for treatment of medically refractory epilepsy: a quantitative study

M Shiferaw[1] [1]Injibara University, Neurosurgery, Gojjam, Ethiopia, Ethiopia

**Purpose**: Epilepsy is a disabling brain disorder caused by abnormal neuronal discharges, stemming from structural or functional brain issues. While most cases can be managed with medication, some patients do not respond and may benefit significantly from surgical treatments, which can even lead to cures. My project aims to assess the perception of the non-neurosurgical workforce regarding the role of neurosurgery in treating medically refractory epilepsy.
**Method**: A prospective collection of data was conducted using structured and semi-structured questionnaires among non-neurological surgery health professionals from a randomly selected medical centres in Ethiopia and Kenya.
**Results**: A total of 518 individuals participated in the study, primarily from Ethiopia (68.7%). The largest age group was 26-30 years (44.6%), with a trend towards significance noted for prioritization of care (p = 0.053). Ethiopian participants had a higher percentage of males (77.0%) compared to Kenya (53.7%). In education, more Kenyans held bachelor's degrees (40.1%) than Ethiopians (30.9%). While both groups had similar distributions of participants with less than five years of experience, a greater percentage of Kenyans (27.8%) had between five to ten years compared to Ethiopians (19.4%). Additionally, more Kenyans reported training in neurological surgery (30.9%) and worked in setups with neurosurgery services (72.2% vs. 64.0% for Ethiopians). Although most participants had not assisted in neurological surgeries, those numbers were lower in Kenya (48.8%) than Ethiopia (38.5%). Notably, working in neurosurgery services was significantly associated with

positive attitudes ($p = 0.008$) and care prioritization ($p < 0.001$). Only 12% agreed that surgery could cure epilepsy, with mean scores indicating scepticism (3.75, SD = 1.09) regarding the role of neurosurgery in treating medically refractory epilepsy.
**Conclusion**: Healthcare providers largely hold negative attitudes toward neurosurgical interventions for medically refractory epilepsy, highlighting the need for focused education to address concerns and improve perceptions.

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## Modelling seizure-related predictors of epilepsy diagnostic gap in urban informal settlements of Nairobi using machine learning

D Mwanga[1,2], F Ouma[1], F Wekesah[3], J Kinuthia[3], P Otieno[3], G Davis Jones[4], A Sen[4], CR Newton[4], G Asiki[3], D Kadengye[1], EPInA Study Group [1]African Population and Health Research Center, Data Synergy and Evaluations, Nairobi, Kenya, [2]University of Nairobi, Mathematics, Nairobi, Kenya, [3]African Population and Health Research Center, Chronic Disease Management, Nairobi, Kenya, [4]University of Oxford, Oxford Epilepsy Group, Oxford, United Kingdom

**Purpose**: Up to 70% of people with epilepsy can achieve remission if properly diagnosed and treated. Yet, the diagnostic gap in low- and middle-income countries is still high. Identifying predictors of this gap is critical for targeted, effective interventions to reduce it. We employed machine learning to identify seizure-related predictors of the diagnostic gap in the Nairobi Urban Health and Demographic Surveillance System (NUHDSS).
**Method**: Data are from a two-stage population-based (census) survey. In Stage I, 56,425 NUHDSS residents were screened for possible convulsive (CE) and non-convulsive epilepsy (NCE) using a standard screening questionnaire. In stage II, possible cases were invited for assessment by neurologists. Seven machine learning models were trained on 75% of the data and evaluated on the remaining 25%. SHapley Additive exPlanation (SHAP) was used to interpret predictions for each feature and findings triangulated with the conventional logistic regression model.
**Results**: A total of 528 had confirmed epilepsy. Among them, 100% (n=160) of confirmed cases with NCE and 71% (n=260) with CE had not been previously diagnosed. Extreme gradient boost and random forest were the best-performing models (area under curve>0.9). Experiencing fewer seizures, non-convulsive seizures, or relatively *less severe* convulsive seizures were associated with a higher diagnostic gap. Experiencing a higher number of different types of seizures, having ever fallen and biting the tongue, becoming pale, losing touch with surroundings, and experiencing abnormal smells were associated with a lower diagnostic gap.
**Conclusion**: Efforts to reduce the diagnostic gap should include community sensitization about both CE and NCE, identifying epilepsy symptoms, and the importance of seeking medical care for any seizure-like symptoms early. Training primary healthcare workers to diagnose all types of CE and NCE, along with training community health promoters to refer potential cases to primary care, is essential for ensuring early diagnosis and timely treatment initiation.

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## Neurocysticercosis, a leading cause of epilepsy; what are the opportunities and challenges in its control in Zambia

KE Mwape[1], C Trevisan[2], G Zulu[1,3], C Mubanga[4], S Gabriel[5] [1]University of Zambia, Clinical Studies, School of Veterinary Medicine, Lusaka, Zambia, [2]Institute of Tropical Medicine, Biomedical

Sciences, Antwerp, Belgium, [3]Ministry of Health, Lusaka, Zambia, [4]University of Zambia, Disease Control, School of Veterinary Medicine, Lusaka, Zambia, [5]Ghent University, Ghent, Belgium

**Purpose**: Neurocysticercosis due to *Taenia solium* is responsible for almost 30% of epilepsy globally indicating an urgent need for its control. This study was conducted to assess the opportunities and challenges in the control of *Taenia solium* in Zambia.
**Method**: An interventional study was conducted in Katete district of Zambia. Interventions, namely, mass drug administration (MDA) for humans (praziquantel or niclosamide) and pigs (oxfendazole) including vaccination of pigs were piloted and implemented every four months for 2 years. Data on treatment/vaccination coverage in both humans and pigs were collected at each intervention. Focus group discussions (FGDs) and questionnaires were conducted to assess local perceptions and acceptance of the piloted intervention strategies.
**Results**: Five villages with a human population of 1050 and a pig population of 154 pigs were included in the study. MDA coverage in humans ranged from 48 to 81% while that of pigs from 40 to 68% of the total population. Seventy per cent of the participants indicated a willingness to be treated. About 92% of the pig owners had allowed their pigs to be treated/vaccinated and all were willing to do it again in future. About 50% of the pig owners indicated willingness to pay for the treatment or vaccine. The feedback from the FGDs was improved health among the people and their pigs, and fewer cysticerci in pork were observed. The participants also indicated in increase in latrine use, hand washing, meat inspection and proper cooking of pork.
**Conclusion**: The acceptability of the intervention measures revealed in this study renders a positive opportunity towards their implementation. However, coverage of the intervention remained a challenge throughout the intervention period, especially in the pig host. Extensive community engagement would be required to improve coverage to achieve control or elimination of the parasite.

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### Burden of epilepsy and associated risk factors in Tanzania Mainland: Use of District Health Information system-2

B Mmbando[1], V Mushi[2], D Bhwana[1], H Hyera[3], F Chaky[4], C Newton[5], R Colebunders[6] [1]National Institute for Medical Research, Tanga Centre, Tanga, Tanzania, United Republic of, [2]University of Dar es Salaam, Dar es Salaam, Tanzania, United Republic of, [3]Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of, [4]Malaria Control Programme, Dodoma, Tanzania, United Republic of, [5]KEMRI-Wellcome Trust Research Programme, Kilifi, Kenya, [6]University of Antwerp, Global Health, Antwerp, Belgium

**Purpose**: Data on epilepsy prevalence and risk factors are limited in Tanzania. This study was designed to use DHIS-2 data to determine areas with high burden of epilepsy and associated risk factors.
**Method**: This study analysed monthly data from DHIS-2 for 184 district councils across 25 regions in mainland Tanzania from 2019 to 2023. Eclampsia, birth-asphyxia, home delivery, and severe malaria variables were used as proxies for factors associated with epilepsy. Health-seeking behaviour was assumed consistent across districts. Epilepsy burden was defined as the 75th percentile of the monthly epilepsy cases divided by the mid-year population size, per 1000 person-years, while explanatory variables were derived from the median patient counts. District councils were categorized into those in and out of onchocerciasis focus. The linear regression model was

used on log-transformed epilepsy burden and explanatory variables. A p-values less than 0.05 was considered significant.
**Results**: The overall median of epilepsy cases was 17,997 (IQR: 15,667–19,484) per month, with the highest median in 2019 (19,403) and the lowest in 2022 (13,767). Ruvuma, Morogoro, Dodoma and Njombe Regions exhibited the highest epilepsy burdens, while Katavi and Simiyu recorded the lowest. Notably, high-burden councils included Ulanga (Mahenge) in Morogoro, Madaba in Ruvuma, and Chamwino in Dodoma. Significant predictors were councils in onchocerciasis focus areas (coef=0.8, 95%CI: 0.51–1.01, p<0.001) and cases of birth asphyxia (coef=0.20, 95%CI: 0.07-0.34, p=0.002) and eclampsia (coef=0.25, 95%CI: 0.1–0.41, p=0.002) were significant predictors of a high epilepsy burden.
**Conclusion**: Targeted interventions addressing these factors are essential to reducing epilepsy incidence.

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## State of epilepsy surgery in Lusaka, Zambia - A single center study (Maina Soko Military Medical Center)

K Simfukwe[1,2] [1]Maina Soko Military Medical Center, Neurosurgery, Lusaka, Zambia, [2]Levy Mwanawasa Medical University, Neurosurgery, Lusaka, Zambia

**Purpose**: The most prevalent major neurological ailment in Zambia is epilepsy, which also happens to be one of the most prevalent noncommunicable diseases in the country. Patients with drug-resistant epilepsy have been demonstrated to experience a considerable improvement in their quality of life subsequent to undergoing epilepsy surgery. Here in, we aim to illustrate the state of epilepsy surgery at a single centre in Lusaka, Zambia, which is a low-middle-income Country (LMIC).
**Method**: In a retrospective study, we showcase the road to the development of an epilepsy surgery centre. We also highlight successes and challenges in building a successful epilepsy surgery unit in a low- and middle-income setup.
**Results**: In offering effective surgical therapy for epilepsy patients in underdeveloped nations, challenges include the unavailability of human and technological resources, as well as the development of presurgical evaluation procedures. With the use of fundamental investigative technologies, such as magnetic resonance imaging (MRI) and 24hour video-electroencephalography (EEG), neurosurgeons, epileptologists and other members of an epilepsy committee who have received adequate training are able to select patients that can benefit from epilepsy surgery.
**Conclusion**: These treatments are feasible in underdeveloped countries with a skilled team comprising of an epilepsy surgery committee.

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## Prevalence and cost of surgically amenable abnormalities on magnetic resonance imaging in rural South Africans with active convulsive epilepsy

EA Buckson[1], RG Wagner[2,3], J Ouma[1] [1]University of Witwatersrand, Department of Neurosurgery, Division of Neurosciences, Faculty of Health Sciences, Johannesburg, South Africa, [2]University of Witwatersrand, School of Public Health, Faculty of Health Sciences, Johannesburg, South Africa, [3]Barrow Neurological Institute, Phoenix, AZ, United States

**Purpose**: Magnetic resonance imaging (MRI) can play a critical role in the management of epilepsy as it identifies and defines potential anatomic epileptogenic lesions; some of these lesions may be amenable for epilepsy surgery. Understanding the burden and cost of potentially amenable epilepsy cases for surgery is the first step in advocating for more routine epilepsy surgery. These data are currently lacking from rural South Africa.

**Method**: This study utilized secondary quantitative data collected as part of the Studies of the Epidemiology of Epilepsy in Demographic sites (SEEDS) study to estimate the prevalence of surgically amenable abnormalities from MRI results of patients with active convulsive epilepsy (ACE). The cost analysis for the management of the surgically amenable abnormalities was undertaken using the uniform patient fee scale 2024 (UPFS).

**Results**: A total of 91 individuals diagnosed with ACE had a brain MRI undertaken. The ages ranged from three to 82 years with a majority being females (n=48; 52.8%). Thirty (33.0%) had no formal education and 52 (57.1%) were single. Those with abnormal MRI scans were 62 (68.1%), with 24 (26.4% of those scanned) had surgically amenable abnormalities. The commonest abnormality observed was mesial temporal sclerosis (MTS) which accounted for 14 (58.3%) of all amenable abnormalities. The temporal lobe was the most affected with a total frequency of 19 (79.2%), with a slight right sided predominance of ten (52.6%). The average direct medical cost of conducting epilepsy surgery in the public sector was determined to be R 27 026 (USD 1465).

**Conclusion**: Our research suggests that there may be a non-inconsequential burden of surgically amenable cases of epilepsy and the cost of these surgeries may be considered acceptable. Our study shows that there may be a place for epilepsy surgery in the management of people with ACE and might considered in the South African public health sector.

**Platform Session** **14:15 – 15:45**
**Saturday, 17 May** **Room 2**

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### Cerebral palsy, an important cause of paediatric epilepsy in sub-Saharan Africa: gaps in care with lessons from Malawi

T Katangwe- Chirwa[1], M Mallewa[1], A Chitedze[2], P Kamanga[3], S Mughogho[2], Y Chimalizeni[1], I Jahan[4], N Badawi[5], G Khandakher[6] [1]Kamuzu University of Health Sciences, Paediatrics and Child Health, Blantyre, Malawi, [2]Mulanje District Hospital, Physiotherapy, Mulanje, Malawi, [3]Malawi Liverpool Wellcome Trust, Blantyre, Malawi, [4]Central Queensland Hospital and Health Services, Rockhampton, Australia, [5]Sydney Children’s Hospital Network, Grace Centre for Newborn Intensive Care, Sydney, Australia, [6]Central Queensland Hospital and Health Services, Central Queensland Public Health Unit, Rockhampton, Australia

**Purpose**: To describe paediatric epilepsy and existing care gaps in children living with cerebral palsy (CP) in rural Malawi.

**Method**: A descriptive cross-sectional cohort study of 577 children (1 to 18 years old) living with CP in rural Malawi and registered in the Malawi CP Register (MCPR). Children were described as per the Surveillance of Cerebral Palsy in Europe (SCPE), clinical classification. Motor severity was determined using the Gross Motor Function Classification System (GMFCS). Epilepsy semiology, aetiology, and treatment were also reported.

**Results**: Epilepsy was confirmed in 21.7%; n=125 of the cohort; mean age (SD) of 10.7 (5.5) years. Most had spastic CP (74.4%; n=93), severe motor impairment, GMFCS IV & V (65.6%; n=82), and moderate to severe intellectual impairment 47.2% (n=59). Cerebral malaria (31.3%; n=20) and

epileptic encephalopathies (29.7%; n=19) were the most reported aetiologies. There was a statistically significant association between postnatally acquired CP and epilepsy in comparison to pre/perinatally acquired CP (51.2%; n=64 vs 44.0%; n=55; P <0.001). Schools were accessed by 12.8%,16 of these children. Only 22.7%; n=27 had health passports confirming their epilepsy diagnosis and access to outpatient services. Generalized epilepsies were the most documented (92.6%; n= 25). Anti-seizure prescriptions were identified for 13.6%; n= 17 of these children and Phenobarbitone was the only prescribed medication.
**Conclusion**: Cerebral malaria remains an important cause of cerebral palsy and epilepsy in Malawi. Most of the children with epilepsy living in rural Malawi remain undiagnosed and untreated. There is poor access to a broader range of anti-seizure medications.

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## Anxiety disorders in people with epilepsy: a hospital-based study in Cameroon

D Gams Massi[1,2], R Feudjio[1], C Eyoum[1,3], AM Magnerou[4,1], C Kuate Tegueu[4,5], NY Mapoure[1,2]
[1]University of Douala / Faculty of Medicine and Pharmaceutical Sciences, Clinical Sciences, Douala, Cameroon, [2]Douala General Hospital, Medicine and Specialties, Douala, Cameroon, [3]Douala Laquintinie Hospital, Mental Health, Douala, Cameroon, [4]Douala Laquintinie Hospital, Neurology, Douala, Cameroon, [5]University of Yaoundé 1 / Faculty of Medicine and Pharmaceutical Sciences, Internal Medicine, Yaoundé, Cameroon

**Purpose**: The aim of this study was to determine the prevalence and factors associated to anxiety in people with epilepsy followed up in a tertiary health facility in Cameroon.
**Method**: This was a comparative cross-sectional study with an age- and sex- matched control group, conducted between February 12 and May 15, 2024, in two referral hospitals of Douala. It included individuals (PWE and controls) ≥ 18 years. Participants with a general health problem that could have a significant impact on mental status (hypertension, HIV, diabetes, renal failure, heart failure, dementia, bipolar disorder) or an inability to communicate were excluded. Recruitment was done through an online and in-person survey using a form. We used the Generalized Anxiety Disorder Questionnaire (GAD-7) to assess AD. Binary logistic regression was used to identify the predictive factors of AD in PWE. The significance threshold was p<0.05.
**Results**: Among the 633 participants, 211 were people with epilepsy (PWE). The prevalence of anxiety (18.48% vs 11.37%) was significantly higher in PWE compared to controls (p=0.02). The median age was 30 years old in both PWE and controls. Female represented 53.08% in both PWE and controls. No difference was found in the marital status in both groups (p>0.05). The proportions of PWE with primary education level (2.32% vs 0.00, p=0.004), secondary education level (34.12% vs 11.61%), unemployed (23.69% vs 6.63%), undetermined monthly income (68.25% vs 59.24%) were significantly higher in PWE (p<0.05). After multivariable analysis, married (aRR:3.49, 95%CI:1.055 – 11.570, p=0.041), no health insurance (aRR: 6.12, 95%CI:1.376 – 27.223, p=0.017), partial health insurance (aRR:9.584, 95%CI:1.353 – 67.900), Levetiracetam (aRR:7.962, 95%CI:1.311 – 48.352, p=0.024).
**Conclusion**: PWE were more likely to suffer from anxiety disorders compared to controls. Educational and socioeconomic levels tend to be lower in PWE. Married status, no or partial health insurance, and Levetiracetam were predictive factors of anxiety disorders in PWE.

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## Leveraging large-language models for clinical data extraction and anti-epileptic drug selection in pediatric epilepsy: A feasibility study

R Mazumder[1], J Kayaga[2], P Anzoa[2], M Yigit Turali[3], R Jules[1], T Mansoor[3], V Roychowdhury[3], R Idro[2]
[1]University of California, Los Angeles, Neurology, Los Angeles, United States, [2]Makerere University, Paediatrics, Kampala, Uganda, [3]University of California, Los Angeles, Engineering, Los Angeles, United States

**Purpose**: This study evaluates the feasibility of using large-language models (LLMs) to extract clinical data from medical records and develop a machine-learning algorithm to guide anti-epileptic drug selection for pediatric epilepsy.

**Method**: Medical records of pediatric epilepsy patients (aged 1–18 years) treated at Uganda's Makerere University-Mulago Hospital referral neurology outpatient service (2015–2023) were reviewed. Epilepsy was diagnosed and classified per ILAE guidelines. Clinical characteristics—including age of onset, seizure type, comorbidities, family history, risk factors, and seizure frequency at baseline and one-year follow-up—were extracted. Treatment regimens prescribed by neurologists were recorded. A machine learning pipeline was designed to systematically extract structured clinical data from free-text medical reports.

**Results**: In this preliminary analysis, data from 187 patients were analyzed (median age: 4 years; 59.6% male). The median seizure onset was 2 years. The most prescribed anti-seizure medications were sodium valproate (48%), carbamazepine (37.1%), lamotrigine (3.6%), and levetiracetam (3.6%). At one-year follow-up, 31% were seizure-free, 53% had reduced seizure frequency, and 15.9% showed no improvement or worsening symptoms.

**Conclusion**: LLM-based models can effectively extract patient data and treatment outcomes, demonstrating feasibility in resource-limited settings. This study highlights the potential of integrating machine learning into clinical practice to enhance epilepsy management in children.

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## Disorders of cortical development as a cause of global developmental delay and epilepsy among children at a referral pediatric neurology clinic in Uganda

TT Namata[1], J Namajja[1], R Sebunya[1] [1]St. Francis Hospital Nsambya, Pediatrics, Kampala, Uganda

**Purpose**: Disorders of cortical development (DCD) are major causes of global developmental delay (GDD) and epilepsy among children. Data from low-resource settings like Uganda is scarce. This study aimed at determining the prevalence, clinical characteristics, and treatment of DCD among children at a pediatric neurology clinic at Nsambya Hospital, Kampala, Uganda.

**Method**: We performed a retrospective study where we reviewed medical records of children aged 0-18years, who presented with GDD from January 2023 to December 2024. Children with neuroimaging-confirmed DCD were included.

**Results**: Of 650 children with GDD, 129 (19.8%) had DCD. The median age at diagnosis of DCD was 3.5 (IQR: 2–6) years, with 60% male. Neuroimaging demonstrated various malformations, including, Lissencephaly (22.5%), Band heterotopia (21.7%), Schizencephaly (12.4%), Perisylvian syndrome (12.4%), Colpocephaly (10.9), Cortical dysplasia (10.0%), Polymicrogyria (7.0%), and Hemimegalencephaly 4 (3.0%). Epilepsy was diagnosed in 112 (86.8%) children with DCD, with more than half (70/112) having focal epilepsy. Other clinical manifestations included behavioral challenges (27%), hemiplegia (19%), or visual impairment (7.8%). Of the 112 children with Epilepsy, 53% had seizure freedom with one anti-seizure medication (ASM), 38% patients required two or more ASMs to achieve seizure freedom while 9% of patients only achieved reduced seizure

frequency on two or more ASMs. Overall, 85% of children had gradual improvement in development milestones, with no mortalities.
**Conclusion**: Our clinic treated a high number of children with DCD presenting with GDD and epilepsy. Prompt diagnosis requires a high index of suspicion. Establishing robust multidisciplinary services is required to improve outcomes for affected children.

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## Functional neurological disorder among children attending a pediatric neurology clinic at an urban teaching hospital in Uganda

TT Namata[1], J Nabaweesi[1], J Namajja[1], R Sebunya[1] [1]St. Francis Hospital Nsambya, Pediatrics, Kampala, Uganda

**Purpose**: Functional neurological disorder (FND) presents with neurological symptoms inconsistent with known medical or neurological conditions. In Uganda, data on pediatric FND is limited, leading to frequent misdiagnosis. This study investigated the clinical presentation, associated factors, and outcomes of children diagnosed with FND at St. Francis Hospital Nsambya.
**Method**: A cross-sectional study was conducted from July to December 2024, enrolling children <18 years diagnosed with FND using DSM V criteria.
**Results**: We diagnosed 46 children with FND, median age was 13 (IQR; 10-14) years, 70% (32/46) were female. Common symptoms included pseudoseizures 63% (29/46), headaches 39% (18/46), fainting attacks 35% (16/46), chest pain and/or difficulty in breathing 17% (8/46). 54% (25/46) of the children presented with combined symptoms. About 90% (41/46) of children had identifiable psychosocial stressors, including separation of parents 63% (29/40), recent change of school, loss of a parent and psychological trauma 7% (3/46). 63% (29/46) of the children brought EEGs at presentation; EEGs were normal in half of cases, and abnormal in only 11% (5/46). A trial of antiseizure medications plus counselling during clinic visits relieved symptoms among children who had abnormal EEGs. Despite referral, only 15% (7/46) saw a psychologist. About 20% sought a second opinion, leading to antiseizure medication initiation. Symptom resolution occurred in 57% (26/46) following counselling at diagnosis from the clinic.
**Conclusion**: FND significantly affects children in Uganda, with pseudoseizures and fainting attacks being common presentations. Training of healthcare providers and enhanced access to clinical psychologist services is required to improve FND management among children.

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## Implications of access to genetic testing in children with Dravet Syndrome

FA Mosha[1], AI Esterhuizen[2], JM Wilmshurst[3] [1]University of Cape Town, Pediatric Neurology, Cape Town, South Africa, [2]Institute of Infectious Diseases and Molecular Medicine, Department of Pathology, University of Cape Town, Division of Human Genetics, Cape Town, South Africa, [3]Red Cross War Memorial Children's Hospital, Neuroscience Institute, University of Cape Town, Pediatric Neurology, Cape Town, South Africa

**Purpose**: To explore genetic testing impact on the care of children with Dravet syndrome (DS) in a resource-limited setting by documenting diagnostic challenges, and treatment modifications, inclusive of precision medicine to improve seizure control and quality of life.

**Method**: Retrospective longitudinal analysis from a subgroup of patients in a parent study conducted at Red Cross War Memorial Children's Hospital, Cape Town, South Africa (2015-2022). Children attending the Epilepsy service with genetically confirmed Dravet Syndrome (DS) were enrolled (n=18). Descriptive statistics analysed hospital admissions, treatment changes, seizure control, genetic closure and associated co-morbidities.
**Results**: Median seizure onset age was 5.5 months, with significant delays in diagnosis (clinical suspicion: 30 months, genetic confirmation: 48 months). Genetic confirmation correlated with treatment shifts namely 44% switching anti-seizure medications (ASMs), 44% commenced Stiripentol, 67% initiated on other adjunctive therapies and emergency care-plans implemented in 44%. Seizure control remained sub-optimal (28%), however hospital admissions reduced by 83%. Comorbidities included psychosocial problems (94%), intellectual disability (89%), communication issues (94%), and behavioural problems (94%). Long-term dependency was profound, with 83% requiring full assistance for daily living. Psychosocial benefits included improved care accessibility (89%), genetic closure (100%) and special school placement (61%) fostering the importance of multi-disciplinary management.
**Conclusion**: The benefits of genetic testing for epilepsy syndromes in LMICs are significant, given the high burden of disease and the need for tailored medical management. This study demonstrated the critical impact of genetic testing on the management of DS in the resource-constrained South African healthcare setting. Key findings included targeted treatment adjustments with precision medicine (stiripentol) and implementation of emergency care plans improved overall clinical outcomes and reduced hospital admissions. Psychosocial benefits, including genetic diagnostic closure and enhanced family support, emphasize the broader role of genetic testing and multidisciplinary approach to the overall holistic care for DS patients.

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## The causes of epilepsy in sub-Saharan Africa: Insights from a community-based case-control study in rural Rwanda

I Garrez[1], DE Teuwen[1], F Sebera[2], A Ndayisenga[3], G Umuhoza[3], J Kayirangwa[4], UE Düll[5], J-J Nshizirungu[6], E Achten[7], E Abatih[8], A Mertens[1], S Heyndrickx[1], P Dedeken[1], P Boon[1] [1]Ghent University, Neurology, Ghent, Belgium, [2]Ndera Neuro-Psychiatric Teaching Hospital, Neurology, Kigali, Rwanda, [3]King Faisal Hospital, Neurology, Kigali, Rwanda, [4]Ruhengeri Referral Hospital, Musanze, Rwanda, [5]Medicalized Health Center, Gikonko, Rwanda, [6]King Faisal Hospital, Radiology, Kigali, Rwanda, [7]Ghent University, Neuroradiology, Ghent, Belgium, [8]Ghent University, Statistics, Ghent, Belgium

**Purpose**: The higher epilepsy burden in low-income countries suggests different risk factors. However, scarce resources hinder the assessment of epilepsy types and underlying causes. In sub-Saharan Africa, the epilepsy prevalence is 16/1000. Rwandan rates range from 29-76·2/1000. We assessed epilepsy types, structural abnormalities, and risk factors related to this high prevalence using electroclinical and magnetic resonance imaging (MRI) findings.
**Method**: We diagnosed epilepsy types in 133 epilepsy cases (52·6% female, mean age 30y±18·2), identified during a cross-sectional community-survey in rural Rwanda, by integrating seizure-onset based on history-taking, electroencephalogram (EEG), and MRI-findings. Risk factors were assessed via questionnaires and blood samples in cases and age- and gender-matched controls (1:1), using conditional logistic regression.
**Results**: Focal-onset seizures occurred in 54·9% (73/133), generalised-onset in 6·8% (9/133), and unknown-onset in 38·3% (51/133). EEGs were abnormal in 57·9% (77/133), with 46·8% (36/77)

focal. MRI abnormalities occurred in 52·7% (68/129), and epileptogenic lesions in 27·9% (36/129). Final epilepsy types were focal in 72·9% (97/133), generalised in 7·5% (10/133), and unknown in 19·5% (26/133). Common imaging lesions included neurocysticercosis (10·9% [14/129]), posttraumatic gliosis/encephalomalacia (8·5% [11/129]), and perinatal/developmental lesions (7·0% [9/129]). Risk factors included febrile seizures (OR 3·66, 95%CI 1·27–10·59), family history of epilepsy (first-degree: OR 3·16, 95%CI 1·45–6·88; extended-degree: OR 2·93, 95%CI 1·11–7·74), and cerebral infections (OR 2·83, 95%CI 1·06–7·52).
**Conclusion**: Focal epilepsy is prevalent in rural Rwanda, driven by identifiable, amenable causes. Site-specific preventive health policies may alleviate the epilepsy burden in resource-limited settings. An interplay of environmental and genetic predispositions warrants further research.

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| **Platform Session** | **14:15 – 15:45** |
| **Sunday, 18 May** | **Room 1** |

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### *Taenia* larvae suppress inflammatory gene expression in an *ex vivo* model of neurocysticercosis

J Kanyemba[1] [1]University of Cape Town, Human Biology, Cape Town, South Africa

**Purpose**: Neurocysticercosis (NCC), a parasitic infection of the central nervous system (CNS) caused by the pork tapeworm *Taenia solium* (*T. solium*), is the leading cause of adult-acquired epilepsy. The parasite can reside in the brain for extended periods without causing any symptoms; however, little is known regarding the host-specific inflammatory gene expression changes during this asymptomatic phase. Therefore, this study investigated how the inflammatory genes *Timp1*, *Lcn2* and *Ccl5* respond to either lipopolysaccharide (LPS), *Taenia crassiceps* (*T. crassiceps*) homogenate, a closely related parasite, or a combination of both in astrocytes and microglia cells.
**Method**: Mouse hippocampal organotypic brain slice cultures were prepared from post-natal day 6-8 mice. Hippocampi were sectioned and treated with either LPS to model innate immune activation, *T. crassiceps* homogenate to model viable *Taenia* infection or both. The level of gene expression was measured using *in situ* hybridization chain reaction, and confocal microscopy was used quantify gene expression by measuring mean fluorescence intensity.
**Results**: LPS significantly unregulated *Timp1, Lcn2* and *Ccl5*, with astrocytes predominantly expressing *Timp1* and *Lcn2*, and microglia expressing *Ccl5*. The combination of LPS and *T. crassiceps* homogenate significantly suppressed inflammatory gene expression. All the genes showed lower expression in slices treated with *T. crassiceps* homogenate alone. There was no significant difference between the experimental controls and the *T. crassiceps* homogenate-treated slices.
**Conclusion**: The results show that *T. crassiceps* homogenate suppressed LPS induced expression of *Timp1, Lcn2* and *Ccl5*. This suggest that the homogenate may act by competing with LPS for binding to TL4 on glial cells, thereby inhibiting its pro-inflammatory effects. This highlights the immunosuppressive nature of *Taenia* larvae observed during asymptomatic NCC. Similarly, since treatment with *T. crassiceps* homogenate did not result in any significant changes, this is further evidence that viable *Taenia* larvae do not trigger a pro-inflammatory response.

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## Targeting the CREB pathway with Forskolin: A preclinical therapeutic approach for autism spectrum disorder

A Jain[1], B Medhi[1], A Prakash[1] [1]Postgraduate Institute of Medical Education and Research (PGIMER), Pharmacology, Chandigarh, India

**Purpose**: Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder characterized by impaired social interactions and repetitive behaviors. It is more prevalent in males than females (4:1). Dysregulation of cAMP-responsive element-binding protein (CREB) signaling was previously reported in autism. Studies have shown that Forskolin is a potent adenylyl cyclase (AC) activator. Hence, we aimed to investigate Forskolin's therapeutic potential in a valproic acid (VPA)-induced ASD model in Wistar rats.
**Method**: Initially, molecular docking and dynamics simulation, along with ADME properties, were determined to understand the druggability of Forskolin. In *in vivo* studies, VPA (600 mg/kg, i.p.) was administered to pregnant Wistar rats to develop an ASD model. VPA and control rats underwent a battery of early-age behavioral parameters to assess developmental impairments. Control rats (saline administered) and treatment controls (risperidone, 2.5 mg/kg, p.o.) were also included along with the Forskolin (10 – 30 mg/kg, p.o.) intervention group. These groups of animals were subjected to a battery of behavioral parameters like anxiety, social deficit, repetitive, spatial memory, cognition, and motor coordination behavior.
**Results**: The *in-silico* analysis revealed a docking score of -7.206, and a stable interaction pattern was seen throughout the molecular dynamics simulation. ADME results showed there were no Lipinski rule violations. *In-vivo* data showed that VPA rats had significant developmental impairments. Moreover, systemic Forskolin administration improved phenotypic characters in a dose-dependent manner. Forskolin (30 mg/kg) administration significantly reduced VPA-induced neuronal damage in the prefrontal cortex (PFC) ($p=0.0132$), hippocampus (HC) ($p=0.0035$), and cerebellum ($p=0.0078$). Furthermore, Forskolin (30 mg/kg) significantly increased the intracellular CREB ser133 protein phosphorylation ($p=0.0019$) and upregulated CREB signaling mRNA expression. Forskolin intervention also alleviated oxidative and neuroinflammatory markers.
**Conclusion**: Our preclinical data suggests that Forskolin could activate CREB signaling thereby providing neuroprotection in a VPA-induced ASD model. This highlights Forskolin as a potential therapeutic candidate for ASD.

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## Promoting access to paediatric EEG training in sub-Saharan Africa

V Kander[1], J Wilmshurst[2] [1]University of Cape Town, Department of Neurophysiology, Cape Town, South Africa, [2]University of Cape Town, Department of Neurophysiology and Paediatric Neurology, Cape Town, South Africa

**Purpose**: Neurological conditions represent a significant burden in sub-Saharan Africa (SSA). A shortage of paediatric neurologists and EEG technicians poses challenges in the management of paediatric epilepsy. The Red Cross War Memorial Children’s Hospital, (RCWMCH), and African Paediatric Fellowship Program, (APFP), have made substantial strides in training paediatric neurologists for the region. However, the absence of paediatric EEG technicians remains limiting.
**Method**: In 2019, a dedicated project was established to train paediatric EEG technicians. The program offers 3- and 6-month courses, with the 6-month course recognized as the gold standard for minimum teaching requirements. Participants complete an exit examination and perform a

minimum of 300 EEGs during training. Using this novel approach, nurses have been identified as ideal candidates for this training model, empowering them with skills necessary for safe and effective EEG practice.
**Results**: The program has successfully trained 1 technician from Kenya, 1 nurse from Tanzania, 1 nurse from Ghana, along with 2 nurses from East London, South Africa. One nurse from Uganda, currently in training and a nurse from Zimbabwe will begin training in June 2025.
**Conclusion**: The RCWMCH/APFP training program has effectively produced skilled specialists from multiple countries within SSA, addressing the challenges faced by the shortage of child neurology specialists. These specialists return home to advocate for improved paediatric neurological care, focussed on building effective teams. The training program's utilization of nurses has successfully bridged a gap in paediatric EEG personnel, demonstrating substantial potential for widespread adoption and implementation in SSA and other low-income countries.

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### From anxiety to depression in PTZ-induced kindling model of epilepsy: an assessment of comorbidity versus exposure to seizures

GT Ngoupaye[1], AF Foutsop[1], FB Yassi[2], MB Adassi[3] [1]University of Dschang, Department of Animal Biology, Dschang, Cameroon, [2]University of Ngaoundere, Department of Biology of Organisms, Ngaoundere, Cameroon, [3]University of Maroua, Department of Biologiocal Science, Maroua, Cameroon

**Purpose**: The present study was designed to characterize the sequence of occurrence of the two most prevalent comorbidity of epilepsy, anxiety and depression following kindling in a rat model.
**Method**: Animals were divided in groups as follow, control groups, a group subjected to kindling (CKEOD+0), a group subjected to kindling which received 7 extra injections following kindled state (CKEOD+7), and a group subjected to kindling which received 14 extra injections following the kindling state (CKEOD+14). Animals were then subjected to EPM, OFT to evaluate anxiety, to SPT and FST to evaluate depression. 24h following the last behavioural test, animals were decapitated and their blood, hippocampi, prefrontal cortices (PFC) were collected to assess oxidative stress (GSH, CAT, MDA), inhibitory signalisation (GABA and GABA-T), excitatory signalisation (glutamate and EAAT-2), neuroinflammatory signalisation (IL-1β, TNF-α and TGF-1β), and HPA-axis (corticosterone and CRH) and histological changes were also assessed.
**Results**: Results revealed that anxiety manifests before depression. The expression of the anxious phenotype is maximum and optimum in CKEOD+7, and depressive phenotype was maximum and optimum in CKEOD+14. Biochemical analysis demonstrated that oxidative stress was enhanced in all kindled groups both in the hippocampus and the PFC. Depressed inhibitory signalling coupled to an increased excitatory signalling pathway as well as increased CRF in hippocampi of both anxious and depressed animals and increased plasma corticosterone levels in depressed animals was shown. In addition, there was an enhancement of pro-inflammatory and a dampening of anti-inflammatory mechanisms in the hippocampus of kindled animals. Histological analysis revealed an altered hippocampal structure. These changes were however heightened in CKEOD+7 and CKEOD+14.
**Conclusion**: Taken together these results demonstrate that on a sequential basis, anxiety occurs before depression, thus preclinical screening of anxiolytic and anti-depressive drugs in epilepsy animal models should consider this time scale for optimum response.

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### Oxford Martin School Programme on Global Epilepsy: Novel electroencephalogram headsets for low resource settings

G Crooks[1], R Kariyawasam[1], S Bailie[1], H Benson[1], I Whomsley[1], R Toth[1,2], A Kavoosi[2], P Walters[1], J Fleming[2], A Minarik[3], S Mahone[3], MV Gule[4], A Sen[3,5], M Zamora[1], T Zhu[1], T Denison[1,2] [1]University of Oxford, Department of Engineering Science, Oxford, United Kingdom, [2]University of Oxford, Brain Network Dynamics Unit, Nuffield Department of Clinical Neurosciences, Oxford, United Kingdom, [3]University of Oxford, Oxford Martin School, Oxford, United Kingdom, [4]University of Cape Town, Department of Neurology, Cape Town, South Africa, [5]University of Oxford, Nuffield Department of Clinical Neurosciences, Oxford, United Kingdom

**Purpose**: The Oxford Martin School Programme on Global Epilepsy aims to reduce the epilepsy diagnostic gap in low- and middle-income countries (LMICs) by developing an affordable, portable EEG system for patient triage. This initiative combines innovative EEG hardware and machine learning algorithms for scalable classification of patient recordings, guiding treatment decisions.
**Method**: A novel EEG headset was designed to be affordable, portable, and user-friendly, featuring low-maintenance, dry electrodes that avoid the need for gel. The hardware features modular components, a five-band structure, and adjustable electrode placement to accommodate diverse users, built with low-cost materials like 3D-printed parts to ensure scalability. Rigorous testing evaluated signal quality, impedance, and mechanical durability of the EEG headset. The headset collects EEG data of sufficient quality for a machine-learning algorithm to estimate the probability of a patient having epilepsy. The hardware was designed in combination with the algorithm - selecting the number of channels and their target location, with built-in immunity to a single electrode drop out.
**Results**: Impedance testing consistently recorded levels below 50 kΩ, ensuring good signal acquisition, and mechanical testing confirmed robustness. User feedback highlighted comfort and ease of use, with an average field test score of 8.5/10. The modular design facilitated iterative improvements, tailored to LMIC needs.
**Conclusion**: This portable EEG headset, combined with machine learning models fine-tuned using good quality data collected during deployment, represents a significant advance in affordable, scalable epilepsy diagnostics. The system is poised to enhance accessibility, enable timely screening, and address critical healthcare gaps in underserved communities.

| **Platform Session** | **14:15 – 15:45** |
|---|---|
| **Sunday, 18 May** | **Room 2** |

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### Integrating traditional medicine with conventional approaches in epilepsy management: a collaborative framework

E Busera[1] [1]Afro Asia Institute of Strategic Studies, Department of Medical Anthropology, Nairobi, Kenya

**Purpose**: This study aims to explore the potential benefits of integrating traditional medicine with conventional treatment methods for epilepsy management, focusing on fostering collaboration between traditional healers and healthcare professionals.

**Method**: A qualitative approach was adopted, involving semi-structured interviews with 30 traditional healers and 20 neurologists in Nairobi, Kenya. Participants were selected based on their experience in treating epilepsy. The interviews aimed to assess perceptions of traditional practices, identify gaps in knowledge, and explore opportunities for collaboration. Data were analyzed using thematic analysis to extract key themes and insights.
**Results**: The study revealed that traditional healers employ a variety of herbal remedies and spiritual practices believed to alleviate epilepsy symptoms. Both groups recognized the need for collaboration; however, significant barriers exist, including scepticism from conventional practitioners and lack of standardization in traditional practices. Approximately 70% of traditional healers expressed willingness to partner with neurologists to improve patient care, highlighting the potential for integrated treatment plans.
**Conclusion**: The findings indicate that a collaborative framework between traditional healers and conventional medical practitioners could enhance epilepsy management in Kenya. Addressing the barriers to collaboration and establishing guidelines for integrated care may improve health outcomes for patients with epilepsy. Future research should focus on developing training programs to bridge the knowledge gap between both groups.

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## Gaps in treatment of epileptic seizures in a Zambian rural area

R Mambo[1,2], C Trevisan[3,4], A M. Phiri[1], G Zulu[2], C Mubanga[1], C Mwelwa[1], I K. Phiri[1], V Schmidt[5], P Magnussen[6], P Dorny[3], S Gabriel[4], A S. Winkler[5,7], E K. Mwape[1] [1]University of Zambia, School of Veterinary Medicine, Lusaka, Zambia, [2]Ministry of Health, Lusaka, Zambia, [3]Institute of Tropical Medicine, Antwerp, Belgium, [4]Ghent University, Brussels, Belgium, [5]Technical University of Munich, Munich, Germany, [6]University of Copenhagen, Copenhagen, Denmark, [7]University of Oslo, Oslo, Norway

**Purpose**: Epilepsy is a multifactorial neurological disorder, including parasitic infections of the brain such as neurocysticercosis (NCC). People with epileptic seizures (PWES) in low and middle-income countries often do not receive appropriate treatment, which besides epileptic seizures, may also lead to reduced quality of life and possibly death. The objective of this study was to describe gaps in treatment of epileptic seizures in a Zambian rural area.
**Method**: A cross-sectional study was conducted in Sinda district of Zambia between August and October 2018. PWES identified from clinic records and with the help of community healthcare workers were recruited. Two questionnaires, one to PWES and the other to local healthcare workers, were administered to describe the treatment gap.
**Results**: A total of 146 PWES and 43 healthcare workers were interviewed. Of the146 PWES, 131 had taken anti-seizure medication (ASM) at some point since their seizure onset, of which 49.6% were on current treatment. Only 18.3% were on continuous ASM, an overall treatment gap of 83.6%. Over 55% of healthcare workers did not know the relationship between epilepsy and NCC. The risk factors associated with lack of appropriate treatment were stock-outs of ASMs, lack of diagnostic equipment, poor patient follow up, and PWES opting for traditional medicine.
**Conclusion**: The treatment gap is substantial in Sinda district. The causes are multifactorial, involving shortcomings at the level of healthcare facilities, communities, and individuals. Directed training of healthcare workers and significant improvements in the supply and dispensing of ASMs will be key in substantially reducing the gap.

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## Experiences of caregivers of people living with epilepsy in the Shai Osudoku and Ningo Prampram districts, Greater Accra Region, Ghana

S Asiamah[1,2], E Kwame Darkwa[3], S Mahone[4], C R. Newton[5], A Sen[6], F Atuguba[7], A Akpalu[8], C Sottie[9], P Adjei[8] [1]Dodowa Health Research Centre, Ghana Health Service/University of Ghana, Communication Unit/Social and Behavioural Science Department, Dodowa/Accra, Ghana, [2]Dodowa Health Research Centre, Ghana Health Service/University of Ghana, Communication/Social and Behavioural Science, Dodowa/Accra, Ghana, [3]Dodowa Health Research Centre, Ghana Health Service/University of Ghana, Health and Demographic Department/Epidemiology Department, Dodowa/Accra, Ghana, [4]Oxford University, History Department, London, United Kingdom, [5]Oxford University, neurology Department, London, United Kingdom, [6]Oxford University, Neurology Department, London, United Kingdom, [7]Dodowa Health Research Centre, Ghana Health Service, Research, Dodowa/Accra, Ghana, [8]University of Ghana, Medical School, Accra, Ghana, [9]Ghana Health Service, Research, Dodowa/Accra, Ghana

**Purpose**: This study explores the lived experiences of caregivers of people living with epilepsy (PLWE) in the Shai Osudoku and Ningo Prampram districts of the Greater Accra Region, focusing on caregiving practices, challenges, and coping mechanisms.
**Method**: Employing a qualitative approach, in-depth interviews were conducted with 10 caregivers, purposively sampled for their diverse caregiving experiences. Participants included mothers, fathers and family members providing formal or informal care. The data were transcribed, coded, and analyzed thematically using NVivo software to capture the multifaceted experiences of caregiving.
**Results**: Key findings were that caregiving for PLWE involves substantial emotional, financial, and social burdens. Caregivers often navigate fragmented health systems, traditional and spiritual care pathways, and societal stigma, which exacerbate their challenges. Some caregivers described feelings of isolation due to fear of discrimination, while others expressed frustration with the limited availability of affordable and effective healthcare services. Despite these challenges, caregivers employed various coping strategies, including community support, religious faith, and resilience-building practices, to manage their caregiving roles.
**Conclusion**: Our study underscores the urgent need for integrated care models that recognize the roles of formal healthcare systems, traditional medicine, and religious practices in epilepsy management. We advocate for caregiver-focused interventions, such as mental health support and caregiver training, to alleviate the caregiving burden and enhance the quality of life for both caregivers and PLWE. These findings contribute to the broader discourse on epilepsy care in Ghana and similar contexts, offering actionable insights for policymakers, health professionals, and community stakeholders. By focusing on caregiver experiences, this research highlights pathways to more inclusive and effective epilepsy care systems.

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## Magnitude and factors associated with the epilepsy treatment gap in rural settings in Kilifi and urban informal settlements in Nairobi, Kenya

M Odhiambo[1,2], S Kariuki[1,3,4], J Sander[5,6], K Kipper[5], G Asiki[3], F Wekesah[3], D Mwanga[3], C Ngilandala[1], C Newton[1,4] [1]KEMRI Wellcome Trust Research Programme, Neuroscience, Kilifi, Kenya, [2]The Open University, Milton Keynes, United Kingdom, [3]African Population and Health Research Centre, Nairobi, Kenya, [4]University of Oxford, Oxford, United Kingdom, [5]UCL, Queen Square Institute of Neurology, London, United Kingdom, [6]West China Hospital, Chengdu, China

**Purpose**: The epilepsy treatment gap (ETG) in poor countries is as high as 100% but, the magnitude and associated factors remain under-explored in clinical settings including rural and urban informal settlements in Africa. Therefore, we estimated the ETG among people with epilepsy in Kilifi and Nairobi, Kenya.
**Method**: Baseline data of a randomized controlled trial designed to improve adherence to anti-seizure medications using text and voice messaging were analysed. People with epilepsy attending a clinic in Kilifi (N=1044) and seven health facilities in Nairobi (N=648) were included. Drug levels were measured to determine adherence and consequently, the ETG. Logistic regression was performed to examine associated risk factors.
**Results**: Out of 1,692 participants, 16% reported skipping their last dose while 30% had undetectable drug levels. Adults with lower education status (adjusted Odds Ratio (aOR)=2.51 (95% confidence interval (CI): 1.19-5.30)) and individuals with medication-related side effects (aOR=2.01 (1.20-3.37)) were twice as likely to have undetectable levels compared to their counterparts. Overall, 68% (95%CI: 64-71%)) of the participants had levels below optimal range making up the ETG; with the proportion being 71% in urban informal settlements in Nairobi and 65% in rural Kilifi. Having generalized seizures (aOR=1.49 (95% CI: 1.01-2.19)); active epilepsy, defined as one or more seizures in the last year, (a0R=1.80 (1.09-2.98)); poor quality of life (beta coefficient (b)=-0.007 (-0.012 to -0.003) and being on polytherapy (aOR=3.14 (2.20-4.48)) were associated with the ETG. Having generalized seizures remained significant in Kilifi (aOR=1.61 (1.01-2.57)); while poor quality of life (b=-0.005 (-0.010 to -0.001)) remained significant in Nairobi.
**Conclusion**: The ETG remains a public health problem in rural and urban clinical settings in Africa with varying factors affecting different settings and age groups. Lobbying for subsidized medication costs, educational interventions to reduce stigma and reducing the pill burden are recommended to reduce the ETG in poor countries.

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### Policy dialogue on Intersectoral Global Action Plan on epilepsy and other neurological disorders implementation and domestication: A Multisectoral Anti-Stigma Awareness Campaign approach in Cameroon

NK Ninying[1] [1]Community Development and Epilepsy Foundation - CODEF, Not applicable, Bamenda, Cameroon

**Purpose**: The objectives were to hold a national dialogue on epilepsy with policy makers from different sectors, and advocate for the integration of epilepsy awareness and stigma reduction strategies into national policies and plans.
**Method**: A mixed-methods approach was used – sharing of lived experiences by 04 persons with epilepsy and caregivers, using IBE Africa Stigma Reduction Toolkit, Epilepsy Health Laws (Adv. Nkandu Nchindila et al. In: Report on the IBE Africa 21 state Epilepsy Health Laws Mapping exercise Lusaka May 2021; 28-29) and 06 PowerPoint presentations on IGAP strategic objectives from the WHO IGAP document and IBE IGAP Unpacked guide, reviewing 02 policy documents, breakout groups, plenary discussions and questionnaires.
**Results**: Policy makers and government officials were assigned specific tasks to review and change policies and laws detrimental to persons with epilepsy. District and regional health coordination meetings were adopted as forums for awareness, education and sensitization. A national epilepsy campaign program proposed by CODEF was adopted, 87.5 % of knowledge improvement on intersectoral global action plan on epilepsy and other neurological disorders

(IGAP), Collaborations were revitalized, and Northwest regional and district health annual work plans were adopted as agora for the integration of IGAP recommendations. This aligns with IGAP's strategic objective 01: *"Raise policy prioritization and strengthen governance."*
**Conclusion**: These results call for piloting to determine the scope of the implementation and domestication of IGAP, and more importantly the interplay between civil society organizations and policymakers that are responsible for the implementation and domestication.

***With funding support from BAND Foundation and IBE***

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## Beliefs and attitudes of traditional healers regarding epilepsy in Cameroon

AM Magnerou[1,2], D Gams Massi[1], G Meyo[3], EL Gueumekane Bila[1], C Kuate Tegueu[2] [1]University of Douala, Faculty of medicine and pharmaceutical sciences, Clinical science, Douala, Cameroon, [2]Laquintinie Hospital, Internal Medicine/Neurology Department, Douala, Cameroon, [3]Higher Institute of Medical Technology Nkolondom, Yaounde, Cameroon

**Purpose**: People living with epilepsy suffer from stigmatization, overprotection, or exclusion, thus, part of these population in developing countries uses traditional medicine as a first resort. We prospectively conducted a study to determine the Knowledge, Attitudes and Practices (KAP) of Traditional Healer (TH) concerning epilepsy.
**Method**: Over a period of 9 months, we included 208 TH practicing in the Littoral, Center and West regions of Cameroon who agreed to participate in the study. TH were interviewed using a questionnaire. Data were analysed using Epi Info version 7.2 software. Comparison of variables using the Chi-square test.
**Results**: Two-hundred and eight TH were recruited, with an average age of 49.9 ± 11.4 years, and 169 (81.2%) were male. Primary 77(37.0%) and secondary 67(32.2%) levels of education were the most represented, and most of TH had more than 10 years of professional experience. One hundred and forty-one TH (68,7%) had poor knowledge about epilepsy. The independent factors associated with poor knowledge were female sex, Muslim religion, and marital status of cohabitation. One hundred and eighty-four TH (88.4%) had a good attitude and practices towards a person having epileptic seizures. Factors independently associated with poor practices and attitude were rural residence, Muslim religion, and education level.
**Conclusion**: Our result confirmed that TH had poor knowledge about epilepsy but good attitudes and practices about epilepsy. TH were in favour of future collaboration with modern medicine in the care of people living with epilepsy.

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## Epilepsy Stigma Bench Model

K Ezekiel[1], A Kavemba[2] [1]IFEA-South Sudan, Health, Juba, South Sudan, [2]Shine Epilepsy Support, Health, Nairobi, Kenya

**Purpose**: The Epilepsy Stigma Bench Model, pioneered by the International Bureau for Epilepsy (IBE), is a community-based intervention designed to address stigma and discrimination against persons with epilepsy (PWE). It provides a structured yet informal space where PWE and key community gatekeepers can openly share experiences of exclusion and discrimination without fear of repercussions.

**Method**: The model follows a structured approach to ensure effective community engagement and sustainability:

1. Training Facilitators – Select and train facilitators, preferably individuals with epilepsy, on moderation skills, stigma reduction strategies, and epilepsy awareness.
2. Briefing the Chief and Local Leaders – Engage community leadership to introduce the initiative and seek their endorsement and support.
3. Securing Approval – Obtain formal approval from community authorities to implement the model.
4. Setting Up the Bench – Identify a safe and accessible location for discussions.
5. Community Awareness and Mobilization – Spread awareness through chief messengers and local networks, informing the community about the initiative.
6. Developing a Calendar – Establish a regular session schedule to ensure consistency and sustainability.
7. Launching the Sessions – Kick off the initiative, ensuring continuous monitoring and adaptation based on community feedback.

**Results**: Since its launch, the Epilepsy Stigma Bench Model has reached 1,600 people within eight months across Kenya and South Sudan. Of these, 800 people have directly participated in discussions, with 20% being persons with epilepsy. The initiative has contributed to:

- Increased engagement: More PWE and community members participating in open discussions.
- Reduced stigma: A noticeable shift in perceptions, with epilepsy being increasingly recognized as a medical condition rather than a supernatural affliction.
- Greater inclusion: Individuals with epilepsy experience enhanced social and economic acceptance within their communities.

**Conclusion**: The Epilepsy Stigma Bench Model offers a scalable, community-driven solution to epilepsy-related stigma. The model’s success highlights the potential for grassroots advocacy to drive meaningful and sustainable stigma reduction efforts across Africa.

## In–Person Poster Presentations

### Building Capacity in Epilepsy Care

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### Enhancing epilepsy care in resource-limited settings: Implementation of mobile EEG services at the John C. Kelly Mental Health Clinic, southwestern Uganda

TD Djoyum[1], L Kilonda Fataki[2], G Centinary[3], R Twebaze[3], I Niwagaba[3], S Tumuhaise[3] [1]Harvard Chan School of Public Health, Global Mental health, Boston, United States, [2]Purple Point Neurodiagnostics, Indiana, United States, [3]John C. Kelly Mental Health Clinic, Kabale, Uganda

**Purpose**: Epilepsy affects 50 million people worldwide, and 80% of people with epilepsy (PWE) live in low- and middle-income countries (LMICs). Sub-Saharan Africa has an epilepsy treatment gap of over 75%, caused by limited diagnostic tools, poor medication access, few trained healthcare workers, and stigma that discourages care. Our project aims to address these care gaps by adding **mobile EEG diagnostics** to existing mental health and epilepsy services in southwestern Uganda.
**Method**: In 2023, the John C. Kelly (JCK) Clinic partnered with Purple Point Neurodiagnostics (PPN) to introduce mobile EEG services. Two residents with no prior EEG experience completed a 9-month training program. From June 2023 to February 2024, 110 EEGs were performed, with 102 analyzed for patients already diagnosed with epilepsy. The data collected in the first stage include demographics and prior diagnostics with no EEG in the second phase, demographics and diagnostic findings with EEG, and treatment changes.
**Results**: Most patients (82.4%) remained stable on their treatment plans, a positive indicator of the program's impact. However, we experience the challenge of climate change, with rain and landslides preventing us from having access to some of the patients after diagnostics, and sadly, two patients died during this process.
**Conclusion**: Adding **mobile EEG diagnostics** improved diagnostic accuracy and informed treatment decisions. However, closing the epilepsy care gap will require more than diagnostics. Similar projects should consider partnerships with pharmaceutical companies for more medication, work with the healthcare systems, and educate communities to reduce stigma. Continued research will explore long-term patient outcomes, medication adjustments, and how to replicate this model in similar settings. JCK Clinic and PPN partnership demonstrates how technology, training, and community engagement can improve epilepsy care in resource-limited areas.

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### Rehabilitation needs in Asian patients' community

S Pal[1], T Roy[2] [1]SFCCP NGO, Med, Meerut, India, [2]SFCCP NGO, Meerut, India

**Purpose**: To analyze rehabilitation issues/needs & their status. urgently needed to focus on development of progam guidelines for paralysis cases. policy paper for implementation in rural/tribal areas needed.
**Method**: Our NGO volunteers-nurses conducted this pilot study in six rural-villages of India .7 nurses, 2 physicians & 1 counselor participated. 246 Patients, 34 caregivers, 18 spiritual/Community Leaders participated. Relief of distressing-symptoms reported in 80%.

Responses on rehabilitation-needs analyzed using Questionnaires while Community/spiritual Leaders participated through focus group discussions. 90% participants expressed need for better rehabilitation/palliative-services.
**Results**: Rehabilitation services for geriatric epilepsy patients not easily available in Asia. Spiritual Pain control had highest correlation to QOL in comparison to functional/emotional/physical/social wellbeing. 90% of patients and caregivers reported free communication about illness. We also need to modify attitudes of caregivers towards psychosocial needs of patients & their families epilepsy care hospitals must have separate departments for handling these issue
**Conclusion**: Resource-poor-nations need NGO to develop rehabilitation programs in absence of government-run-healthcare-setup. We NGO activists need IALE Africa 2025-platform to discuss this project ideas/concerns/difficulties with senior researchers from USA/EUROPE. IALE must take initiative in propagating such efforts in African developing-nations. Development of comprehensive care program for paraplegics is distant dream in resource poor nations.

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### The Challenging Management of First Unprovoked Seizures (FUS) in African Countries

T Obeid[1] [1]University of Medical Science and Technology. Khartoum, currently in Rwanda, Medicine, Kigali, Rwanda

**Purpose**: As there is no evidence-based guidelines to address management of first unprovoked seizures (FUS) in African countries, the author discusses the difficulties in applying the guidelines suggested by the American Academy of Neurology and the American Epilepsy Society .This is due to the rarity and availability of EEG and CT/MRI machines.
The author is suggesting a practical approach that needs further discussions and studies.
**Method**: To review the availability of EEG and CT/ MRI and the presence of any guidelines in Africa to treat FUS.
**Results**: There are no available suggestions for the management of FUS.
In a survey in 2022, it was found that one MRI machine per million people in a third of African countries The number of EEG machines and trained technicians and neurologists in EEG reporting is unknown.
**Conclusion**: Anti-seizure medications (ASM) can be started immediately in a single seizure pending further investigations in following situations:

- A focal seizure based on clinical semiology.
- A nocturnal seizure.
- Status epileptics though there is no evidence to support this.
- One unprovoked seizure of late-onset age above 60 years as there is high mortality and morbidity.
- One seizure in the presence of neurological signs suggesting a previous cortical lesion.
- A syndrome or reflex epilepsy.
- Acute symptomatic seizure if a structural lesion is suspected and the patient should be referred urgently to a nearby hospital with CT/MRI facilities.

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### Navigating diversity: Validating the epilepsy diagnostic companion in a South African context

S Jacobs[1], T Linnen[1], LM Tucker[1,2], G Fieggen[1,2], S Dalvie[1,3], DJ Stein[1], I Duta[4], A Sen[5,6], GD Jones[4,6], M Gule[1,2] [1]Neuroscience Institute, Department of Mental Health and Psychiatry, University of Cape

Town, Cape Town, South Africa, [2]Neuroscience Institute, Division of Neurology, University of Cape Town, Cape Town, South Africa, [3]Neuroscience Institute, Division of Human Genetics, Department of Pathology, University of Cape Town, South Africa, Cape Town, South Africa, [4]University of Oxford, Nuffield Department of Women's & Reproductive Health, Oxford, United Kingdom, [5]University of Oxford, Women's Centre, Centre for Global Epilepsy, Wolfson College, University of Oxford, Oxford, United Kingdom, [6]University of Oxford, Nuffield; Department of Clinical Neurosciences, John Radcliffe Hospital, Oxford, United Kingdom

**Purpose**: The Global Epilepsy Research Database (GERD) is an initiative by the Oxford Martin School Program on Global Epilepsy. GERD is comprised of 150 validated yes/no questions aimed at identifying convulsive and non-convulsive seizures, while capturing relevant clinical information. We assessed the feasibility of using GERD in a pilot sample of patients in South Africa.
**Method**: Trained research assistants administered the GERD questionnaire to all new patients at the epilepsy clinic at Groote Schuur Hospital (GSH) in Cape Town. Interviews were conducted in English using the Research Electronic Data Capture (REDCap) platform. Each patient underwent a routine electroencephalogram prior to answering the GERD questionnaire, followed by a consultation with a neurologist for diagnosis confirmation.
**Results**: The GERD questionnaire was piloted on 54 new patients, of whom 56% were diagnosed with epilepsy and 12% with psychogenic non-epileptic seizures. Approximately 25% were classified as uncertain by the neurologist and required further assessment. The average interview time was 45-60 minutes per patient. All patients came from low-income communities, with most having limited or no formal education. Many questions required rephrasing or elaboration due to challenges in comprehension. The absence of an accompanying witness often hindered accurate responses from patients experiencing loss of consciousness.
**Conclusion**: These findings underscore significant challenges in assessing epilepsy within this South African population. Language barriers, limited formal education, and patients attending unaccompanied all made administration of the questionnaire more time consuming than expected. These issues highlight the complexities in acquiring large datasets from underrepresented communities.

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## Comparative study of the oral health status and care needs of patients with and without epilepsy

AM Magnerou[1,2], Y Hotou Tchapda[3], SH Tchoukoua[4], CM Pilipili[3], C Kuate Tegueu[2] [1]University of Douala, Faculty of medicine and pharmaceutical sciences, Clinical science, Douala, Cameroon, [2]Laquintinie Hospital, Internal Medicine/Neurology Department, Douala, Cameroon, [3]Universite des Montagnes, Odontostomatology, Bangante, Cameroon, [4]Universite des Montagnes, Public Health, Bangante, Cameroon

**Purpose**: The oral health of patients with epilepsy is a significant concern due to stigma, marginalization, and a lack of attention to their dental issues.
**Method**: A cross-sectional analytical study was conducted from February 19 to May 17, 2024, in the neurology department. The study included PLWE diagnosed at least six months prior and non-PLWE who consented to participate, matched by age, sex, and lifestyle. Variables analyzed included epilepsy characteristics, Oral Hygiene Index Simplified (OHI-S), Community Periodontal Index of Treatment Needs (CPITN), Decayed, Missing, Filled (DMF) index, or traumatized teeth, and

dental care needs. The chi-square test was used to compare the two groups at a 5% significance level.

**Results**: A total of 210 participants were examined, including 70 PLWE. Generalized tonic-clonic seizures were the most common type (35.7%). Nearly half of the PLWE were taking Carbamazepine (45.7%). PLWE were 16 times more likely to have poor oral hygiene (85.7%) compared to non-PLWE (27.1%) [OR=16.105 (7.486–34.649), p < 0.001]. Gingivitis was the most prevalent condition, affecting 71.4% of PLWE compared to 57.9% of non-PLWE [OR=7.018 (3.441–14.312), p=0.001], followed by periodontitis, observed in 18.6% of PLWE versus 6.4% of non-PLWE [OR=10.702 (4.052–24.503), p=0.001]. Over 58% of PLWE required dental restoration [OR=1.756 (0.982–3.140), p=0.057].

**Conclusion**: More than 8 out of 10 patients with epilepsy have poor oral health, with gingivitis being the most common condition, affecting three-quarters of them. Greater attention should be directed toward the oral health of these patients.

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## Advancing electroencephalography and artificial intelligence (AI) for epilepsy diagnosis in low- and middle-income countries

A Minarik[1], M Zamora[1], J Fleming[1], MV Gule[2], T Denison[1], A Sen[1] [1]University of Oxford, Oxford, United Kingdom, [2]University of Cape Town, Cape Town, South Africa

**Purpose**: Around 80% of people with epilepsy live in low- and middle-income countries (LMICs), yet 75% of them are untreated. With proper treatment, seizures could be controlled in up to 70% of affected individuals. Electroencephalography (EEG) is an important adjunct in diagnosing epilepsy and enabling appropriate treatment. The high cost of necessary equipment and the specialised expertise required for accurate interpretation often makes EEG inaccessible in LMICs. Here, we review how advances in EEG technology and artificial intelligence (AI) can improve epilepsy diagnosis in LMICs by increasing accessibility, automating analysis, and enabling portable, cost-effective solutions. We examine current applications, identify key challenges, and highlight opportunities for adapting technologies to the specific needs of these regions.

**Method**: A narrative review was conducted using Embase and PubMed to identify studies on EEG and AI technologies for epilepsy diagnosis in LMICs. Principal criteria for inclusion were accessibility, technological advancements, challenges, and implementation strategies in LMICs. From these, key themes were synthesized to evaluate current applications and future opportunities.

**Results**: Screening identified 374 articles, of which a minority met specified criteria. Several promising technologies were identified, including low-cost portable EEG systems that have the potential to bridge the diagnostic gap in LMICs. These devices are designed to be more affordable and accessible, with some groups developing systems that can be deployed in rural areas. AI applications in automating analysis and providing diagnostic support enhanced the utility of these devices, though application of this in LMIC settings is still limited.

**Conclusion**: Low-cost, portable EEG systems and AI technologies show potential to improve epilepsy diagnosis in LMICs, particularly in rural areas. These innovations could break down barriers to diagnosis and treatment. For successful implementation and meaningful impact, challenges such as infrastructure constraints, expertise shortages, affordability, and the need for cultural contextualization must be thoughtfully addressed.

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## Community-based epilepsy care in an onchocerciasis-endemic area: A 3-year cohort study in Mahenge, Tanzania

D Bhwana[1], L-J Amaral[2], O Kamoen[3], A Mhina[1], V Mushi[4], W Makunde[1], W Matuja[4], B Mmbando[1], R Colebunders[2] [1]National Institute for Medical Research, Tanga Research Centre, Tanga, Tanzania, United Republic of, [2]Global Health Institute, University of Antwerp, Antwerp, Belgium, [3]Global Health Institute, Antwerp, Belgium, [4]Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of

**Purpose**: In onchocerciasis-endemic areas, limited access to antiseizure medications (ASMs) contributes to a high epilepsy burden. This study evaluated the impact of a community-based epilepsy care program in Mahenge, Tanzania, an onchocerciasis-endemic area with high epilepsy prevalence.
**Method**: A baseline survey (2017-2018) identified persons with epilepsy (PWE) in four rural villages. Subsequently, PWE were invited to enrol in the epilepsy treatment program (2019-2022), where trained community health workers (CHWs) screened for epilepsy, promoted ivermectin intake to treat onchocerciasis, distributed ASMs, and monitored seizure frequency and ASM adherence monthly under supervision from the project clinician trained in epilepsy diagnosis and treatment. Mixed-effects negative binomial regression analyzed risk factors for weekly seizure incidence rate.
**Results**: Of 206 participants, 77.7% reported bilateral tonic-clonic seizures, and 32.0% reported focal seizures. Weekly seizure frequency decreased significantly from a mean of 1.9 seizures (interquartile range [IQR] = 0-2) at enrollment to .4 seizures (IQR = 0-0) at the last follow-up (Wilcoxon test $p < .0001$), with significantly improved ASM adherence (57.5%-94.7%, McNemar test $p < .0001$). Factors associated with lower weekly seizure incidence included longer program participation, ASM adherence, carbamazepine use compared to phenobarbital, and ivermectin intake in 2022. ASM adverse events were associated with increased seizure frequency. The mortality rate was 32.7 deaths per 1000 person-years, with most deceased not fully adhering to ASM (88%) and having epilepsy-related causes of death (60%).
**Conclusion**: The community-based program using CHWs was associated with a significant reduction in seizure frequency and improved ASM adherence. Ivermectin's impact on seizure frequency merits further investigation in onchocerciasis-endemic areas. Community-based epilepsy care is a promising strategy for scaling up epilepsy care in rural areas in Africa

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## Benefits of providing a new gold-standard inpatient long-term epilepsy monitoring service at a tertiary referral centre in Nairobi, Kenya: two years of experience

E Mshamba[1], J Said[1], H Ekea[1], D Sokhi[1] [1]Aga Khan University, Nairobi, Kenya

**Purpose**: Inpatient epilepsy monitoring units (EMUs) with long-term electroencephalography (ltEEG) are important services in the diagnosis and management of patients with epilepsy and epileptic-like attacks. However, there are very few EMUs in sub-Saharan Africa due to lack of resources and specialised personnel. Data from our survey across Kenya, previous presented at the African Epilepsy Congress (2017), highlighted the dearth of EMUs in the country; as a result, we set up an adequately equipped EMU supported by appropriately trained staff, with quality standards borrowed from supportive colleagues in higher-income countries. The service provides for patients to be admitted for 24-96 hours of ltEEG, and we present here the outcomes of these EMU admissions since deployment.

**Method**: We did a retrospective cross-sectional chart review of all adult patients (age ≥18 years) admitted to the EMU at the Aga Khan University Hospital, Nairobi, from its launch in August 2022 to December 2024.
**Results**: We admitted 66 adult patients: the majority [67% (22/44)] were female, median [interquartile range (IQR)] age was 36 (27-46) years, and males were admitted for a median of 48h and females 24h. The majority [80% (53/66), with 38/53 being female] were admitted for diagnostic ltEEG, of which: 45% (24/53) had no attacks and had normal recordings; 28% (15/53) had an attack and/or abnormal ltEEG confirming a diagnosis of epilepsy; and 23% (12/53) had attacks with semiologies and normal ltEEG confirming functional seizures [75% (9/12) were female (p=0.3)]. Overall, diagnostic ltEEG gave a positive result in 51% of admissions. The remainder of patients were known to have epilepsy and were admitted for either seizure localisation or non-convulsive status monitoring, of which 70% (9/13) had positive ltEEG findings that definitively altered further management.
**Conclusion**: Providing ltEEG in a resource-limited setting gives results which are beneficial towards informing appropriate management of patients with epilepsy and related disorders.

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## Adherence to Status Epilepticus treatment protocols in a paediatric emergency department in sub-Saharan Africa: A retrospective and post-intervention prospective study

C Birmeh[1], H Buys[2], J Wilmshurst[3] [1]University of Cape Town/Red Cross War Memorial Children's Hospital, Paediatric Neurology, Cape Town, South Africa, [2]University of Cape Town/Red Cross War Memorial Children's Hospital, Department of Emergency Medicine, Cape Town, South Africa, [3]Red Cross War Memorial Children's Hospital, Neurosciences Institute, University of Cape Town, Department of Paediatric Neurology, Cape Town, South Africa

**Purpose**: Non-adherence to treatment recommendations for status epilepticus significantly affects outcomes with a resultant increased intervention requirement, morbidity and mortality. Aim of this study was to assess level of adherence to status epilepticus treatment protocols in a paediatric emergency department and to evaluate the impact of a standardized training program on healthcare practitioners' knowledge and subsequent adherence to existing treatment protocols.
**Method**: The study consists of three phases: The on-going first stage is a retrospective audit of status epilepticus management at the emergency department of the Red Cross War Memorial Children's Hospital. The study will subsequently undertake a knowledge survey of healthcare practitioners before and after a training intervention, and a prospective audit of status epilepticus management after training. Children under 16 years of age presenting with convulsive status epilepticus and doctors at the frontline of status epilepticus management are included.
**Results**: The first month of the retrospective study recruited 19 children fulfilling inclusion criteria. Median age was 32 months. Breakthrough seizures accounting for 42% were more common in children over 5 years whilst infections, accounting for 31.5% were predominant in under-fives. Limited adherence to protocols including wrong dosage and deviation from recommended sequence was evident in 40 % of cases. The study continues to recruit and analyze patients until May 2025.
**Conclusion**: This study highlights the significance of targeted interventions to reduce the impact of epilepsy complications such as status epilepticus, with the goal of implementing this model across resource-limited settings.

## Drug Therapeutics

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### Losartan: A promising novel therapeutic for drug-resistant epilepsy

M Hamati[1], A Abu Ahmad[1,2], L AlHadeed[1], M Avoli[3], L Maxime[3], F Boyer-Ayme[4], A Ni Shaoraigh[5], B Murphy[5], M Albitar[6], A Alshanti[1], B Shafiq[1], Z Alhosainy[6], O Prager[2,4], A Friedman[1,2,4] [1]Dalhousie University, Department of Medical Neuroscience, Halifax, Canada, [2]Ben-Gurion University of the Negev, Brain Sciences and Cognition, Beer-Sheva, Israel, [3]McGill University, Montreal, Canada, [4]Ben-Gurion University of the Negev, Physiology and Cell Biology, Beer-Sheva, Israel, [5]Trinity Institute of Neuroscience, Dublin, Ireland, [6]AL Faisal University, Riyadh, Saudi Arabia

**Purpose**: Epilepsy, a neurological disorder affecting 50 million people globally, is characterized by recurrent seizures. While anti-seizure medications (ASMs) are the primary treatment, 30% of patients are drug resistant. Blood-brain barrier (BBB) dysfunction, linked to transforming growth factor beta (TGFβ) signaling, astrocyte activation, and neuroinflammation, plays a key role in epileptogenesis and drug resistance. The FDA-approved antihypertensive drug losartan has been shown to block TGFβ signaling, reduce BBB permeability, and prevent epileptogenesis in rodent models. This study aims to evaluate losartan's potential to mitigate BBB dysfunction, block TGFβ signaling, and reduce seizure frequency in established model for temporal lobe epilepsy (TLE).
**Method**: We utilized paraoxon-induced status epilepticus (SE) in rats and the pilocarpine model in mice to study TLE. Seizures were monitored via continuous ECoG recordings with epidural electrodes in rats and hippocampal electrodes in mice. After a two-week baseline, animals received losartan (30 mg/kg/day) for two weeks. Seizures and interictal ECoG features were analyzed blindly. Ex vivo brain slices were exposed to FITC-albumin or serum albumin, with or without losartan, for histological or molecular analysis. FITC-albumin-labeled cells were quantified, and Western blotting assessed the P-Smad2/Smad2 ratio to study TGFβ signaling.
**Results**: We report a decrease in the frequency of seizures and epileptiform interictal EEG features in losartan-treated rodents. Additionally, our ex vivo experiments showed that Losartan blocked the uptake of albumin into brain cells and prevented albumin induced TGFβ signaling.
**Conclusion**: Our study supports the use of losartan to target BBB pathology and reduce seizure burden, highlighting its potential as a novel treatment for drug-resistant epilepsy.

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### Epilepsy care in Uganda: the twin challenges of medication access and provider knowledge

N Mukiza[1,2], R Nabulya[1], S Nekesa[3] [1]Rinecynth Advisory, Research, Kampala, Uganda, [2]King Ceasor University, Public Health, Kampala, Uganda, [3]Epilepsy Support Association of Uganda, Kampala, Uganda

**Purpose**: This study assessed the availability of antiepileptic drugs (AEDs) and the knowledge of healthcare workers on epilepsy management at selected National and Regional Referral Hospitals, and Health Center IVs (HCIVs).
**Method**: A cross-sectional study was conducted at two National Referral Hospitals (Mulago and Butabika), one Regional Referral Hospital (Jinja), and two HCIVs. Pharmacy records and 18 respondents provided quantitative data on AED availability. A knowledge survey of 13 HCIV clinicians and nurses assessed epilepsy management expertise and training gaps. Key informant interviews (11) with policymakers, supply chain managers, and healthcare providers explored

procurement and stock management challenges. Data analysis involved descriptive statistics and thematic analysis.

**Results**: Carbamazepine was available at all facilities but in inadequate quantities (4–572 packs). Phenobarbital was absent in 40% (2/5) of hospitals. Phenytoin and Midazolam were unavailable except for one pack of Midazolam at Jinja Hospital. Sodium Valproate was stocked at 60% (3/5) of facilities but absent at HCIVs. Stockouts (60%) were linked to procurement challenges, budget constraints, and poor stock tracking. Epilepsy guidelines were lacking in 75% of facilities. Nearly half (46%) of healthcare workers couldn't identify Sodium Valproate, 54% were unaware of Diazepam's role, and only 12% had epilepsy training in five years.

**Conclusion**: Inadequate AED availability and healthcare worker knowledge hinder epilepsy management in Uganda. Enhancing procurement, increasing budgets, and standardizing training and guidelines can improve care and reduce epilepsy-related morbidity.

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## Stiripentol in Dravet syndrome – Additional results from two randomized placebo-controlled clinical trials

B Serraz[1], R Guerrini[2], L Chancharme[3], C Chiron[4] [1]Biocodex, Orphan Disease Division (HQ), Gentilly, France, [2]A. Meyer Children's Hospital, University of Florence, Pediatric Neurology, Neurogenetics and Neurobiology Unit and Laboratories, Neuroscience Department,, Florence, Italy, [3]Biocodex, R&D Department, Compiègne, France, [4]APHP, Necker-Enfants Malades Hospital, Pediatric Neurology and Reference Center for Rare Epilepsies, Paris, France

**Purpose**: Stiripentol (STP) was the first anti-seizure medication approved for Dravet syndrome (DS) based on two placebo-controlled trials: STICLO-France and STICLO-Italy. Here, we investigate new STP data from their open-label extension periods (OL) and quality of life (QoL).

**Method**: After a 2-month-blind period, patients continued OL (1-month) without breaking the blind, with PBO patients switching to STP ('OL-PBO') and STP patients staying on treatment (50mg/kg/d). Data from both STICLO studies were pooled, and %-change-GTCSF, responder rates, seizure freedom, time-to-onset efficacy, and QoL (assessed via longest CSFd from patient diaries) were calculated.

**Results**: 64 patients were included during the 2m-blind (STP 33, PBO 31), 43 during the OL, 53 patient diaries were collected. A significant, lasting difference between groups emerged from day 4 (p=0.020). Median %-change-GTCSF significantly differed at 2m-blind (-84.3% vs -5.8%, p<0.001, STP vs PBO), but not after OL (-77.8% vs -85.2%, p=0.5, OL-STP vs OL-PBO).Similarly, ≥75% responder rates were 56.2% *vs* 3.4% (p<0.001, STP *vs* PBO) and 57.1% *vs* 68.8% (p=0.53, OL-STP *vs* OL-PBO) at 2m-blind and OL periods respectively. No PBO patients achieved seizure freedom, while 37.5% did in the STP group (p<0.001) at 2m-blind. During OL, rates were similar (35.7% vs 31.2%, p=1, OL-STP vs OL-PBO). Median CSFd at 2m-blind end: 32.5 vs 8.0 days (p<0.001, STP vs PBO).

**Conclusion**: Analyses confirm STP rapid and high efficacy maintained over time in reducing GTCS frequency. STP displays significant improvement in term of seizure free days, which has been correlated to higher QoL of DS patients and their caregivers. Supported by Biocodex.

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## STP intrinsic anti-seizure activity: an update on its mechanisms of action

JH Cross[1], A Bacq[2], B Serraz[3] [1]University College London National Institute for Health Research Biomedical Research Centre Great Ormond Street Institute of Child Health, London, United Kingdom, [2]Biocodex - Research and Development Center, Compiègne, France, [3]Biocodex Orphan Disease Division (HQ), Gentilly, France

**Purpose**: **I**n 2007, stiripentol (STP) was granted its first marketing authorization as Diacomit® in Europe. At this time, STP was known as a positive modulator of GABA-A receptor (GABAA-R) mediated neurotransmission. Since then, several studies investigated and characterized STP biological properties.
**Method**: This work summarizes additional pharmacological activity of STP.
**Results**: STP is a positive allosteric modulator of GABA_A-R, with the highest effect on α3 subunit-containing receptors, highly expressed in immature brain, explaining its efficacy in childhood-onset epilepsies like Dravet syndrome. Its activity is potentiated by benzodiazepines, with studies suggesting independent actions that enhance combined effects.
STP has also been found to inhibit lactate dehydrogenase, reducing ATP production, limiting K_ATP channel inhibition, and decreasing neuronal excitability.
In neuronal glial cells exposed to oxygen-glucose deprivation, STP was neuroprotective when used prior the insult. In cells exposed to high glutamate levels STP at high concentrations was also neuroprotective. A significantly decreased cell injury after lithiumpilocarpine-induced status epilepticus was also observed in hippocampus of young and adult rats.
Recent data suggest STP interacts with voltage-dependent calcium channels, inhibiting T-type and P/Q-type channels, potentially affecting thalamo-cortical oscillations in absence seizures.
**Conclusion**: STP is an antiepileptic drug harbouring multiple mechanisms of action. Its therapeutic efficacy observed in epilepsy derives from the sum of its biological properties and pharmacological actions rather than a single action. Further research is needed to better understand the relation between the different biological properties. and beneficial effects observed as well as characterize additional utility for other rare forms of epilepsy.

## Education and Training

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### Analyzing perceptions, attitudes and knowledge about epilepsy among nurses in resource poor settings

T Roy[1] [1]SFCCP NGO, Med, Meerut, India

**Purpose**: To assess knowledge, perception and attitudes of nurse in care of epilepsy-patients.
**Method**: From October 2014 : Questionnaires based study consisted of two sections. 1] Information about neurological disorder like epilepsy 2] Methods to elicit nurses' knowledge perception and attitudes in care of epilepsy patients.
All questionnaires were returned and analyzed using simple statistical method. We also designed framework for orientation/CME that would novices to experts in providing nursing care for epilepsy patients. This presentation outlines role of nurses, impact on patient outcomes and education required for competent practice.
**Results**: N=23 nurses aged between 20-35 years enrolled from District hospital & rural catholic mission in rural/tribal India . 18 females, 5 males. knowledge, perception and attitudes of nurses towards epilepsy care is minimal with only 10 showing special skill, perception and good attitudes

towards caring for epilepsy patients as opposed to 9 with little knowledge and low perception to caring for epilepsy patients and the remaining 4 with no specific knowledge and perception towards nursing care of epilepsy patients.
**Conclusion**: nursing care is an important specialty but neglected in rural Africa. Resources are scarce for such initiatives. Trained nurses can improve QOL of epilepsy patients. This presentation will highlights role of cancer-nurses, impact on patient QOL, and education required.

## EEG

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### Utilizing EEG biomarkers for enhanced epilepsy management in low-resource settings

S Lash[1], A Malunga[2], L AlHadeed[1], K Saadeh[1], A Abu-Ahmad[1], F Benninger[3], G Ben-Arie[4], N Fearns[5], H Imtiaz[1], S Kunst, A Minarik[1], M Masamu[6], G Mshanga[2], O Neal[7], A Racz[8], T Ruber[8,9], Y Serlin[10], M Shamir[11], T Welte[12], B Whatley[13], A Friedman[1,14], S Zimba[15] [1]Dalhousie University, Medical Neuroscience, Faculty of Medicine, Halifax, Canada, [2]Mambwe Health District, Mambwe District, Zambia, [3]Rabin Medical Center, Department of Neurology, Petach-Tiva, Israel, [4]Soroka University Medical Center, Beer-Sheva, Israel, [5]Epilepsy Center Munich, Department of Neurology, Munich, Germany, [6]Mambwe District Hospital, Eastern Province, Zambia, [7]Nova Scotia Health, Division of Neurology, Halifax, Canada, [8]University Hospital Bonn, Department of Epileptology, Bonn, Germany, [9]University Hospital Bonn, Department of Neuroradiology, Bonn, Germany, [10]National Institute of Neurological Disorders and Stroke, Neurophysiology of Epilepsy Unit, Bethesda, United States, [11]Koret School of Veterinary Medicine, Rehovot, Israel, [12]University Hospital Erlangen, Department of Neurology, Erlangan, Germany, [13]Nova Scotia Health and Dalhousie University, Division of Neurology, Halifax, Canada, [14]Ben-Gurion University of the Negev, Departments of Physiology and Cell Biology, Beer-Sheva, Israel, [15]University Teaching Hospital, Department of Internal Medicine, Lusaka, Zambia

**Purpose**: Epilepsy affects over 50 million people globally, with a disproportionate impact on low- and middle-income countries (LMICs). Effective management is hindered by limited access to healthcare professionals, scarce availability of antiepileptic medications, and the persistent stigma associated with the condition. Electroencephalography (EEG) remains a cost-effective and widely used diagnostic tool; however, its interpretation requires specialized expertise often unavailable in rural and underserved regions of LMICs. These challenges highlight the critical need for reliable, quantitative EEG biomarkers to enhance diagnostic accuracy, prioritize patients for advanced neuroimaging, and monitor treatment efficacy, ultimately improving outcomes in resource-limited settings.
**Method**: This study investigated paroxysmal slow wave events (PSWEs), transient markers of cortical network slowing, in scalp EEG recordings from epilepsy patients at the Kakumbi Rural Health Centre in rural Zambia. A total of 127 EEGs and 42 computerized tomography (CT) scans were analyzed. PSWE characteristics, including occurrence, duration, and spatial distribution, were analyzed. Source localization of PSWEs was performed using sLORETA software.
**Results**: PSWEs were observed in all patients with epilepsy. They were more prevalent in younger patients and those with earlier disease onset. PSWE characteristics, including temporal and spatial distribution, were associated with disease severity. Focal PSWEs source localization suggested the presence of an intracranial lesion on CT.
**Conclusion**: The study supports previous research on the potential of PSWEs as a quantitative EEG biomarker in epilepsy. Automated analysis of PSWEs can enhance diagnostic accuracy and assist

in screening patients for brain imaging, particularly in resource-constrained settings. This approach offers a practical solution to bridge the diagnostic gap in LMICs, improving epilepsy management and patient outcomes.

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### Epilepsy and novel electroencephalographic findings in Leigh Syndrome with mitochondrial complex II deficiency

C Nwanze[1,2], P Pearl[1,2] [1]Boston Children's Hospital, Boston, United States, [2]Harvard Medical School, Boston, United States

**Purpose**: Leigh Syndrome is a progressive neurodegenerative disorder associated with dysfunction of mitochondrial oxidative phosphorylation, with central nervous system manifestations. However, there is no consensus on the prevalence of epilepsy in patients with Leigh Syndrome, with a predominance of complex I mutations in patients with comorbid epilepsy (Lee S et al. Front Neurol. 2019;10:496, Kaiyrzhanov et al. Brain Communications. 2025; 7:453). We report a case of an infant with Leigh syndrome and mitochondrial mutation presenting with novel EEG findings.
**Method**: We report clinical, biochemical, and imaging features in a patient with Leigh syndrome and mitochondrial complex II deficiency with a novel EEG finding, repetitive high-amplitude delta with superimposed (poly)spikes (RHADS), previously unreported in this disorder or other respiratory chain defects.
**Results**: A 10-month-old, former full-term male presented with episodic apnea and hypotonia. Urine organic acids showed elevated succinic, 3-methylglutaconic, and 3-hydroxy-3-methylglutaric acids. Echocardiogram demonstrated cardiomyopathy with reduced ejection fraction. MRI demonstrated T2-prolongation involving the periaqueductal pons and midbrain, cerebral peduncles, medial thalami, globi pallidi, putamina, and left caudate nucleus. MR Spectroscopy demonstrated nonspecific reduction in N-acetylaspartate. Continuous EEG showed RHADS in the occipital regions with evolution to electrographic seizures. Genetic testing revealed biallelic variants in succinate dehydrogenase complex flavoprotein subunit-A (SDHA) gene, consistent with mitochondrial complex II deficiency. Therapeutic interventions included arginine, a mitochondrial cocktail containing ubiquinone and riboflavin, and titration of lacosamide, clobazam, and levetiracetam.
**Conclusion**: We present a case of infantile-onset Leigh Syndrome and succinate dehydrogenase (complex II) deficiency with a novel electroencephalographic finding of RHADS, previously associated with POLG-related disorders. This case expands the phenotypic spectrum of Leigh Syndrome and demonstrates the presence of RHADS, previously considered pathognomonic of Alper’s hepatocerebral degeneration/POLG-related disorders, in this respiratory chain abnormality. We highlight the utility of whole exome and mitochondrial DNA sequencing for diagnostic and prognostic counselling in patients with Leigh Syndrome.

## Epidemiology

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### Epilepsy prevention in Mahenge, Tanzania

V Mushi[1,2], D Bhwana[3], I Massawe[3], P Magili[3], H Kimambo[4], H Hyera[1], W Kidima[2], W Matuja[1], A Sen[5], J Sander[6,7,8], H Cross[9], R Colebunders[10], C Newton[5,11], B Mmbando[3] [1]Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of, [2]University of Dar es Salaam, Dar es Salaam, Tanzania, United Republic of, [3]National Institute for Medical Research, Tanga, Tanzania, United Republic of, [4]Muhimbili National Hospital, Dar es Salaam, Tanzania, United Republic of, [5]University of Oxford, Oxford, United Kingdom, [6]UCL Queen Square Institute of Neurology, London, Tanzania, United Republic of, [7]West China Hospital, Sichuan University, Chengdu 610041chi, China, [8]Stichting Epilepsie Instellingen Nederland, 2103 SW Heemstedenethne, Netherlands, [9]UCL Great Ormond Street Institute of Child Health, London, United Kingdom, [10]University of Antwerp, Antwerp, Belgium, [11]KEMRI-Wellcome Trust Research Programme, Kilifi, Kenya

**Purpose**: Epilepsy is prevalent in Mahenge and is thought to be related to onchocerciasis, which is endemic in this region. This study investigated the current burden of epilepsy and the impact of biannual community-directed treatment with ivermectin (CDTi) on onchocerciasis control.
**Method**: The study was a cross-sectional survey involving 56,604 participants, with school-aged children (6–11 years) serving as the population to assess the impact of biannual CDTi. A standardized questionnaire was used for epilepsy screening, whereas suspected individuals were confirmed by trained clinicians. Blood samples were collected to test for onchocerciasis. A questionnaire survey was administered to gather data on ivermectin coverage, and pre-biannual CDTi data from four villages were used as baseline information.
**Results**: The prevalence of epilepsy was 21.1 cases per 1,000 persons, highest in medium-altitude (29.5%) and lowest in the lowlands (12.7%). Annual epilepsy incidence was 117 cases per 100,000 person-years. Onchocerciasis-associated epilepsy prevalence was highest in medium-altitude (40.3%) and lowest in the lowlands (33.9%). Onchocerciasis prevalence in children aged 6-10 years was 11.8%, with the highest rates in medium-altitude (21.7%). Self-reported ivermectin use was 88.4%. Following biannual CDTi, onchocerciasis prevalence in children under 11 years decreased from 20.7% in 2017 to 11.8% in 2021 and 10.7% in 2024.
**Conclusion**: Biannual CDTi reduced the prevalence of onchocerciasis. Continued strengthening of biannual CDTi and vector-targeted interventions is essential to controlling onchocerciasis and associated epilepsy in Mahenge.

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### Epilepsy in the context of neurocysticercosis: Evidence from rural Zambia

G Zulu[1], KE Mwape[2], S Gabriel[3], AS Winkler[4] [1]Ministry of Health, Kabwe, Zambia, [2]University of Zambia, Department of Clinical Studies, School of Veterinary Medicine, Lusaka, Zambia, [3]Ghent University, Faculty of Veterinary Sciences, Ghent, Belgium, [4]TUM University Hospital and Center for Global Health, Department of Neurology, Munich, Germany

**Purpose**: Neurocysticercosis (NCC) is a zoonotic disease that occurs following infection of the central nervous system with cysticerci of the pork tapeworm, *Taenia Solium.* Neurocysticercosis is one of the leading causes of preventable epilepsy and has been associated with over 30% of epilepsy cases globally affecting 2.6-8.3 million people. This abstract aims to highlight the contribution of NCC towards epilepsy cases in rural Zambia.
**Method**: Cross-sectional studies were conducted in Sinda and Chipata districts (between December 2017 and November 2021; and between June 2019 and December 2022) in the Eastern province of Zambia. Serum samples were collected and tested for the presence of *T. Solium* cysticercal antibodies and antigens. All cysticercosis positive participants received a further

clinical evaluation and cerebral computed tomography (CT) examination for NCC diagnosis and staging.
**Results**: The NCC prevalence among people reporting epileptic seizures (PWEs) was determined to be 38% and 52% in Sinda and Chipata districts respectively. In Sinda district all (6/6) PWEs with NCC had calcifications on neuroimaging and 33.3% (2/6) had additional active stage lesions. In Chipata district, 84.6% (11/13) of the PWEs with NCC had calcifications and 30.8% (4/13) had active lesions. Overall, 53% (52/99) of lesions in PWEs were in the brain parenchyma.
**Conclusion**: Epilepsy and epileptic seizures are common among people with NCC in Zambia. Though the frequency of epileptic seizures is often higher in cases of active/degenerating stage lesions, they are common in patients with calcified parenchymal brain cysticerci. Neurocysticercosis should therefore be considered among patients with epilepsy in rural Zambia.

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### Demographic and socioeconomic characteristics of adults with neurocysticercosis-associated epilepsy at the University Teaching Hospital in Lusaka, Zambia

D Mwansa[1], M Chilando[1], F Mutete[1], C Muleya[1], T Shankanga[1], N Chiwaya[1], D Saylor[2], C Mashina[3], M Asukile[3] [1]University Teaching Hospital, Lusaka, Zambia, [2]University of North Carolina at Chapel Hill, North Carolina, United States, [3]University of Zambia, School of Medicine, Lusaka, Zambia

**Purpose**: To describe the demographic and socioeconomic characteristics of NCC-associated epilepsy at the University Teaching Hospital (UTH) in Lusaka.
**Method**: A cross-sectional case-control study of adults with NCC (cases) and with non-NCC focal epilepsy (controls) at UTH was conducted between December 2021 and April 2024. Descriptive statistics and Chi square tests of association were performed.
**Results**: Of 141 participants, 79 (56%) were cases. Majority were male (67%), with proportionately more male cases, 79% (62/79) than controls, 53% (33/62), p=0.002. Cases were younger, medianage38 (IQR 30,48) years versus 46 (IQR 36,63), p=0.001. HIV rates were 29%, slightly higher in controls. Education levels were similar, with majority (74%) attaining at least secondary school. Unemployment levels were 34% and majority were traders. Cases were more likely to be traders (24% vs 11%). Cases were more likely to consume pork (83% vs 71%, p=0.01), consume it more frequently (75% vs 56%, p=0.025), purchased from community vendors (89% vs 67%, p<0.01). Despite similar water sources and purification methods, cases were more likely to drink untreated water (56% versus 44%, p<0.01) while controls more likely used water filtration systems (19% versus 5%, p<0.01). The majority used water closet toilets (46%) or pit latrines (43%). Alcohol consumption was higher in cases. Epilepsy risk factors were low, except for a positive family history in 17%.
**Conclusion**: In this study, adults with NCC were predominantly young males with higher exposure to NCC risk-factors. Further investigation is recommended to explore community-based preventive measures and reasons for the male preponderance observed.
**Acknowledgement:** The study supported by Early Career Grant from Royal Society of Tropical Medicine and Hygiene awarded to Dr Asukile and Forgaty International Early Career Development Award given to Dr Chomba.

## Etiologies

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## Systematic review of genome wide association studies (GWAS) of epilepsy identifies common risk variants and associated genes

S Jacobs[1], O Wootton[2], V Ives-Deliperi[1], LM Tucker[3,4], DJ Stein[1], S Dalvie[5] [1]Neuroscience Institute, University of Cape Town, Psychiatry and Mental Health, Cape Town, South Africa, [2]Neuroscience Institute, University of Cape Town, Mental Health and Psychiatry, Cape Town, South Africa, [3]Neuroscience Institute, Division of Neurology, University of Cape Town, Cape Town, South Africa, [4]Neuroscience Institute, Psychiatry and Mental Health, Cape Town, South Africa, [5]University of Cape Town, Department of Pathology, Division of Human Genetics, Cape Town, South Africa

**Purpose**: The aetiology of epilepsy is known to have genetic contributions yet results from genome-wide association studies (GWAS) have not always been consistent. We undertook a systematic review in order to identify risk variants for epilepsy.
**Method**: This systematic review was conducted in accordance with the PRISMA protocol. The quality of each of the studies was evaluated using the Q-Genie tool.
**Results**: 79 SNPs, located in 64 genes, were significantly associated with epilepsy at the genome-wide level. The majority of the variants were intronic and intergenic, with SCN1A as the most widely reported gene involved across studies. Two SNPs, rs2292096 and rs149212747, linked respectively to focal epilepsy (FE) and status epilepticus, were exclusively identified in individuals of Asian ancestry, alongside an Asian-exclusive synonymous variant (rs3782886) in BRAP and a missense variant (rs671) in ALDH2.
**Conclusion**: Genes which encode for ion and transport channels, transcription factors, ubiquitin ligase and transporter proteins were identified as potentially involved in the aetiology of epilepsy. The review identified one missense and one synonymous variant which deserve further exploration. Future research should include populations of more diverse ancestries, including underrepresented populations of African ancestry, which may reveal unique epilepsy-associated genes.
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## Etiology of epileptic seizures and seizure-like events among infants under two years of age presenting to the emergency department of a tertiary referral hospital in South Africa: A prospective cross-sectional study

O Urio[1], H Buys[2], J Wilmshurst[3] [1]University of Cape Town, Pediatrics and Child Health, Pediatric Neurology, Cape Town, South Africa, [2]University of Cape Town, Department of Emergency Medicine, Red Cross War Memorial Children's Hospital, Cape Town, South Africa, [3]University of Cape Town, Department of Pediatric Neurology, Red Cross War Memorial Children's Hospital, Neurosciences Institute, Cape Town, South Africa

**Purpose**: The prevalence of seizure and epilepsy in infancy surpasses all age groups with a high risk of cognitive and behavioural comorbidities. Non-epileptic paroxysmal events are also common in this age group, hence a potential risk of unnecessary exposure to ASMs and costly investigations. We describe the etiology and short-term outcome of infants presenting with seizure and seizure-like events at the Red Cross War Memorial Children's Hospital emergency department.

**Method**: This ongoing cross-sectional study is being conducted at the medical emergency department of Red Cross War Memorial Children's Hospital in Cape Town on infants under 2 years of age presenting with a referral diagnosis of epileptic seizures. To date twenty-two patients aged less than 24 months who presented at the emergency department during the first month of the study fulfilled the inclusion criteria. Demographic data and clinical information were collected from the patient's medical records. (We will continue to recruit and analyze patients until May 2025).
**Results**: A slight female preponderance was noted at 54.5%. Non-epileptic events were a common reason for presentation n=8 (36.3%), followed by febrile seizures and breakthrough seizures n=7(31.8%) each. Among the patients who presented with febrile seizures n=5(71.4%) presented in status epilepticus. A similar pattern was noted among patients who presented with breakthrough seizures. The mean duration of hospital stay was three days. There was no in-facility mortality recorded within the five first days of presentation among the study participants.
**Conclusion**: Non-epileptic events are common among infants referred with presumed epileptic seizures in this study center. Infants with febrile and breakthrough seizures are likely to present in status epilepticus and hence tools for prompt identification and management are warranted to prevent long-term sequelae.

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## Factors associated with the development of epilepsy in Mahenge area, Tanzania: A case-control study

D Bhwana[1], H Hyera[2], H Kimambo[2], V Mushi[2], A Mhina[1], C Newton[3], W Matuja[2], B Mmbando[1]
[1]National Institute for Medical Research, Tanga Research Centre, Tanga, Tanzania, United Republic of, [2]Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of, [3]University of Oxford, Oxford Epilepsy Research Group, Nuffield Department of Clinical Neurosciences, Oxford, United Kingdom

**Purpose**: Epidemiological evidence suggests a high prevalence of epilepsy in Mahenge, which is associated onchocerciasis. A case-control study was conducted to investigate potential risk factors for epilepsy in Mahenge, Tanzania.
**Method**: This was a case-control study involving persons with epilepsy (cases) and healthy individuals (controls), randomly selected and matched by sex, age and village of residence. Participants' socio-demographic characteristics, medical and family histories, potential risk factors for epilepsy, and clinical data were collected. Participants were tested for antibodies against *Onchocerca volvulus* using OV16 tests and for malaria using rapid diagnostic tests. Bivariate analysis was used to assess associations between risk factors and epilepsy. Factors with a p-value ≤ 0.25 were entered into a multivariate conditional logistic regression model, and variables with a p-value < 0.05 in this model were considered statistically significant.
**Results**: A total of 849 (427 cases) participants (54.5% females) and a median age of 30 years (IQR: 23–40) were enrolled. Among persons with epilepsy, 383 (93.6%) experienced generalized seizure onset, and 295 (73.6%) reported good compliance with anti-seizure medications. Significant risk factors for developing epilepsy included a family history of seizures (aOR 2.4, 95%CI: 1.7–3.8, p < 0.001), delayed cry at birth (aOR 2.4, 95%CI: 1.2–4.9, p=0.007), and a history of febrile convulsions (aOR 2.1, 95%CI: 1.6–3.8, p<0.001). OV16 seropositivity was not significantly associated with epilepsy.
**Conclusion**: A family history of seizures, delayed crying at birth, and a history of febrile convulsions were significant risk factors for developing epilepsy in Mahenge, Tanzania.

## IGAP

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### Leveraging artistic expression to combat stigma in epilepsy and other neurological disorders: A collective approach to achieving IGAP's Global Awareness Objectives

M Bitta[1,2,3], S Dama[1], V Nyadimo[1], J Lumsdon[4], Z Merali[1], C Newton[5,3], N Fothergill-Misbah[4] [1]Aga Khan University, Brain and Mind Institute, Nairobi, Kenya, [2]Harvard Medical School, Global Health and Social Medicine, Boston, United States, [3]University of Oxford, Psychiatry, Oxford, United Kingdom, [4]Newcastle University, Newcastle, United Kingdom, [5]KEMRI Wellcome Trust Research Programme, Kilifi, Kenya

**Purpose**: Stigma is a significant barrier to care for individuals with neurological disorders, including epilepsy. The Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders aims for 100% of countries to implement at least one awareness campaign by 2031. While art has proven effective in addressing stigma in highly stigmatized non-communicable diseases such as mental illness, its utility in reducing stigma in epilepsy and other neurological disorders remains unclear. This review explores how art-based interventions can reduce stigma across neurological disorders and advocates for a collective approach to achieve IGAP's objectives.
**Method**: A scoping review was conducted following PRISMA-ScR guidelines, analysing literature up to 2024 from PubMed, Embase, Web of Science, and grey literature. Eligible studies evaluated art-based interventions—such as visual arts, theatre, film, storytelling, and music—targeting stigma in neurological disorders. Data on intervention characteristics, populations, geographic distribution, and outcomes were synthesized.
**Results**: Of 1,276 records, 53 studies met inclusion criteria, and 14 fully included. Interventions demonstrated effectiveness in raising awareness and reducing stigma among diverse populations: children, educators, and healthcare providers. Approaches included animation, theatre, visual arts, digital storytelling, in-person events, and multimedia campaigns. Most studies were conducted in high-income countries, with the USA (29%) most represented. Only one study was from Africa (Ethiopia). Campaigns addressing multiple neurological disorders were more impactful, highlighting the importance of a collective approach. Cultural adaptation, participatory methods, and patient collaboration were facilitators of positive impacts.
**Conclusion**: Art-based interventions show promise in reducing stigma associated with epilepsy, effectively engaging diverse populations through culturally adaptive and participatory approaches. However, limited data from low- and middle-income countries, particularly in Africa, indicate a lack of awareness of the impact of neurological disorders. Expanding these interventions, particularly in low- and middle-income countries, may positively contribute to achieving the IGAP target of universal awareness campaigns by 2031.

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### CareEpilepsy Ethiopia: A model for IGAP implementation in low-resource settings

E Yewnetu[1], E F. Tizazu[2] [1]CareEpilepsy Ethiopia, Addis Ababa, Ethiopia, [2]Christiana Care, MS Department of Neurology, Newark, United States

**Purpose**: The intersectoral global action plan on epilepsy and other neurological disorders (IGAP) was established to improve access to care and treatment for people living with neurological

diseases, such as epilepsy. It provides aims to address stigma, discrimination, and morbidity and mortality of epilepsy. In this study, we aim to provide a blueprint for the implementation of IGAP in a low-resource country.

**Method**: CareEpilepsy is an organization based in Ethiopia. Through awareness programs, advocacy, clinical training, and the introduction of diagnostic and treatment strategies, CareEpilepsy has significantly reduced the epilepsy treatment gap within Ethiopia.

**Results**: Collaborations with the Ministry of Health, WHO, and other stakeholders have expanded clinical training and community education, leading to decreased stigma and increased help-seeking behavior. Since 2016, the number of people seeking care at CareEpilepsy clinics has increased tenfold, and the neurological workforce has grown 300-fold. This, along with improved access to EEG services and antiseizure medications, has led CareEpilepsy to significantly reduce the epilepsy treatment gap, meeting IGAP objectives.

**Conclusion**: Including low-resource countries in IGAP implementation is crucial to reducing the global epilepsy burden, but stigma and limited government support pose challenges; nevertheless, CareEpilepsy's efforts show progress is achievable and offer a scalable model for others.

## Paediatric Epileptology

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### Prevalence and factors associated with drug-resistant epilepsy among children attending the pediatric neurology clinic at an urban teaching hospital in Uganda

F Kyosiimire[1], C Nyangabyaki[1], TT Namata[1], R Sebunya[1] [1]St. Francis Hospital Nsambya, Pediatrics, Kampala, Uganda

**Purpose**: Epilepsy is among the most prevalent and serious neurological diseases. Anti-seizure medications are still the main stay of management in most epilepsies. Globally, 10-40% of patients have drug-resistant epilepsy (DRE). There is limited data regarding DRE among children in Uganda. This study aimed at determining the prevalence and factors associated with DRE among children with epilepsy at St. Francis Hospital Nsambya, Kampala-Uganda.

**Method**: This was a cross-sectional study carried out between April and June 2023. Children diagnosed with epilepsy and on ASM were recruited.

**Results**: The prevalence of DRE was 12.2% (34/278), 95% CI: 8.6 – 16.7%. Factors associated with DRE included; multiple seizure episodes [APR=6.5, 95% CI: 3.3-17.4, P&lt;0.0001], multiple seizure types [APR=4.4, 95% CI: 3.0-9.4, P&lt;0.0001], diagnosis of an epilepsy syndrome [APR=3.6, 95% CI: 2.5-8.3, P=0.026], prior history of status epilepticus [APR=3.6, 95% CI: 2.7-6.1, P=0.001], focal seizure type [APR=2.3, 95% CI: 1.3-4.2, P=0.002], and symptomatic epilepsy [APR=2.1, 95% CI: 1.4-3.8, P=0.041].

**Conclusion**: The 12.2% prevalence of DRE is within earlier reports. Lower-level clinicians should be on higher alert for children with high risk factors for DRE like; multiple frequent seizures types, likely developmental and epileptic encephalopathies (DEE) and symptomatic epilepsy for timely referral to tertiary epilepsy specialized care. The study further underscores the need to make epilepsy syndromes part of routine epilepsy care.

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### Electroencephalogram profile of children aged 6 to 12 years old in Lubumbashi/DRC

M Tshimbayi[1] [1]University of Lubumbashi, Lubumbashi, Congo, Democratic Republic of the

**Purpose**: The electroencephalogram (EEG) measures the electrical activity of the brain and makes it possible to diagnose several brain pathologies, to have an idea of the functioning of the brain and the state of cerebral maturation. The latter depends largely on endogenous and exogenous factors that differ from one environment to another. The normal EEG profile in children remains poorly documented in Lubumbashi.

**Objective:** Determine the normal EEG profile of school-age children.

**Method**: In order to determine the normal EEG profile, we conducted a descriptive, observational and analytical cross-sectional study in children aged 6 to 12 years, with no neurological history, living in the 11 health zones of the city of Lubumbashi / Haut Katanga / DRC. The CONETEC K T 88 DIGITAL device was used to record 416 EEGs using the 10-20 system.

**Results**: In the majority of cases, 48.80% of cases, a slowdown of the EEG was found (baseline rhythm less than 8 Hertz) and in 48.5% of cases, the EEG had a base rate between 8-13 Hertz. Only 2.64% had a base rate greater than 13 Hertz. The EEG reflects the patient's cerebral electrical activity at the very moment it is recorded. In our environment, the latter is marked by a slowdown that attracts our attention and will motivate other studies for its understanding.

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## Psychiatry

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### Psychosocial health issues in stroke patients with epilepsy: Impact on happiness quotient

S Pal[1], T Roy[2] [1]SFCCP NGO, Med, Meerut, India, [2]SFCCP NGO, Meerut, India

**Purpose**: To study effectiveness of two cognitive-behavioral therapies (CBT), Guided-Mental-Imagery (GMI, Cognitive-Restructuring-Technique (CRT), in changing negative thinking/mind-set of stroke patients with epilepsy in developing-nations. Psychosocial health status crucial in treatment outcome. Limited scientific literature/data available on this burning issue.

**Method**: Four-year longitudinal quasi-experimental research-design. Target: stroke patients with epilepsy. Age 30-65 years, N=118. Control n=50. With aid of inventory of negative thought scale, information collected pre/post training on: Occurrence/frequency of negative-thoughts in response to diagnosis, Incidence of negative-statements as result of automatic dysfunctional-thoughts, underlying-beliefs, incidence of headaches/migraine. Correlation of epilepsy with depression evaluated. Training/data collection for psychoanalysis done by psychiatrists. 14-item structured questionnaire contained: items on characteristics/knowledge of respondents on risk-factors, symptom, Rx-outcomes, current stress levels, beliefs, fear, despair, suicidal-tendencies, family-support, depression-level. All epileptics went through counselling-sessions of CRT/CBT.

**Results**: Applied statistical methods. 80% Subjects received GMI/CR training able to notice/monitor their unhelpful thinking patterns than controls [multivarie-annova] & able to control them better when compared with control-group. [improving-QOL-quotient]. 74% Participants better-equipped to cope with stress/despair [74%], reduced Occurrence/frequency of negative-

thoughts [85%], decreased negative statements [90], reduced incidence of headaches/migraine [92].
**Conclusion**: CBT/CRT techniques in watering seeds of happiness are efficacious in epileptics. This underscores need to train health-care-professionals these psychological techniques. Our study shows importance of ability to cope. Psycho-social support, understanding Emotions, relief of acceptance of Belief System, positive-thinking. future such study with greater sample-size & more QOL-factors needed. **Recommendations:** More participation of developing-nations in such research needed. psychosocial issue management are limited to few resourceful patients. Our NGO-project helps patients in better-recovery & is helpful in better happiness-quotient this improving QOL in stroke-related-epilepsy-patients.

## Social Issues/Nursing

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### Understanding the Impact of Epilepsy: Insights from Mahenge, Tanzania

I S. Massawe[1], P F. Magili[1], D K. Bhwana[1], V Mushi[2,3], H F. Hyera[2], H H. Kimambo[2,4], R Colebunders[5,6], J Hellen Cross[7], J W. Sander[8,9,10], A Sen[11], W Matuja[4], C R. Newton[11,10], S Mahone[12], B P. Mmbando[1], EPInA Study Group [1]National Institute for Medical Research, Tanga, Tanzania, United Republic of, [2]Muhimbili National Hospital, Dar Es Salaam, Tanzania, United Republic of, [3]University of Dar es Salaam, Dar es Salaam, Tanzania, Dar Es Salaam, Tanzania, United Republic of, [4]Muhimbili University of Health and Allied Sciences, Dar Es Salaam, Tanzania, United Republic of, [5]University of Antwerp, Liverpool, United Kingdom, [6]School of Tropical Medicine, Liverpool, United Kingdom, [7]UCL Great Ormond Street Institute of Child Health, London, United Kingdom, [8]Liverpool School of Tropical Medicine,Stichting Epilepsie Instellingen, Oxford Epilepsy Research Group, Oxford, United Kingdom, [9]Stichting Epilepsie Instellingen Nederland, 2103 SW Heemstede, Netherlands, [10]University of Oxford, Oxford, United Kingdom, [11]KEMRI-Wellcome Trust Research Programme, Kilifi, Kenya, [12]Oxford Epilepsy Research Group, University of Oxford, London, United Kingdom

**Purpose**: To explore the lived experiences, including social, economic and psychological impacts among adults with epilepsy in Mahenge area, Tanzania
**Method**: Oral history interviews were used to collect data from individuals with epilepsy. The study was conducted between May 2021 and July 2022 with 45 participants from 20 villages. Interviews, lasting between 45 and 60 minutes, were audio-recorded and interview guides were used to capture key themes.
**Results**: Participants led normal lives before the onset of epilepsy, which were profoundly affected. Many participants discontinued schooling, accidents (such as falling into rivers or fire-related incidents), and social stigma. One participant shared, “*I could have died a long time ago. I fell into the river, but my nephew noticed and immediately alerted my family.*” Epilepsy was widely believed to be caused by witchcraft, leading most participants to seek treatment from traditional health practitioners. Stigma was a major issue, with participants feeling isolated from

relationships, work, and community activities, which impacted their chances of marriage and increased economic difficulties. As a result, many with epilepsy kept their condition hidden to avoid public exposure and rejection. The frequent seizures and resulting injuries led to financial struggles and emotional distress, particularly concerning marriage and family life.

**Conclusion**: Epilepsy is perceived as a disease with significant effects on patients and the community. It is largely perceived to be caused by witchcraft, and its management is often sought from traditional health practitioners. Continuous community awareness programs on epilepsy and its management are required to improve health-seeking behaviour, reduce stigma and improve quality of life.

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### The traditional healer said, 'I had a genie that scared me in my eyes', and that is why I fall": an ethnographic study about experiences of people with epilepsy in traditional healing in Mahenge, Tanzania

P Faustine[1], EPInA team [1]National Institute for Medical Research, Research Monitoring and Evaluation, Tanga, Tanzania, United Republic of

**Purpose**: The study aims to explore the experiences of people with epilepsy in using traditional healers in the management of epilepsy.

**Method**: Ethnographic methods that are culturally specific and focused on oral history, which is contextually rich, were used. A total of 45 oral history interviews with people with epilepsy from 21 villages in Mahenge were conducted. The inclusion criteria were people with epilepsy, aged at least eighteen years, and able to tell their history in Kiswahili, the main language. Data were analyzed manually using the thematic analysis method.

**Results**: Traditional healers often attribute epilepsy to supernatural causes, such as curses and witchcraft, through receiving the information provided by patients about seizure onset and relating them with phenomena like past experiences or specific events that are believed to have triggered the illness. Along with the treatment, some restrictions were imposed on people with epilepsy that are difficult to fulfil, and these may be used as an excuse for not getting better after the treatment. Physical, emotional and sexual harassment are among the negative practices experienced by patients by the healers.

**Conclusion**: There is a firm reliance on traditional healing practices for epilepsy, where cultural beliefs and ritual practices jeopardize diagnosis and care for people with epilepsy. Raising awareness about epilepsy and its management, as well as rights for people with epilepsy among traditional healers and the community in general is important to improve care and safeguard the interests of patients.

## Status Epilepticus

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### Predictors of short-term clinical outcomes of children with convulsive status epilepticus at the University Teaching Hospital-Children's Hospital in Lusaka

VS Soko[1], LK Nkole[1], E Mpabalwani[1], M Asukile[2] [1]University of Zambia, School of Medicine, Paediatrics and Child Health, Lusaka, Zambia, [2]University of Zambia, School of Medicine, Internal Medicine, Lusaka, Zambia

**Purpose**: To identify predictors of short-term adverse outcomes in children with status epilepticus (SE) in Lusaka.
**Method**: A prospective observational cohort study of 130 children, aged 28 days to 16 years, admitted with SE at the University Teaching Hospitals Children's Hospital between September 2023 and May 2024. Probability sampling was used, and patients were followed for 30 days to assess outcomes (death or neurological sequelae). Descriptive statistics and multivariable logistic regression identified predictors.
**Results**: Of 130 children, 45 (35%) were female, 94 (75%) had symptomatic SE, and 70 (54%) had focal SE. The median age was 58 months (IQR 34, 96), seizure duration was 20 minutes (IQR 10, 40), and time to treatment initiation was 60 minutes (IQR 30, 60). Refractory SE occurred in 25%. Adverse outcomes were observed in 55 (42%), 6.2% mortality, and 35.4% neurological sequelae. Among 46 with sequelae, 35% had epilepsy, 35% developmental regression, 11% hemiparesis, 9% behavioural changes, 4% spasticity, 4% hypotonia, and 2% movement disorders. Predictors of adverse outcomes included symptomatic SE (OR 9, 95% CI 2.3–36), male sex (OR 2.8, 95% CI 1.12–8), mechanical ventilation (OR 12, 95% CI 2.6–61), refractory SE (OR 5.4, 95% CI 1.5–19), and prolonged hospital stay (OR 1.08, 95% CI 1.06–1.17).
**Conclusion**: Symptomatic SE, male sex, mechanical ventilation, refractory SE, and prolonged hospital stay predicted adverse outcomes among children with SE in Lusaka. We recommend early SE identification, better primary care at first contact by increasing access to anti-seizure medications (ASM) and prompt treatment of symptomatic SE causes.

## Stigma, Discrimination & Access to Care

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### Epilepsy advocacy by NGO nurses to fight stigma and discrimination

S Pal[1], T Roy[1] [1]SFCCP NGO, Meerut, India

**Purpose**: Numerous "myths" of advocacy exist that preclude young healthcare workers from becoming involved in the policymaking process of epilepsy patients.
**Method**: This is ongoing patient advocacy project. Many have questions, concerns, preconceived notions about advocacy and health policy in epilepsy supportive care career. so, we compiled the

10 most pervasive advocacy-myths and debunked them one-by-one graphically at ILAE/IBE-congress in front of participants with help of leaflets/pictures, educational-material. To remove stigma and discrimination associated with epilepsy.

**Results**: The issues we fought for last 7 months are as:

1. I am too busy—there is not enough time in day to work as patients-advocate.
2. I am physician, not lobbyist or political person.
3. This process is intimidating requiring expertise
4. Why should I bother? It doesn't seem to make a difference. I have written before and not received a response on this issue of epilepsy patients advocate. When I have received a response, it addresses the issue I wrote about, or I totally disagreed with the views expressed
5. My view on sufferings of epilepsy patients is a lost cause, there is no vocal open support for this work in developing nations.
6. My concerns or issues of priority are not being discussed in epilepsy workshops/symposia.
7. I am not an expert in this issue.
8. I cannot make it to epilepsy conferences/symposia venue to meet with my colleagues & seniors to exchange views.
9. I do not get enough resources/finances for this epilepsy patients advocacy work.
10. I do not see good academic/financial future for this profession as epilepsy patient's advocacy.

**Conclusion**: Patient advocacy concept needs to be roped in medical education and care.

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### Epilepsy beyond seizures: Addressing epilepsy stigma in Kilifi County, Kenya

E Chengo[1], F Beuchi[1], S Kariuki[2] [1]Foundation For People with Epilepsy, Mombasa, Kenya, [2]Africa Population and Health Research Centre- Kenya, Nairobi, Kenya

**Purpose**: Epilepsy-related stigma is prevalent in resource poor countries. In Kilifi, epilepsy stigma is the leading cause of poor health-seeking behavior, low rates of schooling, marriage, and employment. A pilot anti-stigma intervention program was implemented through raising awareness and fostering empathy towards individuals affected by epilepsy.

**Method**: An educational campaign was conducted in the Malindi-Magarini region of Kilifi County. Forty community health promoters, 32 healthcare professionals (clinicians and nurses), 16 people with epilepsy (PWE) with normal intellect paired with their caregivers, 43 traditional health practitioners, and 23 religious leaders were trained. Intervention delivery techniques included visual aids, short videos, discussions, and narratives/testimonials from people with epilepsy and caregivers. The Kilifi Epilepsy Belief and Attitude Scale was administered both before and after the intervention to measure any changes in attitudes.

**Results**: One hundred and seventy (N=170) participants from different community groups participated in a series of six workshops held over a six-month period, but N=103 (60.5%)

participated in the post-evaluation survey. Before the training only 22 % of participants held positive attitudes towards epilepsy, believing that PWE could get married, are not mad, and are not responsible for all epilepsy-related psychosocial problems (P=0.002). After the training, 94% of participants showed significant improvement in their attitudes towards epilepsy (P=0.003).
**Conclusion**: There was significant improvement in negative attitudes that perpetuate epilepsy stigma among those trained following educational campaigns targeting communities and epilepsy stakeholders. Multiple strategies that are cost effective should be instituted to eradicate epilepsy stigma in this region.

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## Exploration of contextual factors to improve access to epilepsy care in Western Kenya

C Oduor[1], J Said[1], J Kamano[1], J Von Gaudecker[2] [1]Moi University, Medicine, Eldoret, Kenya, [2]Indiana University, Nursing, Indianapolis, United States

**Purpose**: The study aimed to explore contextual factors that impact access and retention to care and adherence to Anti-Seizure Medications (ASM) in western Kenya.
**Method**: We conducted focus group discussions among People with Epilepsy (PWE) and their care givers, community stakeholders (community health promoters, community leaders), and healthcare workers as well as In-depth interviews of key informants (traditional healers, religious leaders, clinical leaders and hospital administrators). Data were transcribed, translated, and then analyzed by thematic analysis.
**Results**: A total of 32 focus group discussions were conducted with n=235 participants. The participants were healthcare providers (n=36), community health promoters (n=39), community leaders (n=74), persons with epilepsy, and their caregivers (n=86). Additionally, 20 in-depth individual interviews were conducted. The themes that were identified include (1) beliefs and myths surrounding epilepsy, (2) living with the disease, (3) perceived cures for epilepsy, and (4) barriers to medical care. Contextual factors that were derived from the themes included poor knowledge about the cause and treatment of epilepsy, stigma and discrimination of PWE, and financial constraints (high cost of ASM and transport costs to health facilities).
**Conclusion**: Addressing the knowledge gaps, misconceptions, and negative perceptions surrounding epilepsy, fostering a more supportive community environment, provision of affordable and effective ASM are essential to improving the treatment gap for PWE in western Kenya.

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## Healthcare resource utilization and out-of-pocket costs among patients with epilepsy in Kenya and Tanzania

D Muli[1], D Mwanga[2], B Mmbando[3], G Asiki[2], CR Newton[4], A Sen[4], D McDaid[5], M Mugo[1] [1]University of Nairobi, Nairobi, Kenya, [2]APHRC, Nairobi, Kenya, [3]National Institute for Medical Research, Tanga, Tanzania, United Republic of, [4]University of Oxford, Oxford, United Kingdom, [5]London School of Economics & Political Science, UK., London, United Kingdom

**Purpose**: This study examines healthcare utilization and the out-of-pocket costs of persons living with epilepsy (PWE) in an urban Kenyan setting and a rural Tanzanian setting.
**Method**: Data were collected using a standardized questionnaire administered by trained professionals. The data for Nairobi, Kenya were collected between February and September 2023 in four phases embedded in a randomized control trial that examined the effect of short messaging service on adherence to anti-seizure medications. Data for Mahenge, Tanzania were collected during one survey conducted between Dec 2022 and February 2023. Data were summarized using descriptive statistics.
**Results**: In Mahenge, 348 participants were interviewed (male = 49.4%, female = 50.1%). The highest proportion of the participants were farmers (67.8%). The majority of the respondents were single (68.4%). In Nairobi, 634 participants were interviewed (male = 55.8%, female = 44.2%). The majority of the respondents had either some primary school education or completed primary (25,4% and 14.0%, respectively). A larger proportion of the respondents was single (38.7%) followed by children (28.0%).
The median family income in Nairobi was USD 72.92 (Inter-quartile range (IQR) = 36.46, 145.84) per month. The highest medical fees spent were in seeing a doctor, followed by a nurse and a healthcare worker with a median of USD 8.39 (IQR = 2.92, 14.58), 4.92 (IQR = 2.04, 10.94) and 1.46(IQR=1.46,2.19) respectively. The total cost of care to income ratio in Kenya was 25.0%.
In Tanzania, the median income was USD 12.85 (IQR = 8.57, 21.41) per month. The highest medical fee was when seeing a doctor with a median USD 1.28 (IQR=1.28, 3.85). The total cost of care to income in Tanzania was 27.1%.
**Conclusion**: The total costs of medical care were high relative to income which could contribute to poor adherence and hence reduce ability to earn income.

## Traditional Medicine and Epilepsy/Fostering Collaboration with Traditional Healers

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### Supranatural Power as a Cause of Epilepsy and the Role of Faith Healers in Consolidating the Myth

T Obeid[1] [1]Medical Science and Technology, Khartoum - currently in Kigali, Rwanda, Medicine., Kigali, Rwanda

**Purpose**: To underscore the belief in supernatural powers causing epilepsy endures, largely fueled by faith healers, and has significant serious consequences.
**Method**: Three cases from different countries, each with unique cultures and backgrounds, illustrate this situation

**Results**: In May 2021, a 19-year-old Sudanese man suffering convulsions sought help from a faith healer, who claimed his condition was caused by a Jinn. A failed attempt to exorcise the Jinn by strangling him resulted in a syncopal attack and neck bruises, and the father did not disclose this consultation with the healer. A 17-year-old Rwandan girl diagnosed with epilepsy in July 2024 had uncontrolled seizures due to side effects and poor compliance with phenobarbitone. She consulted a pastor, who claimed she was possessed by an evil spirit and advised her to rely solely on prayer rather than pursue medical treatment. A 23-year-old Saudi male with difficult-to-control temporal lobe epilepsy consulted a faith healer who attributed his condition to Jinn possession. The healer attempted to expel the Jinn through strangulation, which was unsuccessful, and then proposed a more forceful method that could potentially induce coma. The patient declined to consent.
**Conclusion**: Despite progress in understanding epilepsy and the ILAE/WHO's "Out of the Shadows" campaign, outdated beliefs in supernatural powers persist, often promoted by faith healers. Public education and communication with these healers are crucial to tackling this issue.

## Women and Epilepsy

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### The impact of community based and online awareness raising activities for epilepsy in Cameroon

E Miranda Nongse[1], D Labelle[1], N Cletus[2], S Stephanie Nji[1], C Oliver[3], T Olivia Mah[4], M Noeler Njohjam[5] [1]Epilepsy Awareness, Aids and Research Foundation, Public Health, Bamenda, Cameroon, [2]Fonab Polytechnique University Mile 3 Nkwen Bamenda, Nursing, Bamenda, Cameroon, [3]Nkwen Baptist Hospital Bamenda, Pharmacy, Bamenda, Cameroon, [4]University of Bamenda, Laboratory, Bamenda, Cameroon, [5]National University Hospital Centre Senegal, Resident Neurologist, Dakar, Senegal

**Purpose**: Epilepsy is one of the most common neurological disorders in Cameroon. Awareness of epilepsy remains critically low resulting in misconceptions, myths and stigmatisation of those affected. This observation prompted us to design and implement community - based and online awareness- raising activities with the aim to educate people and destigmatise epilepsies and promote social acceptance of people living with epilepsy.
**Method**: We designed and implemented a multi - strategic project with awareness - raising activities in churches, schools, street and door to door sensitization, school campaigns, health talks in social gatherings and community groups, online sensitization, community outreach programs, health talks in local and national radios, social media campaigns and distribution of educative flyers on epilepsy.
**Results**: Over the past 2 years, we have reached 3 million people in Cameroon and other African countries with educative messages on epilepsy, distributed over 10 000 educative flyers,

established robust partnerships with hospital, schools, churches and other social groups to ensure continuity of our activities. Over 500 cases of epilepsy have been connected to the hospitals for treatment.

**Conclusion**: Our work highlights how community - based and online awareness raising activities in Cameroon supported by a strong and dedicated team work with other collaborators can mitigate the burden of epilepsy.

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## Pregnancy outcomes and quality of care among women with epilepsy in Ethiopia: A cross-sectional study at a tertiary referral hospital

H Belay[1] [1]Addis Ababa University, Neurology, Addis Ababa, Ethiopia

**Purpose**: Epilepsy during pregnancy poses significant challenges due to the risks of seizures and the potential teratogenic effects of antiepileptic drugs (AEDs). In Ethiopia, where epilepsy is highly prevalent and access to specialized care is limited, pregnant women with epilepsy face additional barriers such as cultural stigma, inadequate AED availability, and lack of awareness. This study aims to evaluate pregnancy outcomes in Ethiopian women with epilepsy, focusing on seizure control, AED use, and neonatal outcomes, and assess the quality of care provided.

**Method**: A descriptive cross-sectional study was done. Data was collected by interviewing and reviewing clinical data of women with epilepsy, who were on follow-up at the Neurology Referral Clinic in Black Lion Hospital. The data was gathered from February 2013 to October 2013 using a data-collecting format. The data entry and appropriate statistical analysis were performed using the 19.0 version of the SPSS.

**Results**: A total of 180 women with epilepsy (mean age 29.9 ± 12.5 years) were included; 60% were never married, and 60.6% were unemployed. Among 82 pregnancies, 23.2% were not on follow-up, and only 15.38% received preconception counseling. Baseline serum ASM levels were checked in one participant, and 3.9% received folic acid. Of 29 women seizure-free for ≥2 years before pregnancy, 79.3% remained seizure-free during pregnancy. During pregnancy, 69.4% were on monotherapy, valproate was avoided in 94.4%, vitamin K was not provided, and no serum AED levels were monitored. Seizures during labor/delivery occurred in 7.5% and were linked to seizures during pregnancy and AED use. During labor/delivery, 75% continued AEDs, 81.8% attended health facilities, and 90.9% had uneventful deliveries. Breastfeeding was practiced by 83.36% of mothers.

**Conclusion**: The study reveals gaps in preconception care, folic acid use, and AED monitoring were identified. Improved care and education are needed to enhance outcomes for pregnant women with epilepsy in Ethiopia.