Characteristics of Patients Referred for Pediatric Epilepsy Surgery Evaluation in the US: Early Findings from the PERC (Pediatric Epilepsy Research Consortium) Epilepsy Surgery Subgroup

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Introduction

The Pediatric Epilepsy Research Consortium (PERC) is a network of US pediatric epilepsy centers that facilitates collaborative research to improve the care of children with epilepsy. The Epilepsy Surgery Subgroup was formed in 2018 to characterize the use of pediatric epilepsy surgery in the US and define current practices for candidate selection and treatment. We demonstrate the feasibility of a multicenter collaboration and report the sociodemographic and epilepsy characteristics of children presenting for epilepsy surgery evaluation in the initial interim analysis.

Methods

- Patients 0-18 years of age undergoing epilepsy surgery evaluation at 13 actively enrolling pediatric epilepsy centers were prospectively enrolled in a shared REDCap database.
- Predefined variables collected included demographics, epilepsy characteristics, presurgical treatment, evaluation, surgical therapy, and outcome of epilepsy surgery. Data was analyzed from project inception (1/1/18) to 4/30/19.
- Descriptive analysis of overall data is presented.

Results

Figures 1-3: Demographics of Patients Referred for Epilepsy Surgery Evaluation

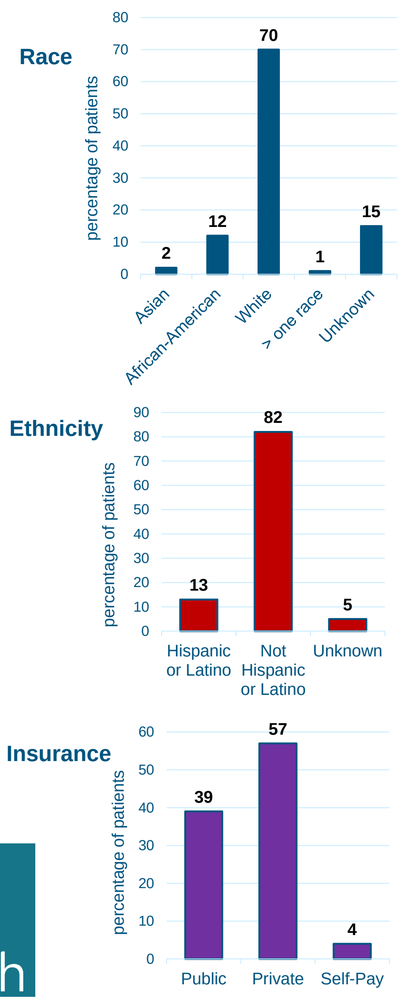

Table 1: EEG and MRI Findings

(N)	N (%)
Seizure onset on EEG (208)	
Focal	129 (62%)
Multifocal	36 (17%)
Generalized	20 (10%)
Mixed Generalized/Focal	9 (4%)
Indeterminate	14 (7%)
MRI Findings (239)	
Normal	67 (28%)
Abnormal	172 (72%)
MRI and EEG localization (171)	
Concordant	133 (78%)
Not Concordant	38 (22%)

- 13 centers enrolled 248 patients.
- 47% had age of seizure onset ≤ 3 years; 26% had age of onset > 3 - 8 years of age.
- Median time from seizure onset to referral: 4 years.
- 13% had epilepsy for more than ten years before referral (range < 3 months to 17 years).
- 40.7% with 2 seizure types; 9% with 3 or more seizure types.
- Mean and median number of anti-seizure medications (ASM) failed at the time of referral: 3.
- 79% were on two or more ASMs at the time of phase I evaluation (range 1-6).
- The most common etiology of epilepsy was structural (congenital 36%, acquired 26%), though with unknown causes comprising 28%.

Conclusions

- This cross-sectional cohort of patients referred for epilepsy surgery evaluation demonstrates that candidates are disproportionally Caucasian, non-Hispanic, and with private insurance.
- Despite meeting criteria for intractable epilepsy, there remains a delay to referral and evaluation for surgical intervention for children.
- Early onset epilepsy was common, and about half of the patients had multiple seizure types.
- Evaluations are ongoing for many patients included in this study; video EEG and MRI are components of nearly every evaluation and the majority demonstrate structural abnormalities consistent with EEG abnormalities.
- These and additional children will continue to be followed through the epilepsy surgery evaluation process, in order to identify and address best practices for the use of epilepsy surgery in children.

Pediatric Epilepsy RESEARCH CONSORTIUM

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