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Delay in pediatric epilepsy surgery: A caregiver's perspective

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ABSTRACT

The timing of epilepsy surgery is complex, and there is not a structured pathway to help families decide whether to continue medical management or pursue surgical treatment. We surveyed caregivers of pediatric epilepsy surgery patients. Fifty-eight respondents answered the majority of questions. Thirty caregivers wished their child had undergone epilepsy surgery earlier compared with twenty who felt surgery was done at the appropriate time, and eight were unsure. In retrospect, caregivers who wished their child's surgery had been performed sooner had a significantly longer duration of epilepsy prior to the surgery [44.1 ± 71.7 (months \pm standard deviation (SD), $N = 27$)], compared with those who felt content with the timing of the surgery [12.8 ± 14.1 (months \pm SD, $N = 20$), $p = 0.0034$]. Caregivers were willing to accept a lower likelihood of seizure freedom than their physician reported was likely. Most caregivers were willing to accept deficits in all domains surveyed; caregivers had high acceptance of motor deficits, cognitive deficits, behavioral change, and language loss. Future studies are needed to focus on how to improve the education of caregivers and neurologists about the benefits and risks of epilepsy surgery and accelerate the pipeline to epilepsy surgery to improve caregiver satisfaction.

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1. Introduction

Improving quality of life in children with epilepsy is directly related to seizure freedom [1,2]. Recommendations exist for children with localization-related epilepsy to undergo an epilepsy surgery evaluation after medication management failure [3]. In adults, temporal lobe surgery improves seizure control and quality of life [4,5]. In pediatric epilepsy, there is a lack of randomized studies comparing ongoing medical versus surgical management, but guidelines overall suggest that children should undergo an epilepsy surgical evaluation following failure of a reasonable number of medication trials. A recent series of articles have looked at this issue to determine how long it takes to be referred to a pediatric epilepsy surgery center and caregivers' perception of the process [6,7]. There is a lack of understanding by physicians of when a child should be referred for an epilepsy surgery evaluation [8]. There have been studies looking at the demographics of children who underwent epilepsy surgery, and socioeconomic factors did differ with the duration of epilepsy prior to surgery [9,10]. Clinical severity (infantile spasms and seizure frequency), prereferral diagnostic magnetic resonance imaging (MRI), private insurance, and Hispanic ethnicity have been associated with shorter time from epilepsy onset to epilepsy surgery

[9,10]. However, there is still a limited understanding of the caregiver's perspective of epilepsy surgery and a need to provide their perspective to pediatric neurologists and epileptologists.

To begin to address this complicated issue, we set out to explore caregivers' impressions of their child's epilepsy surgery evaluation in an effort to determine whether caregivers perceive a delay in epilepsy surgery and how best to improve surgery evaluations and timing. An online questionnaire was developed to understand the families' sociodemographic information, their children's epilepsy, and their satisfaction with the timing, evaluation, and eventual epilepsy surgery. With this cohort of caregivers, we aimed to determine (1) the characteristics of their children's epilepsy, (2) their satisfaction with the timing of their child's surgical evaluation and surgery, and (3) potential areas in which improvements can be made to optimize the pipeline to epilepsy surgery. There is room for improvement in alignment between physicians and caregivers to decrease the time to surgery and improve caregivers' satisfaction in this early onset and refractory epilepsy population.

2. Material and methods

Caregivers of patients who were under the age of 18 at the time of epilepsy neurosurgery were asked to participate in this survey, which was approved by the institutional review board at Stanford University. Caregivers were recruited both in person and online. Caregivers were approached during their children's clinic visits at Lucile Packard Children's Hospital and asked to go online to complete the survey. The survey link was posted on the Facebook pages of the Tuberous Sclerosis

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Alliance, Epilepsy Foundation of America, Pediatric Epilepsy Surgery Support, Epilepsy Foundation of America, Sturge–Weber Foundation, Hemispherectomy Foundation, Hypothalamic Hamartomas, and Intractable Childhood Epilepsy Alliance. The survey was also distributed to the Tuberous Sclerosis Alliance support group via their email newsletter. Caregivers were not compelled to participate, and no incentives were offered for participation. Online consent was obtained from parents before they accessed the survey. Data were collected over a period of 9 weeks.

A Welch two-sample *t*-test was used to discern if there was a difference between the mean time from referral to surgery of parents who wished their child had undergone surgery sooner and parents who were satisfied with timing of surgery. Wilcoxon rank-sum tests were used to find variables that were correlated with whether or not parents reported wishing their child had undergone surgery sooner. A Bonferroni threshold of $p = 0.0083$ was used to adjust for multiple testing. Paired *t*-tests were employed to compare caregiver-reported physician-estimated likelihood of seizure freedom with likelihood of seizure freedom that parents were willing to accept.

3. Results

3.1. Survey demographics

One hundred twenty-nine people opened the survey. Seventy-one answered none or less than 10% of the questions and were not used for the analysis. Fifty-eight people answered over 90% of the questions and were used in this analysis. Surgeries were carried out in 6 countries (Supplementary Table 1), with the majority performed in the United States at 30 different epilepsy centers. Equal numbers of male and female patients were reported, with the majority being Caucasian (Supplementary Table 1). Overall, the respondents are a highly educated population: the majority had advanced degrees, and 43% had at least one caregiver who was in a healthcare profession.

3.2. Epilepsy history

Overall, the patients had early onset epilepsy with a very high seizure burden, though the range of seizure burden was very broad (0.03–7855 seizures/day) (Table 1). Most patients had early onset of seizures: the average age at seizure onset was 9 months, with a range of 0 months to 12 years. Nearly all patients (97%) had an abnormal MRI (Supplementary Table 1). Eighty percent of caregivers felt that their child's seizure burden was worsening prior to surgery. Patients had a mixture of seizure semiologies. Twenty-seven had a history of infantile spasms, further evidence of the early onset and severity of these patients' epilepsy. On average, 6.43 antiseizure medications per patient were tried before surgery. In total, over 22 different medications, the ketogenic diet, and vagal nerve stimulators were reportedly tried.

3.3. Presurgical evaluation

There was a wide range in the number of neurologists (1–9) and duration of the surgical evaluation (0–42 months) prior to surgery (Table 1). Caregivers were asked "Do you wish your child had undergone epilepsy surgery sooner?". Over half of the caregivers (30 of 58) wished their child had undergone epilepsy surgery sooner. The duration of epilepsy prior to surgery significantly differed between the groups: those that were satisfied with the timing of the surgery had a threefold shorter duration of epilepsy (12.8 months, $SD \pm 14.019$, $N = 20$) compared with those that wished their child had undergone epilepsy surgery earlier (44.1 months, $SD \pm 71.742$, $N = 27$). After dividing patients by caregiver satisfaction with the timing of surgery, only the duration of epilepsy was significantly different for families that wished their child had surgery sooner (Wilcoxon rank-sum test, $p = 0.004$, Table 1). All other variables assessed (Table 1) were similar between

Table 1
Seizure characteristics, surgery referral, and caregiver satisfaction.

	Average \pm standard deviation	Minimum–maximum	Number of responses	
Age seizures started (months)	9.0 \pm 20.22	0–144	58	
Seizure frequency prior to surgery (Sz/day)	34.0 \pm 41.6	0.03–7855	49	
Current seizure frequency, postsurgery (Sz/day)	2.0 \pm 8.4	0–60	54	
Longest seizure duration (min)	86.2 \pm 216.9	0.5–1260	49	
Longest seizure-free period preepilepsy surgery (months)	4.4 \pm 11.3	0–72	51	
Age at first suggestion of epilepsy surgery (months)	39.5 \pm 57.6	0–368	55	
Age at first epilepsy surgery referral (months)	41.6 \pm 57.6	0–368	56	
Age at first epilepsy surgery (months)	46.6 \pm 59.3	1–373	56	
Difference between surgery referral and surgery (months)	5.2 \pm 7.8	0–42	55	
Number of neurologists seen prior to surgery	2.6 \pm 1.4	1–9	58	
		Improving	Stable	Worsening
Parents impression of seizure burden prior to surgery	2	8	41	
		Yes	No	Unsure
Wish child had undergone epilepsy surgery sooner?		30	20	8
Feel there was a delay before undergoing epilepsy surgery?		14	43	1
		Satisfied with timing of surgery		
		Yes	No	
Duration of epilepsy prior to surgery (months)	12.8 \pm 14.02	44.1 \pm 71.74*		
Number of neurologists seen preoperation	2.3 \pm 1.23	3.0 \pm 1.48		
Time from referral to surgery (months)	3.24 \pm 4.96	6.93 \pm 9.42		
Number of AEDs trialed before surgery	5.55 \pm 2.56	7.33 \pm 4.02		
Number of AEDs needed after surgery	2.20 \pm 1.25	2.47 \pm 2.22		

* $p < 0.005$.

those satisfied with the timing and those who felt there was a delay, though all variables trended toward more or longer in the patients with a delay.

3.4. Postsurgical outcomes

The majority of caregivers were willing to accept neurologic deficits following the surgery: 50/58 would have accepted motor deficits, 40/58 cognitive deficits, 44/58 behavioral deficits, and 42/58 language deficits.

Caregivers were asked for the lowest likelihood of postsurgical seizure freedom they would have been willing to accept and still choose surgery. There was a wide range of lowest acceptable likelihood of seizure freedom, from 10% to 100% with a mean of 46.6% ($SD \pm 21.6$, $N = 39$). There was a willingness of the caregivers to accept a lower likelihood of seizure freedom than their physician reported was likely: caregivers were willing to accept on average a 46.6% ($SD \pm 21.6$, $N = 39$) likelihood of seizure freedom compared with a physician reported average of 67.4% likelihood of seizure freedom ($SD \pm 18.8$, $N = 45$, $p < 0.00001$).

4. Discussion

This survey provides new insight into caregivers' impressions of the surgical evaluation and outcome. The majority of caregivers wished their child had undergone epilepsy surgery earlier. The duration of epilepsy before surgery was three times longer for those who wished their child had undergone epilepsy surgery earlier. While there were trends for more medication trials, more neurologists seen, and longer surgical evaluation, the only statistically significant difference was the duration of epilepsy prior to referral for surgery. This suggests that most of the

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