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New-onset seizure survey of epilepsy centers in the United States

Luda M. Sorin [a,*], Kelly G. Knupp [b], Anne T. Berg [c,d]

[a] Department of Pediatric Neurology, Advocate Children's Hospital – Park Ridge, 1675 Dempster St., Park Ridge, IL 60068, USA
[b] Departments of Pediatrics and Neurology, School of Medicine, University of Colorado Anschutz Medical Campus, 13123 East 16th Ave., Aurora, CO 80045, USA
[c] Epilepsy Center, Ann and Robert H. Lurie Children's Hospital of Chicago, Box 51, 225 E Chicago Ave., Chicago, IL 60611, USA
[d] Department of Pediatrics, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA

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ABSTRACT

Objectives: Children presenting with new-onset seizures have variable access to resources and may not receive timely and adequate treatment. Some may experience adverse consequences when not evaluated in a timely manner by appropriate medical providers. Consequences can be especially severe for children under the age of two and for children who have psychiatric, cognitive, and behavioral comorbidities. There are no published data on how children with new-onset seizure are evaluated and treated across the US. Our goal was to gain insight into how different epilepsy centers across the country evaluate and treat children with new-onset seizures.

Methods: We conducted a survey of Epilepsy Centers in the US that are part of the Pediatric Epilepsy Research Consortium (PERC) and focused on children presenting with new-onset seizures; PERC is a group of pediatric epilepsy providers and researchers who participate in collaborative multicenter research in pediatric epilepsy with the goal of improving outcomes in children with pediatric epilepsy. The questionnaire was developed by the authors of this study. It was designed to provide a descriptive assessment of the consistency and variability in how patients with new-onset seizure are evaluated and treated at epilepsy sites across the country. The questionnaire was designed to assure all points of interest were explored. The questions were aimed at describing access to care, how care is delivered, whether centers prioritize based on clinical presentation and/or age, and availability of resources. The survey was sent to 80 epileptologists at 42 different Epilepsy Centers that are part of PERC.

Results: Respondents included 29 pediatric epileptologists representing 24 unique centers. In the cases where there were multiple respondents from each center, response of the most senior epileptologist was used. It is possible that the senior epileptologist may have not known about the center as much as a junior epileptologist, but this was used to establish consistencies among centers with multiple respondents. Results showed that 30% of centers had a dedicated new-onset seizure clinic. The median time for children to be seen was two to four weeks, and 12% reported that it takes more than five weeks until the patient is seen. There was a trend toward centers with new-onset seizure clinic having less wait times. Most centers identified lack of adequate care based on insurance coverage, resources, long wait times, and long travel times.

Significance: Most centers (70%) do not have a dedicated new-onset seizure clinic. Children presenting with new-onset seizures often do not receive timely and comprehensive care because of limitations in resources and lack of established standard of care. Standardizing care for patients presenting with new-onset seizures has not yet occurred in the US. Many centers do not have a screening process and employ staff other than physicians or nurses for screening and triaging patients. This study shows that having a neurologist or epileptologist in charge of triaging does not reduce wait times. This survey revealed that there is substantial variability in how these patients are evaluated. Although this study shows a trend for epilepsy centers with new-onset seizure clinic having less wait times, even when there is a new-onset seizure clinic, wait times can be greater than five weeks. Overall, however, a new-onset seizure clinic may be an effective way to improve access to timely and efficient care for these patients.

1. Introduction

Epilepsy is one of the most common neurological disorders presenting in childhood [1]. Approximately 45,000 children per year receive an initial diagnosis of epilepsy in the US. [2]. Epilepsy represents a wide

* Corresponding author.
E-mail addresses: luda.sorin@advocatehealth.com (L.M. Sorin), kelly.knupp@childrenscolorado.org (K.G. Knupp), atberg@luriechildrens.org (A.T. Berg).

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spectrum of disorders each of which may require specific diagnostic, therapeutic, and management approaches. Establishing standards for evaluation and management could have an impact on long-term seizure and developmental outcomes. Because of limitations in resources, patients may not receive timely and adequate treatment. This may result in inappropriate treatment for the type of epilepsy or seizures, delayed treatment, and inadequate evaluation for underlying causes, which themselves may be treatable. This is of particular urgency for children under the age of two and for those with psychiatric, cognitive, and behavioral comorbidities [3].

Some practice parameters exist regarding the use of electroencephalography (EEG) and magnetic resonance imaging (MRI) in the evaluation and diagnosis of children with epilepsy [4]. Quality metrics, some evidence-based guidelines for treatment of, for example, infantile spasms [5] and childhood absence epilepsy also exist; however, contemporary recommendations on how children with new-onset seizures should be evaluated, treated, and managed are lacking [6,7]. We performed a survey of US-based hospitals with pediatric epilepsy programs to gain an understanding of the different approaches and models that are currently being implemented to provide care to children presenting with new-onset seizures. This information may be used to inform future studies aimed at establishing the optimal unifying approach for providing comprehensive care for these children.

2. Methods

We conducted a survey of Epilepsy Centers in the US that are part of the Pediatric Epilepsy Research Consortium (PERC). The survey was conducted from February 4, 2016 to March 16, 2016. The survey was sent to 80 epileptologists at 41 different Epilepsy Centers, and focused on children presenting with new-onset seizures. These are tertiary or quaternary centers, and patients may have been assessed before referral to these centers. The goal was to use one person per center, but in a few instances, there were two or more respondents. In those instances, we primarily relied on the senior epileptologist's responses. The questions addressed access to care and resources, how care is delivered, whether the centers prioritize based on clinical presentation and/or age, whether the centers screen for comorbidities, and limitations to care. The study also assessed whether having a specialist or other personnel triaging a patient improved quality of care. Additionally, the presence of a dedicated new-onset epilepsy clinic was assessed. The questions used multiple-choice and Likert scale formats as well as open-ended comment boxes. A copy of the survey can be found in the Appendix A section. The survey was sent out by email through a computerized survey software, Qualtrics (Qualtrics, Provo, UT), which is a secure web-based program designed to collect and analyze research data. Two reminders were sent at two- to three-week intervals.

Study data were collected and interpreted using Qualtrics software. Data were summarized by counts and proportions. Posthoc analysis included comparison of typical wait time for a patient with potential new-onset epilepsy to be seen. Subgroups addressed whether there was a specialist triaging patients, whether there was a dedicated new-onset clinic, and whether there was a standardized new-onset case evaluation approach. Statistical significance of any differences between groups was determined by Mann–Whitney tests. All tests were two-sided and a p value of less than 0.05 was considered significant. All data were processed in Microsoft Excel 2013 and analyzed using IBM SPSS version 22. IRB: AHC IRB #6136.

3. Results

3.1. Respondents and centers

3.1.1. Respondents

Respondents to the survey included 29 pediatric epileptologists representing 24 unique centers.

3.1.2. Geographic distribution

The majority of centers (70%) identified themselves as one of two or more centers in their respective cities. About 30% of the centers identified themselves as the only center in their respective region. Some centers reported serving patients from a large geographical area with one-center reporting >100-mile radius and another center reporting > 200-mile radius.

3.1.3. Facilities

All but two centers had satellite clinics in order to cover a larger radius. Most (27%) had two satellite clinics, and 23% had more than five. Satellite clinics generally did not have the same resources as the hospital-based centers. Most provided clinical care without EEG monitoring capabilities (55%). Only two centers offered continuous EEG monitoring at satellite locations. An epileptologist staffed these satellite clinics at 82% of the centers, with some overlap with pediatric neurologists (also 82%). When an epileptologist or neurologist was not available, these patients were evaluated by advanced practice providers, such as nurse practitioners or physician assistants (64%) and pediatricians (5%). Interestingly, most centers reported that there were other providers in the area who provide care to these children but less so for younger children. For example, other providers such as pediatric neurologists, pediatricians, adult neurologist, nurse practitioners, and epileptologists provided care for 92% of adolescents, 83% of school-aged children, and 75% of children under the age of 2 years. Those who answered yes to other providers providing care to children with seizures had variable responses as to who staffed these clinics.

3.1.4. Providers

The range of employed epileptologists at each center was 3–16. Aside from the epileptologists, all centers had a separate child neurology team ranging from 4 to 45 neurologists, with four centers also employing child neurologists as part of their epilepsy service. All except one center had nurse practitioners or physician assistants with the range of one to five.

The primary provider seeing patients with new-onset seizures also varied from center to center with most being an epileptologist (88%) and/or child neurologist (83%). Many centers employed advanced practice providers such as nurse practitioners or physician assistants (67%) for straight forward cases such as idiopathic generalized epilepsy or syncope.

The number of patients with new-onset seizures seen per week varied among centers with average about 38%, and did not correlate with the number of providers. This survey did not inquire as to whether new-onset seizures were differentiated from nonepileptic events, such as syncope. A significant proportion of children seen in a new-onset seizure setting are found to have nonepileptic events [8]. This is a portion of the patients typically seen in this setting; however, we did not attempt specifically to delineate treatment courses for such patients. Amount of time allowed for a new visit also varied among centers. Initial appointments were 30–60 min in 96% of centers with one center reporting an initial appointment time as less than 30 min.

3.2. New-onset seizure clinic

About 30% of centers had a designated new-onset seizure clinic. In addition 30% of facilities maintained dedicated urgent clinic appointments to accommodate new-onset seizure patients. Two facilities described that when the primary care provider called the clinic with a concern, these patients could be seen sooner (i.e., fast-tracked).

3.2.1. Referrals and triaging

Referrals for new patients came primarily from the pediatrician (50%), followed by the emergency room (29%), child neurologist (13%), and NICU/PICU (4%). Two centers commented that patients were referred either from the center's website or based on insurance.

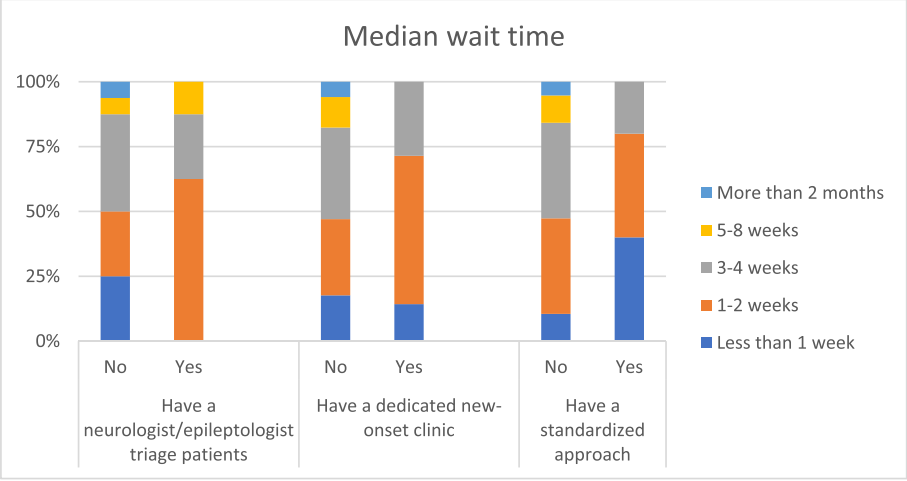

Fig. 1. Median time from when a patient with potential new-onset epilepsy is referred for an evaluation to being seen by center features.

Sites reported that between 30% and 70% of their patient population were on state-funded insurance.

About 80% of epilepsy centers had a triaging process. Patients were triaged by a designated neurologist/epileptologist/nurse/nurse practitioner (89%) vs. central scheduling (42%) that would evaluate the reported symptoms and patient characteristics and determine appropriateness for a first seizure clinic visit, hospitalization, or other course.

Having a neurologist or epileptologist triage patients vs. advanced practice providers or the contact center made no difference in wait times. There was, however, a trend for centers with new-onset seizure clinic to have shorter wait times and centers with protocols in place tended to have lower wait times.

Multiple factors were considered when triaging patients. These factors included, from most common to least common, age of child, seizure type, seizure frequency, seizure duration, hospital follow-up, whether or not the patient has access to another neurologist, and case complexity. For centers that had a screening process, information used included review of previous records (90% of centers) and requirement of EEG prior to visit for 30% of centers.

The vast majority of centers (92%) prioritized patients based on certain factors such as age and presentation. Nearly all centers (96%) prioritized patients based on epilepsy syndrome, such as infantile spasms or Doose syndrome. In most centers, patients with new-onset seizures were seen by epileptologists, child neurologists, or advanced practice providers. Less commonly, patients were seen by pediatric residents and fellows under the supervision of a child neurologist or epileptologist.

3.2.2. Metric goals

Half of all centers had certain goals established for time to initial appointment. All centers set metric goals for patients to be seen within two weeks; however, only half met this goal. The median time to initial appointment was one to four weeks. Time to an initial evaluation was more than five weeks in 12% of the centers.

3.2.2.1. Evaluations performed in the new-onset service included

3.2.2.1.1. EEG. Most of the time, the centers accepted an outside EEG but only if accompanied by a tracing that could be reviewed. Approximately 30% of centers required the EEG to be done at their center. Only a single center accepted any outside EEG regardless of quality. Most centers either required the EEG to be done at the epilepsy center or accepted an EEG from an outside institution if the tracing could be viewed.

3.2.2.1.2. Neuroimaging. Nearly all centers (92%) obtained neuroimaging in children presenting with infantile spasms. The majority of centers (61%) performed neuroimaging in children presenting under the age of 2 years vs. 45% of children ages 2–5 years and 36% of children older than 5 years. For specific diagnoses of childhood absence epilepsy or childhood epilepsy with central-temporal spikes, neuroimaging was performed in 18% for both syndromes (it is not clear if these were atypical cases as these syndromes typically do not require imaging), and 39% in other epilepsies. Neuroimaging was obtained in 48% of children who also presented with developmental delay.

3.2.2.1.3. Standardized protocols. Most centers (79%) did not have a protocol for new-onset seizure evaluations. This was regardless of the presence of a new-onset seizure clinic. An example of those with a standardized protocol included scheduling an EEG followed by an appointment in clinic. One center reported that these patients were seen in first seizure clinic where a determination was made whether the patient needed an EEG or other work-up. One center reported standardized questions in new-onset seizure clinic but not in other clinics.

3.2.2.1.4. Genetic/metabolic testing. Centers had variable requirements for genetic and metabolic testing based on age, presentation, family history, and exam findings. Nearly all centers obtained metabolic and genetic studies on patients under the age of 2 years.

Other guidelines for genetic and metabolic testing in patients with new-onset seizures were implemented in 21% of centers and varied according to patients, seen inpatient vs. outpatient. There were other influences on genetic testing that were mentioned including patient's insurance and whether the family was out of state. One center commented that while epilepsy-specific genetic testing is highly desirable, it is nearly impossible to perform with state-funded insurance.

3.2.2.1.5. Screening for comorbidities. Most centers routinely screened for developmental, cognitive, psychiatric, and behavioral comorbidities in children evaluated for new-onset seizures. This was done in 68–100% of cases for preschool-aged children and in 74–95% of school-aged children. All but two centers used questionnaires to screen for comorbidities, and the other two centers referred to neuropsychological testing. All centers screened for developmental delay and autism spectrum disorder in preschool-aged children. Although there was variation among centers in formal screening, each physician typically did this on an individual basis. Two centers commented that they did not screen routinely, but based on suspected comorbidities, screened for anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), learning disabilities, or sleep disorders with review of systems or in history of present illness.

Some epilepsy centers utilized standardized assessments to screen for comorbidities, most common being the Vanderbilt (33%) to screen for ADHD (psychology-tools.com/vadrs-vanderbilt-adhd-diagnostic-rating-scale), mCHAT (29%) to screen for autism (www.mchatscreen.com), and Denver Developmental Scale (25%) to screen for developmental delays (https://denverii.com/denver-ii-test-

New-Onset Seizure Survey

Dear Colleagues,

We are trying to learn how children with newly presenting seizures or new-onset epilepsy are evaluated and treated at pediatric epilepsy centers in the US. This survey is being conducted with member centers of the Pediatric Epilepsy Consortium. From this survey we hope to learn about the models of care used for potential new-onset epilepsy, novel approaches and solutions, and also barriers to care.

Please tell us a little about your center first:

1. Is your center (please check all that apply):

One of two or more centers in your city that provides epilepsy care to children?

The only center in the city that provides epilepsy care to children?

The only center for my city and a larger region including other towns and cities or rural areas?

The only center in my state?

The only center in my state and the primary or only source of pediatric epilepsy care for other states?

2. Are there other providers in private practices or clinics in your area who provide care for children with epilepsy in the following age groups?

Less than 2 years old: *Yes/No/Don't know*

School aged children: *Yes/No/Don't know*

Adolescents: *Yes/No/Don't know*

form-english). Other scales included the Vineland Adaptive Behavior Scale, Ironton for ages <5 years, and neuropsychological testing (in two centers). Two centers referred patients to a psychologist or developmental pediatrician for any concerns; however, this could entail long wait times and difficulties with insurance coverage. One center commented that screening was not standardized and dependent on the provider.

3.2.2.1.6. Follow-up care. Patients seen for initial evaluation of new-onset seizures were typically followed at the Epilepsy Center, and 30% were seen elsewhere, with some overlap. The response was the same for preschool- and school-aged children. Some centers commented that children had to follow up in the epilepsy clinic as there were no alternative providers in the area.

4. Discussion

Overall, our data indicate that there is great variation in the approach to newly presenting seizures across the country. Less than one-third had a new-onset seizure clinic. We note, however, that all centers prioritized patients with infantile spasms, Doose syndrome, or patients presenting with frequent seizures, especially with accompanied psychiatric symptoms. Sites varied in terms of having a new-onset seizure clinic, types of resources offered at satellite clinics, metabolic/genetic testing, time to see a provider, and screening for comorbidities. It is also uncommon that patients with new-onset seizures were seen by residents or fellows, who raise concern that they are not receiving the exposure that they need to manage such patients in the outpatient setting.

Our survey suggests that having a specific clinic or plan for children with new-onset seizures may reduce wait times; however, even with a clinic in place, the wait times were often more than one month (Fig. 1). Limitations in resources means that some children presenting with new-onset seizures may not receive timely or appropriate treatment. This may mean living with the effects of ongoing seizures, including the potential risk of status epilepticus, side effects from unnecessary inappropriate medications, and delayed identification of underlying etiologies, which may themselves be amenable to treatment or might better guide therapies.

Most centers have a triaging process, allow 30–60 min for initial appointment, see patients on state-funded insurance, and require MRI and EEG testing especially for children under the age of 2 years and those with infantile spasms. Although most centers did not have a standardized approach, most had protocols for infantile spasms and children presenting under the age of 2 years. In the absence of clear guidelines, consistencies in care may be used to initiate commonly accepted guidelines for management of new-onset seizures.

Most centers identified limitations based on insurance coverage, long wait times, and long travel times. Even for patients who have insurance, certain testing such as genetic testing may not be covered. It may be hard to avoid long travel times; as in some regions, there is no local pediatric neurologist or epileptologist. Having a neurologist or epileptologist, triage patients made no difference on wait time. Some of the less complicated cases may not need to be followed at the Epilepsy Center, which may open up more appointment slots and decrease wait times.

Screening for developmental delays and Autism Spectrum Disorder in the very young and screening for behavioral issues in older children are part of the standard public health guidelines recommended by American Academy of Neurology and enforced by American Epilepsy Society [6,7]. Given that children with epilepsy are at higher risk for these conditions, it would be appropriate to include screening in patients presenting with new-onset seizures. Our survey found that while most centers routinely screen for psychiatric and cognitive comorbidities, some do not do this routinely. This may be an area of improvement.

In summary, standardizing care for patients presenting with new-onset seizures has not yet occurred in the US. Our survey highlights the good adherence to the few relevant existing guidelines (EEG and MRI) [4] as well as screening for common cognitive and behavioral problems. In areas where no such guidelines exist, especially time to initial appointment, there is considerable variability. This high variability in standard of care warrants further investigation with future studies. As a field, we need to develop evidence-based and consensus recommendations for establishing a uniform standard of care for children presenting with new-onset seizures.

5. Limitations

There are some limitations to this study. Respondents included 29 pediatric epileptologists representing 24 unique centers, which is not enough to draw statistically relevant conclusions. Only tertiary centers that are part of PERC participated in the survey. This likely represents the best available in the country. It is unlikely that other centers are doing better (at least overall). Also, surveys about centers are not the same as patient registries. More precise data about wait times and proportions of patients require different methods with collection of individual patient data. We do not know what new-onset seizure services look like in hospitals that are not PERC affiliated or in community practices. Our study only addressed physician and center perspective on management of new-onset seizures. Parent and patient perspective were not attained in this project, but in future work should be considered. Therefore a qualitative study may be helpful in the future.

Declaration of competing interest

None of the authors has any conflict of interest to disclose. All coauthors have been substantively involved in the study and/or the preparation of the manuscript. No undisclosed groups or persons have had a primary role in the study and/or in manuscript preparation. All coauthors have seen and approved the submitted version of the paper and accept responsibility for its content.

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The work described is consistent with the journal's guidelines for ethical publication.

Appendix A. New-onset seizure survey

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