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EDITED AND REVIEWED BY  
Fernando Cendes,  
State University of Campinas, Brazil

\*CORRESPONDENCE  
Olubunmi Akindele Ogunrin  
✉ bunmifunmi@hotmail.com

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# Editorial: Epilepsy research in the developing countries: the neuro-ethical issues, cross-cultural differences, and relevance to comprehensive management

Mark Kaddu Mukasa<sup>1</sup>, Albert Akpalu<sup>2</sup>, Adetoun Ejilemele<sup>3</sup> and Olubunmi Akindele Ogunrin<sup>4\*</sup>

<sup>1</sup>Neurology Unit, Department of Medicine, Makerere University, Kampala, Uganda, <sup>2</sup>Neurology Unit, Korle Bu Teaching Hospital, Accra, Ghana, <sup>3</sup>Department of Pathology and Immunology, Texas Children's Hospital/Baylor College of Medicine, Houston, TX, United States, <sup>4</sup>Neurology Department, Royal Stoke University Hospital, Stoke-on-Trent, United Kingdom

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## Editorial on the Research Topic

[Epilepsy research in the developing countries: the neuro-ethical issues, cross-cultural differences, and relevance to comprehensive management](#)

Epilepsy, defined as the sustained predisposition to recurrent seizures with neurobiological, cognitive, social and psychological sequelae, remains the most common disorder encountered in neurological practice (1–3). The often-quoted prevalence of 50 million worldwide is likely inaccurate considering the lack of complete data on epilepsy from developing countries. However, in the past decade and a half, the extant literature that originated from these countries, provided information on the current trends in epilepsy management and scope of epilepsy research (4, 5). An updated and balanced understanding of the impact of epilepsy research on holistic health of affected individuals, including cognitive sequelae, cross-cultural differences in the management, social support, and the ethical, legal, and social issues (ELSI) encountered in epilepsy research are topical and demand our attention but are rarely discussed. Therefore, this volume aims to provide information to bridge these knowledge gaps as they relate to the low- and medium-income countries (LMICs) and stimulate valid and ethically acceptable epilepsy research across cultures and disciplines.

Eight articles from diverse cultures and settings addresses this Research Topic in this volume of *Frontier in Neurology*. One of the articles is an interesting qualitative study that focused on perceived etiology and management of epilepsy among a rural West African community in Ghana (Gyaase et al.). Using an in-depth semi-structured interview, data obtained from 15 participants revealed two causative categories for epilepsy—socio-cultural (mostly related to superstitious beliefs), and biomedical. Authors recommend

comprehensive health education to promote knowledge on causative factors and treatment of epilepsy. Several studies have reported relationship between superstitious beliefs, causation, and management of epilepsy (6–10). Absence of knowledge on causative factors of epilepsy leads to delay in treatment and worsens outcomes in LMICs.

Li et al. describe a nested case-control study exploring the effect of epilepsy education shared during the epilepsy knowledge popularization campaign in China (EKPCIC) on pregnancy outcomes. Their study showed that there was an increase in the use of anti-seizure medicine (ASM), folic acid, breastfeeding rate as well as fewer pregnancy complications. Adverse fetal outcomes were however not affected.

Genetic causes are often not considered in LMICs but etiology of epilepsy is multifactorial often with an interplay between genetics and environment. Xu et al., investigated the role of ferroptosis-related genes in the pathogenesis of epilepsy using the CIBERSORT algorithm analysis and screening gene expression data from the Gene Expression Omnibus (GEO) database. Three ferroptosis related differentially expressed genes (FDEGs)—HIF1A, TLR4, and CASP8 were identified and authors recommend mechanistic studies be performed to investigate the pathways modulated by these genes and their role in epilepsy.

The social impact of epilepsy is not often discussed in LMICs (11, 12) presumably due to patriarchy and gender inequality. Two studies investigated the social and psychological sequelae of epilepsy. One article evaluated marriage and child bearing among PWEs in a hospital population in Turkey (Tokuç et al.). The authors showed that a third of the PWEs experienced stigmatization and that epilepsy diagnosis impacted sexual function adversely. Furthermore, epilepsy diagnosis led to a lack of desire to have children and the ability to care for the children was adversely affected by the use of multiple ASM and female gender. The findings of this study illustrate the scope of impact of epilepsy on the overall quality of life of affected persons, as previously revealed in a few studies (13–15). A separate article studied stress-related symptoms among PWEs in Ethiopia and showed that nearly one out of 4 PWEs has stress symptoms, and that perceived stigma and belief that epilepsy was untreatable were associated factors (Seid et al.).

Pharmacotherapy is the mainstay of epilepsy treatment, and ~60–70% PWEs respond to ASM with 50–60% responding to monotherapy within the first 6 months (16–18). Refractory epilepsy requiring other therapies to improve or achieve seizure control is present in 20–30% (19). Two articles discussed epilepsy management with one focused on drug treatment with Peramppanel among Chinese PWEs (Zeng and Wu). Peramppanel was more effective in treating focal seizures and was well-tolerated when used as first option in individuals who had failed the first ASM. The most

common adverse event leading to discontinuation of medication was aggression and irritability.

Epilepsy surgery is gradually evolving in Africa, with majority of centers performing lesional surgeries. The Armenian article (Sukhudyayn et al.) recorded significant seizure control in ninety percent of patients proving that the model in a middle income country can motivate other LMICs to develop epilepsy surgery.

The final article by Samia et al. addressed the ethical and validity conundrum in epilepsy research in LMICs, a core aspect of this Research Topic. They highlighted the heterogeneous settings of LMICs as relates to endemic infections and metabolic diseases and its impact on epilepsy research. They advocated for support for researchers and other stakeholders involved with epilepsy research, not just through provision of funds but more importantly by ensuring a foundation for ethical template of equality, capacity building and intellectual property protection. They suggested provision of culturally relevant and responsive ethical framework to promote valid research in the LMICs.

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