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# “A journey around the world”: Parent narratives of the journey to pediatric resective epilepsy surgery and beyond

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## SUMMARY

**Objective:** Although shorter time to pediatric resective epilepsy surgery is strongly associated with greater disease severity, other nonclinical diagnostic and sociodemographic factors also play a role. We aimed to examine parent-reported barriers to timely receipt of pediatric epilepsy surgery.

**Methods:** We conducted 37 interviews of parents of children who previously had resective epilepsy surgery at University of California Los Angeles (UCLA; 2006–2011). Interviews were audio-recorded, transcribed, and systematically coded using thematic analysis by two independent coders, and subsequently checked for agreement. Clinical data, including “time to surgery” (age of epilepsy onset to surgery) were abstracted from medical records.

**Results:** The mean time to surgery was 5.3 years (standard deviation [SD] 3.8); surgery types included 32% hemispherectomy, 43% lobar/focal, and 24% multilobar. At surgery, parents were on average 38.4 years (SD 6.6) and children were on average 8.2 years (SD 4.7). The more arduous and longer aspect of the journey to surgery was perceived by parents to be experienced prior to presurgical referral. The time from second antiepileptic drug failure to presurgical referral was  $\geq 1$  year in 64% of children. Thematic analysis revealed four themes (with subthemes) along the journey to surgery and beyond: (1) recognition—“something is wrong” (unfamiliarity with epilepsy, identification of medical emergency); (2) searching and finding—“a circuitous journey” (information seeking, finding the right doctors, multiple medications, insurance obstacles, parental stress); (3) surgery is a viable option—“the right spot” (surgery as last resort, surgery as best option, hoping for candidacy); and (4) life now—“we took the steps we needed to” (a new life, giving back).

**Significance:** Multipronged interventions targeting parent-, provider-, and system-based barriers should focus on the critical presurgical referral period; such interventions are needed to remediate delays and improve access to subspecialty care for children with medically refractory epilepsy and potentially eligible for surgery.

**KEY WORDS:** Epilepsy surgery, Pediatric, Access to care, Parent.



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In appropriately selected children, resective epilepsy surgery is an efficacious and cost-effective treatment with the potential to eliminate and reduce seizure burden, avert developmental regression, and improve quality of life outcomes.<sup>1–5</sup> Despite the accumulating evidence of the benefits of surgery over time and the 2006 International League Against Epilepsy (ILAE) published referral recommendations for epilepsy surgery in children, a substantial proportion of children fail to receive this care in a timely manner.<sup>6</sup> Epilepsy duration prior to pediatric resective epilepsy surgery is still on average 5–6 years, with substantial

variability.<sup>7–9</sup> A significant proportion of children in need of epilepsy surgery—particularly those with seizure onset before age 2 years—experience daily seizures and are at risk for epileptic encephalopathy, making early surgical intervention critical.<sup>6,8</sup> In children, shorter times to surgery have been associated with better seizure and developmental outcomes.<sup>2,10–12</sup>

Although several studies have examined physician- and patient-based barriers to adult epilepsy surgery,<sup>13–23</sup> few have examined in-depth the factors that mediate delays in children,<sup>7,17,24–26</sup> and none have assessed the perspectives of parents of children who have undergone epilepsy surgery. We previously found that although shorter time to pediatric resective epilepsy surgery is most strongly associated with greater disease severity (history of infantile spasms, daily seizures), other nonclinical diagnostic and sociodemographic factors also play a role.<sup>7</sup> In follow-up, we aimed to identify the nature and range of parent-perceived barriers to timely receipt of pediatric epilepsy surgery.

## METHODS

We chose a qualitative methodology to obtain a full range and in-depth assessment of barriers and perceptions in a heterogeneous sample of parents of children who had prior resective epilepsy surgery.<sup>27</sup>

### Sample selection and recruitment

We recruited and interviewed a sample of parents of children who had previously undergone resective epilepsy surgery at UCLA. Inclusion criteria included the following: (1) parent/guardian of child who had resective epilepsy surgery (<18 years; 2006–2011), (2) English or Spanish speaking, and (3) ability to provide verbal informed consent. Parents were recruited with purposeful oversampling of those with longer times to surgery in order to assess barriers to timely epilepsy surgery.

Potential participants (N = 146) were sent an informational invitation letter from the study investigators (CB, GM). A prestamped “opt-out” return card was included if they did not wish to be contacted further (only one potential participant returned the opt-out card). Those interested in participation could return a prestamped card to the study team and the research assistant (RA), who then called them to schedule an interview. The RA also called nonresponding potential participants 2 weeks after the mailing to describe the study in more detail and invite them to participate. We recruited a final sample of 37 individual parents (not dyads), at which point data saturation had been achieved.<sup>28</sup>

### Measures and data sources

#### *Clinical characteristics of children*

Clinical data (date of epilepsy onset and surgery, seizure frequency before surgery, type of surgery, presurgical

history of infantile spasms, number of antiepileptic drugs [AEDs] at surgery, and etiology) were obtained by abstraction of medical records. Details regarding the standardized presurgical evaluation protocols, surgical procedures, and clinical variables have been described previously.<sup>1,2,7</sup> “Time to surgery” was calculated as the interval from date of epilepsy onset to epilepsy surgery.

#### *Parental sociodemographic and baseline information*

A trained RA or the principal investigator (PI; CB) first asked parents structured questions regarding parental sociodemographic characteristics (age, gender, race/ethnicity, education level, employment status, marital status, and primary language), medical insurance of their child (at surgery), physician specialty type involved in care of child (from seizure onset, diagnosis, and presurgical referral for video-electroencephalography [EEG] monitoring), timing of epilepsy care (from seizure onset, diagnosis, two-AED failure, to presurgical referral), information sources for presurgical referral to UCLA, whether their child had received epilepsy specialty care prior to UCLA, and whether their child had experienced any seizure remission periods.

### Semi-structured interviews

Based on clinical experience and published research, study investigators constructed a semi-structured interview guide (Table S1) to elicit parent perspectives on access and barriers to care and surgery in relationship to the timeline of seizure onset, epilepsy diagnosis, two-AED treatment failure, presurgical referral, and surgery. To capture a range of responses, questions were open-ended; directed and nondirected prompts were used to encourage discussion.<sup>27</sup>

### Data collection

The PI (CB) or a trained bilingual (English/Spanish) RA conducted interviews via telephone. Participants were mailed a \$30 gift card. The average duration of the 37 interviews was 29 min (range 10–60 min).

### Analysis

Baseline characteristics and clinical data were analyzed using descriptive statistics. Audiotaped semistructured interviews were transcribed verbatim, translated (Spanish to English, if applicable), and de-identified. A three-person analysis team (CB, HP, and TI) then systematically analyzed the transcripts using thematic analysis.<sup>29</sup> Two members of the team (CB and TI) read each interview to familiarize themselves with the data and then independently assigned initial codes to sections of text in each interview. Coding was reviewed and discrepancies were discussed until agreement was reached. All codes were maintained in a codebook (Microsoft Excel version 14.4.2). Once initial coding was completed

for the majority of the interviews, the analysis team sorted the initial codes into the most salient themes and subthemes identified as frequent and meaningful across interviews.<sup>29</sup> Diagramming was used as a tool to summarize major themes and subthemes.<sup>29</sup>

### Standard protocol approvals, registrations, and patient consents

The UCLA Institutional Review Board approved this study. Parents signed research informed consents and Health Insurance Portability and Accountability Act authorizations that allowed ongoing participation in the pediatric epilepsy surgery database and recruitment for this study. Parent participants provided verbal consent via phone prior to the interview. This study was not a clinical trial.

## RESULTS

### Sample characteristics

Sample characteristics (N = 37 individual parents) are shown in Table 1. There was high agreement for the “time to surgery” between the medical chart and parent reports (intraclass correlation coefficient [ICC] 0.96, 95% confidence interval [CI] 0.92–0.98); the mean “time to surgery” by medical chart was 5.4 years (SD 3.8) and by parent report was 5.1 years (SD 3.7). The majority (70%) of parents did not know that their child was having an epileptic seizure that first time (Table 1). At seizure onset, more than half (57%) of children were seen by a primary care or emergency medicine doctor, whereas 41% were seen by a pediatric neurologist or epileptologist (Table 2). Although epilepsy was diagnosed by a pediatric neurologist (or epileptologist) in most children (95%), nearly one third (30%) were referred for presurgical evaluation by a nonneurologist (n = 8) or were self-referred (n = 3). The time from seizure onset to epilepsy diagnosis was >1 month in 40% of children, and the time from the second AED failure to presurgical referral was >1 year in nearly two thirds (64%) of children (Table 3).

### Parent narratives: themes along the journey to pediatric epilepsy surgery and beyond

Four interrelated themes with associated subthemes were identified along the journey to surgery and beyond (Table 4; Fig. 1): (1) Recognition, (2) Searching and finding, (3) Surgery becomes a viable option, and (4) Life now. At initial onset of seizures, parents were scared and described a sense of urgency to uncover what was happening to their child. Parents depicted a pathway filled with multiple doctors and treatments, insurance battles, and work and life obstacles as they sought a cure for their child’s seizures, becoming ever more knowledgeable about epilepsy. Once parents found the right doctor and were given the option to pursue epilepsy surgery, the once frightening prospect of brain surgery became a source of hope. Whether this journey took only

**Table 1. Sociodemographic and clinical characteristics**

	Mean (SD) or N (%)
Child age at epilepsy onset, years <sup>a</sup>	2.7 (3.5)
Child age at surgery, years <sup>a</sup>	8.2 (4.7)
Time to surgery (epilepsy onset to surgery), years <sup>a</sup>	5.4 (3.8)
Child gender, % male <sup>a</sup>	17 (46.0)
History of infantile spasms <sup>a</sup>	15 (40.5)
≥Daily seizure frequency <sup>a</sup>	25 (69.4)
Number of AEDs taking at time of presurgical evaluation <sup>a</sup>	
1 AED	7 (18.9)
2 AEDs	13 (35.1)
≥3 AEDs	17 (45.9)
Operation type <sup>a</sup>	
Hemispherectomy	12 (32.4)
Lobar/focal	16 (43.2)
Multilobar	9 (24.3)
Etiology <sup>a</sup>	
Cortical dysplasia	16 (43.2)
Hemimegalencephaly	3 (8.1)
Infarction	8 (21.6)
Tuberous sclerosis complex	6 (16.2)
Tumor	4 (10.8)
Parent age at interview, years	41.3 (7.3)
Parent age at child’s surgery, years	38.4 (6.6)
Parent, % mothers	31 (83.8)
Parent race/ethnicity	
Caucasian	25 (67.6)
Hispanic	11 (29.7)
Pacific Islander	1 (2.7)
Parent primary language English	31 (83.8)
Parent born in United States	28 (75.7)
Parent married (at time of child’s surgery)	34 (91.9)
Parent employment (at time of child’s surgery)	
Full- or part-time	20 (54.1)
Homemaker	15 (40.5)
Unemployed	2 (5.4)
Parent level of education (at time of child’s surgery)	
≤High school/GED	7 (18.9)
Vocational school	10 (27.0)
≥4 year college	20 (54.1)
Insurance at time of epilepsy surgery	
Preferred provider organization	21 (56.8)
Health maintenance organization	3 (8.1)
Fee for service	2 (5.4)
Medicaid/California children’s service	8 (21.6)
Tricare	3 (8.1)
Epilepsy specialty care prior to UCLA referral? % yes	29 (78.4)
How heard about UCLA Pediatric Epilepsy Surgery Program <sup>b</sup>	
Referring physician	26 (70.3)
Friends/family	3 (8.1)
Internet	10 (27.0)
Epilepsy support groups	1 (2.7)
Other	4 (10.8)
Parent knew child was having seizure (that 1st time)	11 (29.7)

(N = 37; surgery 2006–2011).

<sup>a</sup>Data from medical chart abstraction.

<sup>b</sup>1 missing.

months or many years, parents expressed that the circuitous journey to surgery felt long because of all the ups and downs and unknowns of the journey. As one parent said, “I wish it

**Table 2. Physician types at different pediatric epilepsy care points**

Physician type	Seizure onset	Epilepsy diagnosis	Presurgical referral
Pediatric epileptologist	8 (21.6)	21 (56.8)	14 (37.8)
Pediatric neurologist	7 (18.9)	14 (37.8)	10 (27.0)
Pediatrician/family medicine	13 (35.1)	1 (2.7)	8 (21.6)
Emergency medicine	8 (21.6)	1 (2.7)	–
Adult neurologist	–	–	1 (2.7)
Neurosurgeon	–	–	1 (2.7)
Self-referred	–	–	3 (8.1)
Other	1 (2.7)	–	–

**Table 3. Timing of pediatric epilepsy care**

Time to surgery (epilepsy onset to surgery), years, mean (SD); range <sup>a</sup>	5.4 (3.8); 0.5–14.7
Time from seizure onset to epilepsy diagnosis <sup>b</sup>	
<1 week	12 (32.4)
≥1 week but <1 month	10 (27.0)
≥1 month but <1 year	8 (21.6)
≥1 year	7 (18.9)
Time from second AED failure to referral to epilepsy center <sup>b,c</sup>	
<1 month	6 (16.7)
≥1 month but <1 year	7 (19.4)
≥1 year but <3 years	12 (33.3)
≥3 years	11 (30.6)
Any period of extended seizure freedom prior to referral <sup>b</sup>	
No period of remission ≥6 months	10 (73.0)
≥6 months but <1 year	2 (5.4)
≥1 year but <2 years	5 (13.5)
≥2 years	3 (8.1)

<sup>a</sup>Data from medical chart abstraction ('time to surgery' parent report 5.1 years, SD = 3.7); high agreement for time to surgery between medical chart and parent report (ICC = 0.96, 95% CI [0.92, 0.98]).

<sup>b</sup>Data from parent-report.

<sup>c</sup>1 missing.

was a more direct flight rather than a journey around the world and very circuitous.”

The more arduous and longer aspect of the journey to surgery was largely perceived to be experienced prior to the presurgical evaluation, or prior to referral to the epilepsy center. “It was a long time only because nobody referred us. But once we found an epilepsy specialist that would refer us, it was very quick,” stated a parent. Once referred, parents felt that the path was more direct and less arduous. As one parent recounted, “We met Dr. X (pediatric neurologist). She said, ‘I’m going to address the seizures as best I can while I’m getting you evaluated for pediatric neurosurgery.’ And it was a straight line from there.”

### Theme 1. Recognition: “Something is wrong”

The initial onset of seizures was often a frightening experience, with many parents describing a feeling of desperation to get a diagnosis and proper treatment.

### Unfamiliarity with epilepsy

At the time of initial seizure onset, the majority of parents reported that they were unfamiliar with seizures and how they could manifest. Many parents mistook their child’s initial seizure for something else—including, for example, “daydreaming,” “the flu,” “hiccups,” or “food poisoning because it looked like she was choking.” Although some parents reported some prior familiarity with seizures, most parents’ conception of a seizure was that of a motor convulsion exclusively.

### Recognition of medical emergency or urgency

Despite not recognizing their child’s initial epileptic seizure as such, parents knew that something was wrong and that they needed to seek medical attention urgently. As one mother expressed, “I didn’t know what was going on and I had no idea. I just knew it was an emergency. So I called 911.”

### Theme 2. Searching and finding: “A journey around the world and very circuitous”

With the recognition that “something is wrong,” parents sought information from multiple sources in an attempt to understand seizures and epilepsy and become better advocates for their child. Through this journey, parents learned to navigate a complicated medical system filled with doctors of different specialties, multiple hospitals, insurance approvals, and numerous treatment options. Parents traversed all of this within the context of their daily lives, having to juggle life responsibilities such as other children and work, in addition to caring for a sick child.

### Information seeking

Parents reported difficulties as they sought information about seizures, epilepsy, medications, and surgery. Parents also reported little initial familiarity with epilepsy and that they felt overwhelmed trying to learn a new language of epilepsy because of the “avalanche of information coming at us.” Parents sought information from a variety of disparate sources including physicians, the Internet, books, and family/friends. As they acquired more epilepsy knowledge, however, many parents felt more empowered and able to ask questions and participate more effectively in the care of

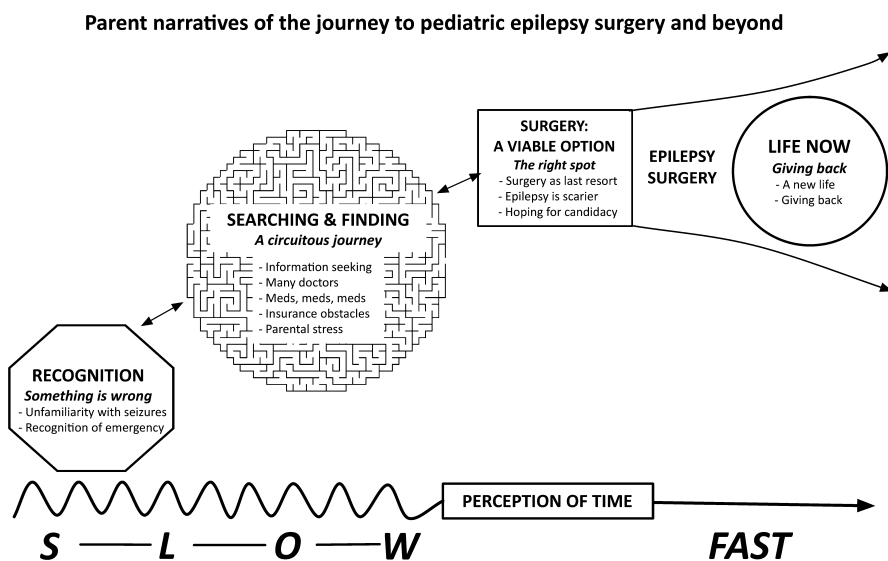
**Table 4. Parent-reported themes along the journey to pediatric resective epilepsy surgery: Themes, subthemes and exemplars (N = 37)**

Themes	Subthemes	Exemplars
"Something is wrong"; Recognition	Didn't know it was a seizure—unfamiliar with epilepsy	"My mom's cousin had grand mal seizures, so when he had a grand mal seizure, I knew... I honestly had no idea of all the other little seizures that they can have..." "I mean the normal person knows a seizure as somebody convulsing, the grand mal type seizure, but she doesn't have that type of seizure. When it first happened we thought she was just very sick from the stomach flu... I was under the assumption that there's only one kind of seizure." "We were all scared, and we needed to go, and take her to the ER, and get some help, and find out what is going on." "My first reaction was to call the pediatrician in a state of panic..."
"A circuitous journey"; Searching and finding	Recognition of emergency or medical urgency Information seeking—learning the language of epilepsy	"I mean, you've heard of epilepsy, but—so it was pretty much an avalanche of information coming at us. So we didn't in the beginning have a clue... It wasn't that easy to find information..." "There's a whole lot of words that neurologists and a hemispherologist use when—and in the beginning you're like what in the—what are you talking about. So, eventually when you start understanding the terminology and you start understanding the treatments, and you start understanding the medication side effects and all the other stuff and then it becomes a little bit easier" "I firmly believe that the more education you have as a parent... the more educated questions you can ask your doctor" "When you suddenly have a child with a serious disability that comes out of left field that you don't know anything about, there's a lot to learn." "We'd been bouncing around hospitals for 4 or 5 months... Not that care was poor—don't get me wrong—but there's a point where it surpasses the local specialty." "Every doctor has their own idea about what the deal is" "I don't believe that doctor really knew what she was doing... By having doctors who were experienced, who knew what they were dealing with, and who knew and had a plan of attack in place. I felt that the XXX, when we were there, there was no plan, there was no guidance..." "She again said that he was doing it for attention and that we needed to go to see the behavioral clinic doctor." "... and so one doctor might see something, but another doctor is gonna see something completely different. It's not black and white. As much as they know, they don't know a lot more." "... and all the medications we were giving her were not controlling them and they weren't stopping. We were just upping, taking it down, and putting her on a different one which wasn't controlled." "When the medications continued to fail and we were on No. 4 and No. 5 and none of it was working, her seizures were getting worse, her behaviors were worse, there were side effects. She would lose short term memory. She wasn't learning. Some days all she did was seize and sleep... It was the medications. We kept trying more medications. Nothing was helping our daughter." "I feel that her medical insurance, particularly when we had the HMO, made it very difficult to get in to see doctors within a reasonable amount of time because we had to get an authorization. It wasn't just a phone call, it was four phone calls, continuous follow-ups..." "We had quite a fight with the insurance to get the MEG approved, and actually because of that fight, our insurance changed our protocol concerning MEG and epilepsy." "It took 6 months just to get a consultation approved through the insurance... And since XXX Medicaid refused to pay, XXXX would no longer accept the insurance, and I would have to pay out-of-pocket in order to have surgery. And I am not a billionaire. I can't pay for brain surgery out of pocket." "... I was at his side in the hospital for the majority of his life, so my marriage, my home, it was difficult" "... because I don't have a life besides taking her to her doctor's. I could never actually have a job or do anything and take care of my daughter." "I mean family and friends are very supportive, but in the workplace they're not. I got fired from too many jobs. I lost too
	Doctors—not enough, too many, finding the right one	
	Many and more medications	
	Out of network or treatment and testing denied—insurance obstacles	
	Being on call 24/7—parental stress	

Continued

Themes	Subthemes	Exemplars
"The right spot": Surgery becomes a viable option	Surgery as scary and treatment of last resort only	<p>many jobs, and I was actually forced to stop working. . . . There was no balance. It was impossible to keep a job"</p> <p>"You feel alone because you just don't have other friends that have kids who have had brain surgeries necessarily."</p> <p>"You hear surgery, but it's always considered a last resort option. I think like a lot of families, we kind of just wrote surgery off. We just continued meds."</p> <p>"I think sometimes with brain surgery, it's scary for a lot of people. The brain is one of the most major organs in the body, and the idea that you as a parent have to say yes or no to them cutting out a portion of your kid's brain, what does that really mean for your child?"</p> <p>"When you say that you're going to cut someone's—half of their brain out—it sounds very extreme, which it is. . . . It sounded like science fiction. I remember thinking there was no way I would ever do that to my child. It seemed insane."</p> <p>"Well in the beginning when she was diagnosed the neurologist at XXX thought that she would outgrow the seizures, so from age 4 until around 11 or 12 we thought she'd outgrow them. And we weren't about to do a radical surgery with the hopes that she would have been cured by age 12."</p> <p>"I think part of my son's problem is that he did go 2 years without a seizure so I think we were hopeful that he had outgrown it or something."</p>
"We took the steps we needed to": Life now	Epilepsy is more scary than surgery	<p>"Because there are people who will tell you scary things about the surgery; I don't have scary things to tell you about the surgery, I have more scary things to tell you about the epilepsy."</p> <p>"Either she was going to die or we were going to make an effort to do something about it. . . . You need to make an informed decision if you choose not to have surgery. Everything has its risks."</p> <p>"It was more like, just hoping that he was a candidate."</p> <p>"But until you find a doctor who thinks a little bit more outside the box and you know, explains the fact that surgical, epilepsy surgery is not a last resort, but it is often the best resort, once you hear that, it's kind of very clear that you need to go talk [laughs] to a surgeon."</p> <p>"It's just an amazing—it was, you know, it was an anxiety-ridden process, but it has been the best decision of our entire life for her. She is a changed person."</p>
"We found some afterward": Life now	Surgery as best option—hoping for surgical candidacy	<p>"Share your story so that other people can, you know, hopefully be helped."</p> <p>"Once my child had surgery someone called us and said, 'I heard your daughter had the surgery.' So my husband and I actually went and met with those parents and told them our experiences. And then my child met with them as well. . . . It was just any trial that you have, if somebody's been through it before, it's encouraging to hear their story."</p> <p>"Find a group of people. . . reach out to other people so that you have someone who has been there, someone who can understand you, someone that you can call and have that support, because it is different from a family member or a friend that really doesn't get it."</p> <p>"Now, I'm the biggest proponent for epilepsy surgery. I have a friend in the community who I'm trying to convince to go to XXX right now and just do the surgery."</p> <p>"We found some afterward (support groups), but there wasn't really any when we were doing this, when we started going through it."</p>
"We found some afterward": Life now	A new life—for child and parent	<p>"Share your story so that other people can, you know, hopefully be helped."</p> <p>"Once my child had surgery someone called us and said, 'I heard your daughter had the surgery.' So my husband and I actually went and met with those parents and told them our experiences. And then my child met with them as well. . . . It was just any trial that you have, if somebody's been through it before, it's encouraging to hear their story."</p> <p>"Find a group of people. . . reach out to other people so that you have someone who has been there, someone who can understand you, someone that you can call and have that support, because it is different from a family member or a friend that really doesn't get it."</p> <p>"Now, I'm the biggest proponent for epilepsy surgery. I have a friend in the community who I'm trying to convince to go to XXX right now and just do the surgery."</p> <p>"We found some afterward (support groups), but there wasn't really any when we were doing this, when we started going through it."</p>
"We found some afterward": Life now	Wanting to give back—importance of shared experience	<p>"Share your story so that other people can, you know, hopefully be helped."</p> <p>"Once my child had surgery someone called us and said, 'I heard your daughter had the surgery.' So my husband and I actually went and met with those parents and told them our experiences. And then my child met with them as well. . . . It was just any trial that you have, if somebody's been through it before, it's encouraging to hear their story."</p> <p>"Find a group of people. . . reach out to other people so that you have someone who has been there, someone who can understand you, someone that you can call and have that support, because it is different from a family member or a friend that really doesn't get it."</p> <p>"Now, I'm the biggest proponent for epilepsy surgery. I have a friend in the community who I'm trying to convince to go to XXX right now and just do the surgery."</p> <p>"We found some afterward (support groups), but there wasn't really any when we were doing this, when we started going through it."</p>

Table 4. Continued.



**Figure 1.**  
Parent narratives of the journey to pediatric epilepsy surgery and beyond.  
Epilepsia © ILAE

their child. A mother who stated, “I just think knowledge is power and it also brings some comfort to making a good decision,” exemplified the sense of empowerment associated with gaining fluency in the language of epilepsy.

#### *Finding the right doctor*

Parents expressed that their children were seen, evaluated, and cared for by a variety of doctors of different specialties throughout their journey. Parents frequently described difficulty finding the “right” doctor(s). Difficulty was associated with a lack of pediatric neurologists in their local area and with different doctors having different recommendations. Several parents experienced feeling doubted by a doctor; some were told that nothing was wrong with their child initially. As one mother revealed, “Initially the first thing she [doctor] thought that I was crazy. Well, she thought I was a little hypochondriac or something. I’m thinking, well, four kids, I’m not here that often. I don’t think that’s the case.” The journey to finding the right doctor was further complicated by parental perceptions that doctors sometimes lacked knowledge of or familiarity with epilepsy. Many parents went to numerous doctors searching for the “right” doctor, or one who had a strong epilepsy knowledge base, could effectively identify the problem, and then make a clear plan of action.

#### *Many medications*

The majority of parents reported that their children tried many AEDs, the use of which were often associated with no improvement in seizure control and numerous adverse effects. Parents frequently described that medication trials continued often with little to no mention of surgery. One mother told of her frustrations with multiple medications, “It was, ‘Let’s work on all the different medical aspects or medicines before going to surgery or even talking about surgery.’”

#### *Insurance obstacles*

Parents reported insurance-related barriers that impacted their journey to surgery, and several parents stated that they purposively changed insurance to make care for their child with epilepsy easier. Parents noted that insurance policies affected their ability to see certain physicians and centers and to have specific diagnostic tests in a timely and stress-free manner. Even if approval was eventually granted, authorizations were needed and parents had to spend significant time and energy navigating how to get specific visits, procedures, or tests approved. Parents had to learn to navigate insurance policies, a learning process that was frustrating and time consuming. One mother explained her insurance frustrations, stating, “I firmly believe that if the insurance companies would have been more responsive, it would have changed the outlook of the whole thing.”

#### *Parental stress*

Parents reported personal and family stress throughout the journey. Caring for children with a chronic, severe, and paroxysmal neurologic condition meant being “on call” all the time; they had to be prepared to respond to an emergency at all times. For many parents, such caretaking roles meant they had less time and energy for other persons and activities in their life—including their spouse, other children, and work. A mother reflected, “It was a miracle I didn’t drink or do drugs. I mean that is the honest truth. . . I always had to be on call. . . I can’t believe my marriage is still intact as well—it was so stressful.” Many parents felt alone in their roles as caretakers of and advocates for their children and in the decisions that they had to make for their children’s care.

#### **Theme 3. Surgery as a viable option: “The right spot”**

After an arduous journey, parents reached the right doctor and center; epilepsy surgery, although previously seen as a



last ditch option, became a viable option and a source of hope.

#### *Surgery as scary and last resort*

Many parents initially perceived epilepsy brain surgery to be “pretty horrific” and a treatment of “last resort.” The prospect of needing to make a decision about surgery for their child was stressful. Although knowing about the possibility of surgery, some parents continued to hold on to a notion that their child might “outgrow” their seizures; such a notion often came from a treating doctor saying that this would happen or from a parent’s prior experience of having a child who had experienced a period of remission.

#### *Epilepsy is scarier than surgery*

On their journey, many parents transformed their view of surgery from a scary, last resort treatment to a necessary and hopeful option. One mother explained, “By the time she got it—it got so serious I was looking toward that as being an answer to our prayers rather than just something that I couldn’t even think about.” This transformation occurred as parents became increasingly aware of the severity of their child’s epilepsy and its impact on their child’s and their future life. Although surgery remained scary, epilepsy was or became scarier than surgery. As some parents feared that their child would die from epilepsy, surgery was no longer perceived as an elective treatment.

#### *Hoping for surgical candidacy*

As parents learned that surgery was a potential viable option for their child, they “hoped” for candidacy. This hoping required persistence and sometimes disregarding doctors who initially felt surgery was not an option. Looking back, one father voiced happiness that he listened to his parental instincts rather than the opinion of one doctor. He (doctor) said, “I don’t believe that she is a surgical candidate.” As a parent, I listened and I wanted to think otherwise. . . . In hindsight, I’m glad I didn’t listen to him.”

#### **Theme 4. Life now: “We took the steps we needed to”**

Although the purpose of the interviews was to examine parental perspectives along the journey to surgery, parents spontaneously spoke of their lives postsurgery.

#### *A new life—child and parent*

Many parents reported that the journey to surgery was a life-changing process for their child and family. For some, life before surgery felt like “another life” and sometimes one that they would prefer not think about. Postsurgery, one family came to refer to the seizures as “things you don’t like to talk about because that’s been taken care of.”

#### *Giving back*

Postsurgery, parents often wanted to give back to others by sharing their story about their journey to surgery,

supporting other parents now going through a similar journey and advocating for brain surgery. Many parents recommended support groups and felt a need to give back to others, particularly because some parents didn’t make “parental connections” until late in the journey.

## DISCUSSION

Parents who traveled the journey to pediatric resective epilepsy surgery identified four main themes. The journey started with recognition that “something is wrong” with their child; unfamiliar with seizures and epilepsy, however, parents still identified their child’s medical urgency. Following this, parents were searching and finding along a “journey around the world” that was “circuitous.” This journey encompassed information seeking, multiple medication trials, insurance obstacles, and parental stress until they found the right doctors. Although initially considered to be a treatment of last resort, parents perceived surgery to be a viable option and hoped for candidacy as epilepsy reached a threshold of being scarier than surgery. Parents spontaneously reflected on life postsurgery and were convinced that they made the right decision in pursuing surgery fueled with a desire to give back to other families. Along this path, parents perceived the more arduous and longer aspect of the journey to surgery to be experienced prior to presurgical referral and evaluation.

These data provide evidence for a spectrum of parent-, provider-, and health-system-based barriers that influence the ease of getting to and the timeliness of receipt of pediatric resective epilepsy surgery. Parents perceived these barriers to be most pronounced early in the journey, prior to the referral for presurgical evaluation. Although prior literature has reported parental difficulty with recognition of initial epileptic seizures in children that may result in delays in seeking medical care,<sup>30,31</sup> we found that although the majority of parents did not know that their child was having a seizure that very first time, most parents, nonetheless, sought urgent or emergent medical attention. Furthermore, the time from second AED failure to presurgical referral was  $\geq 1$  year in nearly two thirds of children, perhaps highlighting that the interval from two AED failures until access at a pediatric epilepsy center for presurgical evaluation is a critical window for interventions targeting barriers.

Parent-based perceived barriers along the journey to epilepsy surgery included knowledge of epilepsy, parental stress, and the perception of surgery as risky and a last resort treatment. Parents reported little baseline knowledge related to seizures and epilepsy, prompting them to “learn the language” of epilepsy, highlighting the need to develop strategies to mitigate stigma<sup>32</sup> and to improve public awareness of epilepsy for families with epilepsy.<sup>33</sup> Our observation that parents experienced significant stress along the path to surgery<sup>34</sup> further

underscores the need for family-centered care and community resources for parental support, including for example, peer-to-peer support groups.<sup>35</sup> Consistent with prior work showing that a high proportion of adults perceived epilepsy surgery to be a very dangerous treatment of last resort,<sup>13,14,19,22,23</sup> we found that many parents shared similar sentiments. In one study of pediatric epilepsy surgery, Italian parents of young children had a more favorable attitude toward surgery compared to parents of adolescents; however, subjects were parents of children with predominantly well-controlled epilepsy who had not undergone surgery.<sup>24</sup> Future research is needed to determine the extent to which such parental attitudes toward surgery mediate the timing of presurgical referral and surgery, in addition to how physician–parent communication about surgery impacts perceptions and decision making.

Parents also reported notable physician-based barriers including variability in perceived knowledge of epilepsy, criteria for presurgical referral and appropriateness of epilepsy surgery. Our finding that 30% of children were referred by a nonneurologist suggests that parents had to find alternate referral routes and that some child neurologists may not be aware of or follow pediatric epilepsy surgery referral recommendations,<sup>6</sup> as has been found previously in adult patients.<sup>17,18,36</sup> To date, studies that have found variability in physician knowledge of AED resistance, presurgical referral criteria, and attitudes toward surgery have focused primarily on adults.<sup>17,18,20</sup> Two non-U.S. surveys of child neurologists demonstrated variable views on the definition of drug-resistant epilepsy and surgery eligibility, in addition to nonadherence to referral recommendations.<sup>17,25</sup> The extent to which these findings are representative of U.S. provider attitudes, knowledge, and referral practices for pediatric epilepsy surgery and their potential impact on the timing of presurgical referral and surgical treatment is not known, although they do suggest that physician-targeted interventions are needed. Although a neurologist-utilized Web-based intervention was developed in Canada to identify potential appropriate adolescent and adult epilepsy surgery candidates, further research is needed to determine its impact on timing of presurgical referral and patient outcomes.<sup>37</sup>

Parents reported numerous health-system–based barriers including health insurance–related obstacles. Although studies have examined insurance disparities in utilization<sup>15,21,26,38</sup> or timing<sup>7</sup> of surgery in adult and pediatric epilepsy surgery, and delays in access to pediatric specialty care,<sup>39</sup> this study reports parents' perceptions of the nature of insurance-related barriers along the path to epilepsy surgery. Parents reported challenges associated with the navigation of complex insurance procedures related to approval of diagnostic testing or care with physicians out of network; they had to learn to navigate insurance policies and the medical system. The extent to which health

insurance policies and authorization procedures are concordant with presurgical referral recommendations<sup>6</sup> at the time of two-AED failure, or medical intractability,<sup>40</sup> however, is unknown.

There are limitations to our study. Interviews provided retrospective parental perspectives only. Such retrospective accounts, however, provided perspectives of the journey through the epilepsy continuum—from seizure onset, epilepsy diagnosis, initial treatment, to presurgical referral and surgery; parents additionally spontaneously discussed life beyond surgery. Although the “time to surgery” reported by parents was in agreement with that documented in the medical chart, the timing of other parent-reported epilepsy care was not reliably recorded in medical records, thereby limiting potential comparisons between parent-reported and medical chart data. Because the goal of our study was to ensure a heterogeneous sample from which to identify the full range of parent-reported perspectives along the journey to surgery, the extent to which they occur in the population of children with surgically remediable epilepsy would have to be quantified in a study with a different design.<sup>27</sup> We focused on parents, as they typically are the proxy decision makers and health care navigators for their children. Because we only interviewed parents of children who had surgery, we did not include parents of children who were never referred for surgery or who underwent a presurgical evaluation for surgery and were not deemed candidates or those who were offered surgery but later declined it. The extent to which children with medically refractory epilepsy are never referred to a comprehensive epilepsy center for evaluation, including potential presurgical evaluation, is unknown, but of significant concern given our observation that the journey to surgery was more arduous for many parents prior to the presurgical evaluation. Although our findings represent the parental perceptions of physician knowledge and attitudes, they do suggest that physician factors may—at least in part—mediate delays in timing presurgical referral and surgery.

Along the journey to pediatric epilepsy surgery, parents perceive a broad array of modifiable parent-, provider-, and health-system–based barriers. Multi-pronged interventions are needed to remediate delays and improve access to subspecialty care for children with medically refractory epilepsy in need of surgery given the multitude of diverse barriers identified.<sup>30</sup> The recent Institute of Medicine report, “Epilepsy Across the Spectrum: Promoting Health and Understanding” noted that “early identification of patients with persistent seizures that would lead to earlier referral” is needed.<sup>33</sup> Given the large burden of barriers and arduous journey of parents prior to presurgical evaluation, the interval from establishment of drug-resistant epilepsy until access at a pediatric epilepsy center for presurgical evaluation is a critical window for interventions that target these barriers.

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## DISCLOSURE OF CONFLICT OF INTEREST

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## SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

**Table S1.** Semistructured interview guide.