

Building a Pediatric Epilepsy Surgery Program in a Limited Resources Country. A Multi-Center Collaborative Model.

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Introduction

There are about 46 million patients with epilepsy and about 80% live in rural areas and low-income countries, where the treatment gap is more than 75% (4). These regions lack resources, including properly trained personnel and infrastructure. Multi-center collaboration between large level 4 centers and medical facilities in poor resource settings is important to develop these epilepsy surgical programs. Involvement of government, private entities, and local epilepsy foundations (when available) is also crucial to create a long-term sustainable project. We demonstrated that building a pediatric epilepsy surgical program takes time and effort. It is also important to create a system based on the available local resources. We could only start with lesional cases and some palliative procedures, with plans to increase the number of surgeries and complex surgeries as the teams continue to integrate.

Method

A multidisciplinary team was assembled to start a pediatric epilepsy surgical program in a low-resource country (El Salvador). The team included 2 pediatric epileptologists and 1 pediatric epilepsy neurosurgeon from 2 different US academic institutions with access to level 4 epilepsy centers, and 2 child neurologists from El Salvador. Patients received support (access to genetic testing, antiseizure medications, transport, accommodation, education and patient connections) by local non-for-profit epilepsy foundation (Fundación Compasión Purpura (FCP)). Children meeting criteria for drug resistant epilepsy (as defined by Task Force ILAE Commission on Therapeutic Strategies) are selected by the local team and then evaluated by the entire team every year. Cases are evaluated first in the capital (San Salvador) and later in the second largest city (San Miguel). Around 40-50 cases are evaluated per visit. Most children have the diagnosis of drug resistant epilepsy. For each case EEG and neuroimaging data are reviewed. If EEG or neuroimaging is not adequate, families receive support from FCP and referred to specialized private centers with availability to high quality neuroimaging and long-term video EEG. Data is then reviewed by the entire team and surgical candidates are selected. Treatment options are discussed with patient and families. Cases can then be operated during a short period of time or during a follow visit. Depending on resources needed a private institution (Hospital de Diagnostico) provides operating rooms and equipment, when public facilities lacked the proper infrastructure for specific cases.

Results

The first attempt to create a pediatric epilepsy surgical program in El Salvador occurred from 2012-2013. This project was prematurely terminated due to lack of local support. Nevertheless, the team was assembled again in 2019 with support of FCP. The team has met since then every year from 2019-2024 with a hiatus during the pandemic. During the 2023 visit, the team met with local government officials (health minister and hospital medical directors) to discuss the need to equip public hospitals with the proper resources needed to build a local epilepsy surgical program, including 3T MRI and neuronavigation. The government officials were very supportive of the project. The team evaluates around 40-50 patients per visit. Most of them with drug resistant epilepsy. Since the project started, the team has been able to complete:

Table 1. Surgical procedures

Surgeries	Number
Hemispherectomies	3
Lesional Focal resections	3
Temporal Lobectomies	6
Subdural Monitoring	4
VNS Implants	3

Table 2. Support provided by Fundación Compasión Púrpura

Support	Number
Digital EEGs	12
vEEG 12 hr	12
vEEG 24 hr	12
MRI Brain	12
Epilepsy Service Dog	7
Psychological therapy	5
Neuropsychological Evaluations	4
Ketogenic Diet	3
Physical Therapy	5
Training for EEG Technicians	4
Genetic Epilepsy Panels	14
Donated EEG Machines	4
Funds Donated for Anti-Seizure Medications	\$24,000

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Conclusion

80% of patients with epilepsy live in rural areas and LRC, where treatment gap is more than 75%⁴. These regions lack resources, including properly trained personnel and infrastructure. Multi-center collaboration between level 4 centers, local physicians and medical facilities in LRC is important to develop epilepsy programs. Involvement of local government, public and private hospitals, and local NPO is also crucial to create a long-term sustainable project. We demonstrated that building a pediatric epilepsy surgical program takes time and effort.

Introduction:

- Limited-resources countries (LRC), usually lack the human and infrastructure resources required to build a pediatric epilepsy surgery program.

Methods:

- A multidisciplinary team (MDT) formed by 2 pediatric epileptologists, 1 pediatric epilepsy neurosurgeon from different US academic level 4 epilepsy centers and 2 local child neurologists was assembled to start a pediatric epilepsy surgical program in El Salvador.
- Patients received support from local epilepsy NPO Fundación Compasión Purpura (FCP). Children meeting ILAE's criteria for DRE were selected by local team and evaluated by MDT.

Results

- The MDT met for patients evaluation, from 2019-2024.
- In 2024, MDT met with local health government officials to discuss the need to continue to train personnel and equip public hospitals with the resources needed to build an epilepsy surgical program, including a 3T MRI, vEEG, and neuronavigation.
- Since the project started, MDT has completed a limited number of surgeries and FCP has strengthened its outreach efforts. (Table 1, Table 2)

Conclusions

- Multi-center collaboration between level 4 centers, local physicians and medical facilities in LRC is important to develop epilepsy programs. Involvement of local government, public and private hospitals, and local NPO is also crucial to create a long-term sustainable project.
- We demonstrated that building a pediatric epilepsy surgical program takes time and effort.



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