Neurosurgical Referral Patterns of Pediatric Medically Intractable Epilepsy Patients: A Single Institution Experience

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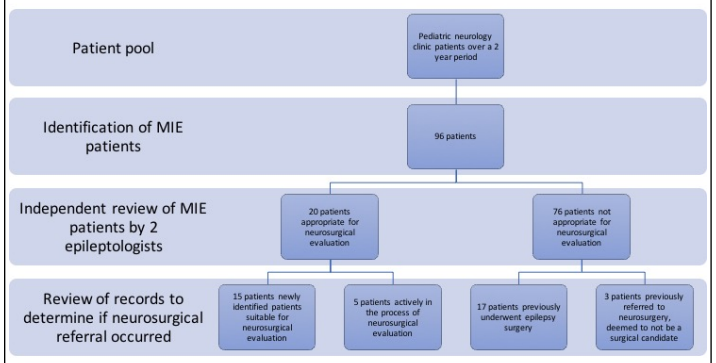
Introduction

Epilepsy surgery for pediatric medically intractable epilepsy (MIE) is underutilized and those who do undergo surgery often experience lengthy delays in neurosurgical referral. Our aims were to retrospectively identify pediatric MIE patients in whom proper neurosurgical referral was not initiated and potential reasons for referral delay.

Methods

A retrospective review of clinic patients from 9/2014 to 9/2016 was completed to identify pediatric MIE patients. MIE was identified using ICD-9 codes, mention of intractable or refractory epilepsy in clinic notes, or presence of 2 or more AEDs with continued seizures. Two epileptologists then reviewed these patients to determine those suitable for neurosurgical referral. Records were then compared to identify patients which had been properly referred for neurosurgical evaluation and those in whom neurosurgical referral had not been initiated. Demographic and clinical data were obtained; the Mann-Whitney U test was used to analyze ordinal data, Fisher's exact test was used to analyze categorical data.

Flowchart depicting methodology



Results

96 MIE patients were identified. Upon independent epileptologist review, 76 patients were deemed not appropriate for neurosurgical referral (the most common reasons being epilepsy of genetic etiology and previous epilepsy surgery) and 20 patients suitable for neurosurgical referral. Intra-rater reliability was high (k=0.94). Of these 20 patients, 5 were in the midst of neurosurgical evaluation while 15 patients had previously not been referred for neurosurgical evaluation. In comparing patients who were properly referred to neurosurgery (includes 17 patients who previously underwent epilepsy surgery, 3 patients previously referred to neurosurgery and deemed to not be surgical candidates, and the 5 patients currently in the process of neurosurgical referral) to the patients who were only identified as suitable for referral on ad-hoc review (15 patients) there were no significant differences in gender, race, insurance status, attending neurologist specialty (epileptologist vs general pediatric neurologist), number of current and failed AEDs, age of seizure onset, time from seizure onset to referral, and imaging characteristics (presence of lesion/abnormality on MRI). Presence of lesion/abnormality on MRI was the characteristic that was the closest to reach significance with newly identified patients suitable for neurosurgical referral trending towards having a higher proportion of negative imaging findings (p=0.06, Chi-squared).

Average time from seizure onset to referral among patients previously referred/in the process of referral was 7 years compared to 9.5 years for patients newly identified as appropriate for referral (p=0.12, Mann-Whitney U)

Of a total of 20 patients identified as suitable for neurosurgical referral, only 5 (25%) patients had referral already initiated, 15 (75%) patients were only identified as suitable for referral on this ad-hoc review. Consequently, up to 75% of MIE patients who may benefit from neurosurgical referral may not receive proper referral.

Conclusions

Of 96 MIE patients, 20 patients warranted neurosurgical referral, 15 of which were newly identified patients. As such, in a single institution review of pediatic MIE patients, up to 75% of patients appropriate for neurosurgical referral may be missed. In comparing characteristics between patients already referred to neurosurgery and patients newly identified as appropriate for referral, there were no significant differences identified although there was a trend among newly identified patients of having image-negative epilepsy.
The average time from seizure onset to neurosurgical referral for pediatric MIE patients remains long.

Learning Objectives

By the conclusion of this session, participants should be able to: 1) Describe the underutilization of epilepsy surrgery in pediatric MIE, 2) Recognize, the long delays in the neurosurgical referral among pediatric MIE patients, 3) Identify factors potentially associated with delays in neurosurgical referral.

References

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