

Bridging the gaps in the setup of a functional epilepsy monitoring unit in Uganda to support epilepsy surgery

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As many as 80 million people in the world have epilepsy. Those living in the developing world are disproportionately affected. Approximately 770,000 people in Uganda are affected by epilepsy. Drug-resistant epilepsy affects approximately 30%–40% of patients with epilepsy, and one-third of these patients may be eligible for surgical management. This article describes the formation of an epilepsy monitoring unit in Uganda as the first step toward establishing a surgical epilepsy program for pediatric patients. A hybrid remote and in-person collaborative model was developed between teams in Mbale and Kampala in Uganda and Chicago in the US. The authors describe a process that spanned 2 years (2021–2023) for developing readiness for referrals for pediatric epilepsy surgery candidates in Uganda.

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THE country of Uganda reports a high epilepsy prevalence, affecting 1.69% of the population, meaning 80 per 10,000 persons in Uganda are affected (approximately 770,000 total).^{1,2} In 2020, the World Health Assembly (WHA) passed a resolution, WHA 73.10, advocating for acceleration of “global actions on epilepsy and other neurological disorders.” Resolution WHA 73.10 called for 194 member states to provide an integrated response to epilepsy and neurological disorders. The International League Against Epilepsy (ILAE) and International Bureau for Epilepsy proposed an intersectoral global action plan (IGAP) approved at the 75th WHA meeting with a 90-80-70 cascade target for epilepsy to motivate a decade of action.³ The goal is to improve the care and lives of more than 50 million people who live with epilepsy worldwide. The IGAP proposes that by 2031, 90% of people

with epilepsy receive the diagnosis; 80% have access to appropriate, affordable, safe antiepileptic drugs; and 70% achieve seizure control with treatment.³ Drug-resistant epilepsy (DRE) affects approximately 30%–40% of patients with epilepsy, and one-third of these patients may be eligible for surgical management.^{4–6} Globally, epilepsy surgery is not commonly available for patients with DRE who may benefit the most in terms of achieving seizure freedom or better seizure control.⁷

Lesional epilepsy is often effectively treated with surgical interventions, which offer higher chances of seizure freedom compared with medical treatment only.⁸ For patients with lesional epilepsy, the practical minimum work-up per the ILAE to identify appropriate candidates for epilepsy surgery includes electroencephalography (EEG) and neuroimaging.⁹ EEG capability is essential. While

ABBREVIATIONS ASET = American Society of Electroencephalographic Technicians; CCHU = CURE Children's Hospital of Uganda; DRE = drug-resistant epilepsy; EEG = electroencephalography; EMU = epilepsy monitoring unit; IGAP = intersectoral global action plan; ILAE = International League Against Epilepsy; LCH = Lurie Children's Hospital; vEEG = video EEG; WHA = World Health Assembly.

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FIG. 1. Setup of the EMU in Mbale, Uganda. Video EEG equipment is shown in a dedicated patient room with staff for EEG monitoring.

multidisciplinary care for epilepsy is more widely available in high-income countries, few such programs are located within low- and middle-income countries. Epilepsy surgery requires a multidisciplinary team approach for appropriate patient selection, and surgery requires resources and technical expertise with support services.^{10–13}

Challenges in multidisciplinary epilepsy surgery program development are multifactorial and can be grouped into three categories: human capital, technology, and resource allocation. We outline the formation of an epilepsy monitoring unit (EMU) in Mbale, Uganda, at CURE Children's Hospital of Uganda (CCHU) as the first step in establishing a sustainable surgical epilepsy program for children. This step includes the foundation of program development and progress in opening the door to accessing a surgical cure for pediatric patients with lesional DRE. This is a process that spanned 2 years (2021–2023) for developing readiness for referrals for pediatric epilepsy surgery candidates in Uganda. The project was supported by a project award grant (to S.L.) from the Robert J. Havey, MD, Institute of Global Health at Northwestern University Feinberg School of Medicine.

Program Development and Implementation

CCHU performs approximately 2000 pediatric neurosurgical procedures annually. Epilepsy surgery at the CCHU was first reported in 2009.¹⁴ Ten patients were treated for temporal lobe epilepsy through a collaboration with a US academic neurosurgery team.¹⁴ This model involved a site visit from a US-based neurosurgeon and travel by a single Ugandan medical officer to the US for EEG training. Data interpretation was confined to the US facility, without skills and knowledge development for EEG in Uganda. The surgical collaboration was concluded, with no further EEG execution or interpretation capability locally at CCHU in Uganda.

The empty EMU room fell into disuse and became an important target for future program design. In 2021, CCHU and the Departments of Neurology at Mulago National Referral Hospital and Nsambya Hospital, in collaboration with the Divisions of Pediatric Neurosurgery,

Neurology, and Neuroradiology at Ann and Robert H. Lurie Children's Hospital (LCH) of Chicago, began to work together around the possible development of a pediatric epilepsy surgery program. Initial needs assessment identified the need for development of EEG knowledge, implementation, and operationalization, as there was already access to new EEG equipment at CCHU, which consisted of Natus Medical Inc.'s Quantum 256-channel digital audio/video EEG (vEEG) machine with the support of a grant from the Rest of World Foundation (Fig. 1). This machine fortuitously matched the configuration of the LCH equipment, allowing for a bidirectional exchange of EEG recordings and evaluation to ensure quality control. CCHU designated a dedicated EMU room with staffing to provide continuous evaluation and provider access.

The accredited LCH Neurodiagnostic Training Program had previously successfully trained 10 cohorts of EEG technicians. The program leaders developed an avenue to provide a hybrid education model in EEG competency through partnership with the global initiatives of the American Society of Electroencephalographic Technicians (ASET), the Neurodiagnostic Society, in the US. The neurodiagnostic training program was modified for hybrid virtual online education and implemented for the first global cohort.

Training and Knowledge Exchange in Developing EEG Capability at CCHU in Uganda

A pediatric epileptologist (D.B.) and EEG technician instructors (K.M., M.V., E.P.) based at LCH used a 6-month instructional program to train Ugandan physicians in EEG. Medical officers ($n = 4$), clinical officers ($n = 2$), and neurosurgeons ($n = 3$) from Uganda participated in the training course for EEG. Three neurodiagnostic EEG technologists from LCH were paired to each learner for training and mentorship. The program schedule included three sections, requiring twice weekly attendance, and required completion of educational modules before each session. The program approach combined didactic teaching via Zoom platform using the ASET-EEG core curriculum (EEG 200–211; Table 1). The ASET emerging international membership encourages global collaboration. Ongoing access to the complete collection of online education materials for 10 participants was donated by ASET. The collection of courses (200–211) prepared participants for comprehending and executing EEG examinations effectively. The program started in June 2021 and ended in December 2021 with 3 EEG instructors from LCH and 1 educational liaison from ASET teaching and evaluating the CCHU team's progress. In addition, EEG instructors created a mini series of lectures on a variety of additional topics including further tips on patient safety, proper electrode placement, hair management techniques, technologist safety during and after connection, as well as managing combative patients.

After completion of the didactic curriculum, the CCHU team proceeded with case-based connection of patients at CCHU in Uganda. The initial EEG recordings were

TABLE 1. ASET-EEG core curriculum: summary section content

Section	Content	Time Requirement
A	EEG 202: Electrodes, electrode placement, & application methods EEG 200: Fundamentals of neuroanatomy EEG 201: Testing procedures & terminology EEG 203: Fundamentals of EEG & patient care	2 mos
B	EEG 204: Digital EEG concepts & electrical safety EEG 208: Artifact identification & troubleshooting EEG 205: Normal adult EEG, normal variants, & drug effects EEG 211: EEG in pediatric patients & neonates	2 mos
C	EEG 206: Instrumentation part 1: differential amplifier, montage design, & filters EEG 207: Instrumentation part 2: waveforms analysis & polarity EEG 209: EEG in epilepsy EEG 210: EEG in neurological disorders	2 mos

reviewed and annotated as a group with the LCH EEG instructors. Over time, the CCHU team annotated studies independently, and these electroencephalograms were reviewed by LCH EEG instructors and an LCH pediatric epileptologist. To ensure adequate knowledge regarding EEG techniques and case conference design, a site visit was made by 2 CCHU teammates (E. Wegoye, S. Khisa) who traveled to LCH in November 2022. This was the beginning of the in-person bidirectional exchange, with strong foundations laid over 18 months of online interaction during the COVID-19 era. During this initial site visit, CCHU teammates undertook direct observation of the EEG laboratory, EMU, multidisciplinary clinical case conferences, as well as epilepsy surgeries.

Multilocation Multidisciplinary Case Conference

During this time, two practicing Ugandan pediatric neurologists (R.I., R.S.) with prior additional specialized training in epilepsy from Oxford University and Cleveland Clinic, joined regular conference activity with the Uganda-US team. The neurologists were based in Kampala, approximately 220 kilometers from Mbale and CCHU, practicing at Uganda Nsambya and Mulago hospitals. They had busy clinical practices and patients with lesional DRE known to them; up to this time, epilepsy surgery was not an option for them in the region.

Once the CCHU EEG training was completed, the multinational multidisciplinary team laid out the next steps. Patients with lesional epilepsy were identified for discussion in online epilepsy conferences. Attendance included the EEG team from CCHU and LCH, neurologists (R.I. and R.S. in Kampala, D.B. in Chicago), a neuroradiologist (E. Widjaja in Chicago), neurosurgeons (E. Wegoye and H. Okechi in Mbale, S.L. in Chicago), as well as learners from all teams. These conferences were conducted on a virtual platform (Zoom and Microsoft Teams). These conferences occurred twice a month with discussion of 2–4 patients per hour. Neuroimaging including brain CT and MRI. All patients had access to CT scans. Only one facility, Nsambya Hospital, had MRI capabilities. The teams from Nsambya, Mulago, and CCHU prepared presenta-

tions for multidisciplinary epilepsy conferences, including history, examination findings, relevant imaging, and vEEG results. The goal of these conferences was to discuss patients with lesional epilepsy and identify potential pediatric patients with DRE who would benefit from epilepsy surgery. Results from the surgical cohort will be reported in an upcoming study with appropriate follow-up.

Limitations and Challenges

The process described spanned 2 years for developing readiness for referrals for pediatric epilepsy surgery candidates in Uganda. Planning started in early 2021. The EEG cohort started in June 2021 and ended in December 2021; implementation of EEG in patients followed in 2022, with additional collaboration to identify lesional DRE candidates in 2022 and early 2023. In Uganda, it is challenging for a single center to undertake an epilepsy surgery program independently. Some human resource and infrastructure limitations are described in this paper. Only patients from Nsambya Hospital had access to an MRI machine and some families were unable to travel due to distance, cost, and time. Additionally, some patients were not able to reach CCHU for vEEG due to costs and travel distance. In addition to travel coordination, the cost of MRI (average \$180 US) was also a barrier. As a result, CT scans (average \$70) were used for evaluation in select patients. A significant investment of nursing staff, EEG technologists, and physicians was required to ensure quality EEG was conducted.

Future of Epilepsy Surgery in Uganda

The first step to establishing a multidisciplinary pediatric epilepsy program requires active participation of local practitioners, neurosurgeons, neurologists, and EEG technicians to develop EEG skill and capacity. We describe a model for treatment of surgical epilepsy in a busy pediatric neurosurgery hospital in Uganda with successful implementation and sustainable operations. In addition to increasing capacity for EEG performance, the program provided appropriate sustainable skill transfer of high-quality EEG interpretation leading to selection of surgical

candidates with lesional DRE. This hybrid collaboration provides a foundation for future programmatic growth.

Our short-term aim is to expand the range and complexity of the services offered.¹⁵ We hope to support an expansion of the EMU in both bed count and personnel that would allow us to provide increased complexity of care to more patients over time.¹⁶ To ensure high-quality care, we aim to strengthen the existing operational model by streamlining the diagnostic workup and evaluating our peri- and postoperative outcomes. Efforts to create a patient database with IRB approval for collaborative research are ongoing.

In the long-term, our aim is to create a nationally accessible pediatric epilepsy program that is consistent with the recommendations of IGAP. This would require further recognition and financial support, such as from the Ministry of Health of Uganda. While there are data in the literature to show that surgical epilepsy programs are beneficial for seizure outcomes, quality of life, and cost-effectiveness, there continue to be barriers to resource allocation.^{3,17–21} Further advocacy is needed for the integration of epilepsy care into national health and social policies.

Conclusions

We have described the establishment of a functioning EMU, leading to a virtual epilepsy conference for discussion of patient selection for candidacy of lesional epilepsy surgery procedures in Uganda. The process required significant investment as a multidisciplinary team and infrastructure for safe surgical outcomes. This approach provides an avenue for the establishment of a functional EMU in resource-limited areas. The involvement of in-country specialists at all levels of patient care allows for sustainability and advocacy. It is the hope that with these ingredients, such an interdisciplinary program can be the start of a model for integration into scalable offerings in national healthcare related to pediatric epilepsy care.

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Disclosures

The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

Author Contributions

Conception and design: Lam, Wegoye, Bieber, Khisa, Idro, Abdelmageed, Garcia, Sebunya, Okechi, Widjaja. Acquisition of data: Lam, Wegoye, Bieber, Khisa, Moskalyk, Mutonyi, Idro, Widjaja. Analysis and interpretation of data: Lam, Wegoye, Khisa, Vicenteno, Garcia, Widjaja. Drafting the article: Wegoye, Khisa, Mutonyi, Nantongo, Idro, Padilla, Abdelmageed, Garcia, Sebunya, Okechi, Widjaja. Critically revising the article: Lam, Wegoye, Khisa, Nantongo, Idro, Abdelmageed, Garcia, Sebunya, Okechi, Widjaja. Reviewed submitted version of manuscript: Lam, Wegoye, Bieber, Khisa, Mutonyi, Idro, Padilla,

Abdelmageed, Garcia, Widjaja. Approved the final version of the manuscript on behalf of all authors: Lam. Administrative/technical/material support: Lam, Wegoye, Padilla, Abdelmageed. Study supervision: Lam, Wegoye, Vicenteno, Sebunya.

Supplemental Information

Previous Presentations

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