

Priorities in pediatric epilepsy research

Improving children's futures today

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ABSTRACT

The Priorities in Pediatric Epilepsy Research workshop was held in the spirit of patient-centered and patient-driven mandates for developing best practices in care, particularly for epilepsy beginning under age 3 years. The workshop brought together parents, representatives of voluntary advocacy organizations, physicians, allied health professionals, researchers, and administrators to identify priority areas for pediatric epilepsy care and research including implementation and testing of interventions designed to improve care processes and outcomes. Priorities highlighted were 1) patient outcomes, especially seizure control but also behavioral, academic, and social functioning; 2) early and accurate diagnosis and optimal treatment; 3) role and involvement of parents (communication and shared decision-making); and 4) integration of school and community organizations with epilepsy care delivery. Key factors influencing pediatric epilepsy care included the child's impairments and seizure presentation, parents, providers, the health care system, and community systems. Care was represented as a sequential process from initial onset of seizures to referral for comprehensive evaluation when needed. We considered an alternative model in which comprehensive care would be utilized from onset, proactively, rather than reactively after pharmacoresistance became obvious. Barriers, including limited levels of evidence about many aspects of diagnosis and management, access to care—particularly epilepsy specialty and behavioral health care—and implementation, were identified. Progress hinges on coordinated research efforts that systematically address gaps in knowledge and overcoming barriers to access and implementation. The stakes are considerable, and the potential benefits for reduced burden of refractory epilepsy and lifelong disabilities may be enormous. *Neurology*® 2013;81:1166-1175

GLOSSARY

NAEC = National Association of Epilepsy Centers.

Epilepsy affects as many as 1 in 26 people.¹ Up to one-tenth of the lifetime risk of epilepsy is realized in the first 3 years of life.²⁻⁴ In contrast to the majority of epilepsies occurring in older children and adults, early-onset epilepsies represent numerous, distinct, and rare disorders; many are devastating and associated with severe lifelong disability, dependence, and significant economic and personal costs.⁵⁻⁷ Currently there is little to guide specific practice in diagnosing and treating these epilepsies. Relatively little is known that can improve long-term outcomes. The “Priorities in Pediatric Epilepsy Research: Improving Children's Futures Today” workshop (October 23–24, 2012, Ann & Robert H. Lurie Children's Hospital of Chicago) brought together parents of children with epilepsy, voluntary advocacy organizations, pharmaceutical industry representatives, health services, clinical, and translational science researchers, educators, adult and pediatric neurologists and epileptologists, nurses, and neuropsychologists to address needs in pediatric epilepsy research and care. A goal of the meeting was to identify the greatest problems and current gaps in knowledge and practice—areas that could become the focus of targeted research efforts to improve practice and patient outcomes. The discussion focused on

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patient-centered issues (barriers to care, parents' needs for information and support), parental perspectives on the highest priorities in care, how to overcome barriers, and utilization of current knowledge and resources to optimize care and outcomes. All workshop participants were invited to read and provide input on the workshop summary report.

WORKSHOP THEMES The concerns and questions raised during the meeting were grouped into 4 driving themes as outlined below.

Patient outcomes. *The single most important outcome for parents of children with epilepsy is seizure freedom.* Seizure control is paramount for the following main reasons:

1. The possibility of irreversible deleterious impact of seizures, particularly early in life, on the child's development, which can result in lifelong disability and dependency.
2. The disruption that seizures cause in the lives of both the child and the family. This can result from the seizures themselves, postictal periods, and associated health care and treatment (e.g., emergency department visits, hospitalizations, and medication burden). Side effects of medications were also of concern as complete seizure freedom cannot come at the price of unacceptable medication effects.
3. The risk of medical complications from seizures, including injury and death: seizure control reduces the risk of seizure-related death including sudden unexpected death in epilepsy and related injury and disability from seizures.

Early seizure control without significant side effects was viewed as necessary, although not always sufficient, to optimize behavioral, cognitive, and social outcomes.

Diagnosis. To achieve the primary goal of early seizure control, the overarching priority identified was early, accurate diagnosis not only of epilepsy, per se, but also of specific forms of epilepsy, seizure types, and underlying causes. This was considered the top priority because of its relevance in selecting the most appropriate treatment for each individual child.

Role of parents and impact on families. The parent is the critical link between the child (patient), the physician, the medical care system, and the services beyond the care system such as insurance companies, voluntary organizations, and parent and patient support/advocacy groups. From the first contact with the medical care system, engagement of the parents in the care process and the information conveyed to the parents as well as when, how, and by whom it is conveyed were identified as key components of the family's interaction with the care system. Issues raised included poor

communication about the diagnosis of epilepsy and different seizure types. Some therapies for epilepsy can be invasive (surgery), time-demanding and complicated (ketogenic diet), or relatively new (immunomodulatory). Inadequate information and communication about options and how to make the best decision for a child were seen as significant impediments to care. Furthermore, with information easily available through the internet, parents often do their own research and bring keen insights into their child's disorder to the attention of the physician. Physicians need to consider this information.

Resources outside the medical system. Voluntary and community agencies and services such as the birth-to-three and special education systems provide information and additional services including early educational and other therapeutic interventions (e.g., speech therapy).⁸ Although parents are typically the primary caretakers, daycare and school personnel spend considerable time with children. They need to be aware of the child's epilepsy, what the seizures look like, the impact that seizures and medications have on behavior and function, and any chronic and emergency treatment plans. They also have an important role in assessing whether seizures are controlled and whether developmental or behavioral difficulties emerge or worsen.

STAKEHOLDERS AND FACTORS IN THE DIAGNOSTIC AND TREATMENT PROCESS Many different factors have input into the process of pediatric epilepsy care and play different roles at different points in the process (table 1).

The child and seizure presentation. Subtle seizures are often not recognized initially and may persist for months or years before being diagnosed.^{9,10} Seizures are also underrecognized in children who are developmentally impaired¹¹ although overdiagnosed in children with autism.¹²

Parent and family. Parental factors include socioeconomic status, race, education, health literacy, language, and cultural beliefs. All of these can influence the understanding of illness and interaction with the medical system.¹³⁻¹⁷

Medical care providers. Providers' training, knowledge, attitudes toward race/ethnicity, skills in communication and shared decision-making, cultural competence, and subtle biases can affect health care utilization and contribute to delayed or unmet access to care.^{18,19} Willingness to refer complicated patients for advanced diagnostic and specialized care may mean loss of practice revenue. Recent trends in epilepsy surgical evaluations raise this concern.²⁰ The model of physician-directed care is changing to one in which the physician is part of a health care team that collaborates with the family to

Table 1 Examples of inputs from stakeholders on different factors influencing diagnosis and care

Child and family factors
We thought our child was just playing (reason for delay in seeking medical attention).
My father saw my son having these staring spells and said they could be seizures. He knows because he has the same kind of seizures (reason that prompted parent to seek care).
Provider influences
Our pediatrician saw our child having spasms in the office and ordered an EEG that day. We had an appointment with a neurologist a few days later.
Our pediatrician said our infant's whole-body crunches were normal baby movements.
Absence epilepsy was misdiagnosed as focal seizures and treated for years with drugs that exacerbated absence seizures with resulting cognitive impairment in young adulthood.
It took 3 years before I heard the word "epilepsy" used for my child's condition, and only after I got the medical records and read the word for myself.
I showed my child's neurologist an article I found on GLUT1 deficiency syndrome. She said my child couldn't have that because he was not severe enough and besides, the CSF glucose had come back normal. The CSF glucose had never been reported back by the lab. It took some years longer before he was tested and we got the correct diagnosis. He has suffered cognitive consequences attributed to ongoing seizures and untreated GLUT1 deficiency syndrome during the delay to diagnosis. Seizures are now controlled with ketogenic diet.
When I told the nurse that we thought our child might have MAE (myoclonic-atonic epilepsy), she said that was impossible, our child would be a "vegetable" if she had that.
Health care system and resources
A developmentally delayed child without seizures was referred to a genetics program for evaluation of delay. During the evaluation process, the child developed myoclonic jerks noted in the chart by Genetics, but no referral was made back to the neurologist for further evaluation.
We have no one to whom to refer a child with developmental delay or autism.
Drug XYZ is only approved for Lennox-Gastaut syndrome, not for Dravet (insurance company denying a specific medication).
Community resources
The school teachers arranged to keep our child in a cooler environment and use a cooling vest (to avoid heat-triggered seizures).

While these are actual incidents, the frequency with which any of them, desirable or otherwise, occurs is unknown. Most examples reflect input from more than one factor.

arrive at the best individualized decision and helps the family navigate the health care system and care choices.²¹

Health care system. Limited geographic availability of specialty care, financial barriers, waiting times for insurance approval, and appointment availability are ubiquitous throughout health care. All pose obstacles to timely, appropriate care for children with epilepsy.²² Uncoordinated care across primary and specialty providers further impedes the goal of early diagnosis and optimized treatment.²³

Community resources. School systems and voluntary organizations are essential in extending and implementing the care and recommendations of physicians and providing additional services. Parents also need support,⁸ which can sometimes be provided through community organizations.²⁴

PROCESS OF DIAGNOSIS AND TREATMENT We conceptualized this process as a series of steps from initial seizure to achieving optimal outcomes. Inputs to the system have different degrees of influence at each stage (figure 1).

Steps 1–3: From seizure onset to first medical contact. Occurrence of a seizure, recognition of the event by a caregiver, and the subsequent decision to obtain medical attention (figure 1) occur before medical system involvement unless the child is already hospitalized

(e.g., in the neonatal intensive care unit) when seizures first occur. Epidemiologic evidence demonstrates that relatively subtle seizure types may go undetected for long periods of time, even years.⁹ A quarter (27%) of children with infantile spasms were not brought to their physician for >2 months in one study.¹⁰ Longer delays to initial diagnosis were associated with poorer developmental outcomes in early childhood.

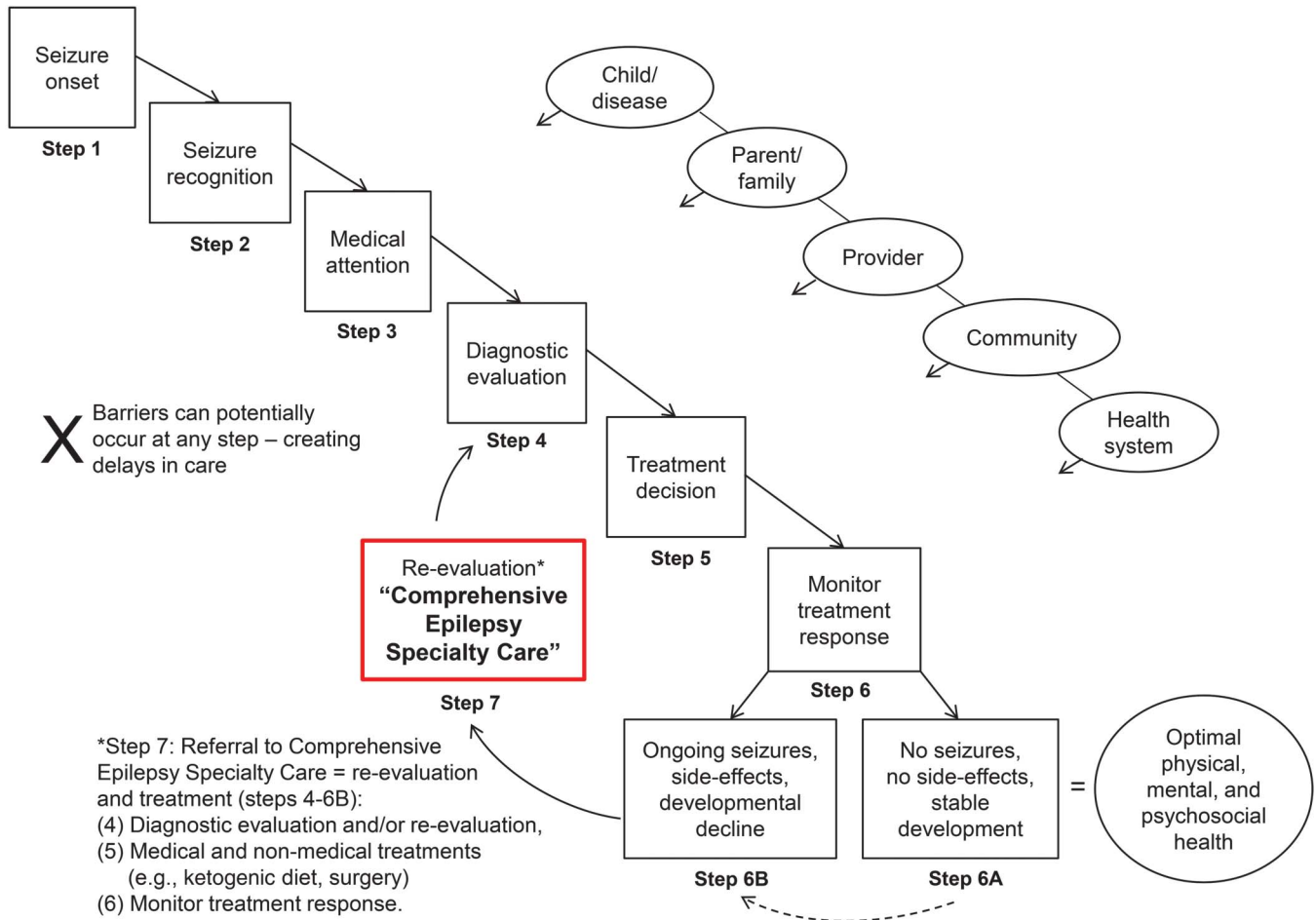
Step 4: Diagnosis of epilepsy. Once a child is brought to medical attention, the diagnostic process involves 2 interconnected stages,²⁵ as discussed below.

Recognition that a child has epileptic seizures. Over- and underrecognition of seizures and epilepsy can occur. Both errors carry consequences. In the first instance, children with nonepileptic events are mistakenly diagnosed as having epilepsy^{26–29} and may be treated while the true underlying condition is not addressed. In the second case, the epilepsy diagnosis is missed. Seizures (and sometimes treatable causes) are untreated.¹¹

Diagnosis of the specific seizure type(s), epilepsy, and underlying cause. Although the first contact medical provider may not be qualified to perform a full epilepsy evaluation, that provider must be able to recognize possible seizures and seizure mimics and then seek the necessary expertise and capabilities for rapid, accurate diagnosis.

Step 5: Epilepsy treatment selection. Ideally, treatment selection should be guided by seizure types, epilepsy

Figure 1 Current disease/care continuum of pediatric epilepsy



The typical sequence of steps taken from onset of seizures (step 1) to achieving optimal care of epilepsy (step 6A) in which specialty-comprehensive care is not sought until and unless difficulties occur (step 6B). Even when difficulties occur (failure to control seizures or developmental declines), referral to comprehensive care may not be sought immediately as physicians attempt to find a better treatment. The distinction between standard neurologic care and specialty care is also not clearly defined; there may be overlap and interactions between the two.

syndrome, cause, or all of these. For example, evidence regarding infantile spasms is sufficient for guidelines targeted at both physicians and parents.^{30–33} Most early-onset epilepsies, however, are individually rare, thus precluding the feasibility of robust randomized clinical trials needed to develop such guidelines. Recent treatment recommendations concluded that rigorous evidence-based guidelines for selecting treatments based on syndromes were not possible at this time.³⁴

Step 6: Evaluation and monitoring of epilepsy treatment response. Parents have an essential role in assessing the effect of treatment. Close collaboration among care providers, parents, and others is needed to monitor seizure occurrence, medication adherence, and side effects.

Successful seizure control. Children with fully controlled seizures and no side effects may need no intervention beyond the care they are already receiving. Often, the epilepsy appears to resolve and remit permanently, and medications can be stopped. Behavioral,

cognitive, and social concerns must still be addressed because these may be present and persist regardless of complete seizure control.

Pharmacoresistant seizures. This determination must be considered in 2 parts³⁵:

1. Deciding that a drug has truly failed to control a patient's seizures assumes knowledge of how to use and assess medications including when to increase doses and when to recognize that seizures have not responded adequately.
2. Deciding that sufficient medications have been unsuccessfully tried and that the next phase of diagnostic evaluations and other therapies should be considered.

There is no single definition of pharmacoresistance. A recent proposal suggested failure of 2 appropriate medications used in informative trials.³⁵ The National Association of Epilepsy Centers (NAEC) recommends referral for specialty care if seizures are

not controlled within a year.³⁶ The National Institute for Health and Care Excellence guideline recommends referral after 2 years of uncontrolled seizures.³⁷

Step 7: Referral to comprehensive care. At the comprehensive care level, results of some earlier tests are reviewed, some tests are repeated, and others done for the first time. The diagnosis, beginning with whether a patient has epilepsy, the type of epilepsy and seizures, and the underlying cause are all reconsidered in an effort to arrive at a more precise diagnosis of all of these and identify the most appropriate treatment options. Even for patients diagnosed and treated since onset at a comprehensive center, recognition of pharmacoresistance should trigger reconsideration of the diagnosis and treatment. In reality, however, comprehensive epilepsy care is not well defined and definitions and expectations likely vary considerably across centers, individual providers, and parents. How comprehensive care interacts with, repeats, and enhances standard neurologic care vs replaces it is not well understood. In addition, the timing of referral and seeking of comprehensive care is highly variable with such care often considered as a last resort or at least after a substantial and unnecessarily long delay.

PATIENT-EXPRESSED PRIORITIES VS THE STANDARD APPROACH: DO WE NEED A NEW MODEL? This 7-step model is typical of epilepsy care in the United States and is reflected in the NAEC recommendations.³⁶ There is inherent tension between this model and the priorities of parents whose children have early-onset epilepsy. Waiting until pharmacoresistance is evident to make a specialty referral seems counterproductive, especially when wasted time may result in lost opportunity to prevent severe, lifelong consequences. It is also inefficient for society and for insurers if upfront savings result in long-term costs. There is typically little emphasis on comorbidities (who should screen for them, when and how often), who provides services, school involvement, or parent engagement, all key issues identified by parents and clinicians alike.

A model was proposed in which specialty care, rather than a reactive measure, could be implemented at onset proactively (figure 2), particularly for children younger than 3 years. Such a model would entail a systematic process in which pediatric epileptologists and other specialists optimally utilize available imaging, genetic, metabolic, and other diagnostic technologies to maximize the chance of obtaining a specific diagnosis for the causes and the epilepsy. They would then use optimal medication strategies and consider more advanced therapies including the ketogenic diet, surgery, and immunomodulatory agents right from the start.^{38,39} Depending on the child's clinical condition, management might be referred back to a less-specialized, perhaps local, provider with specialists serving in a

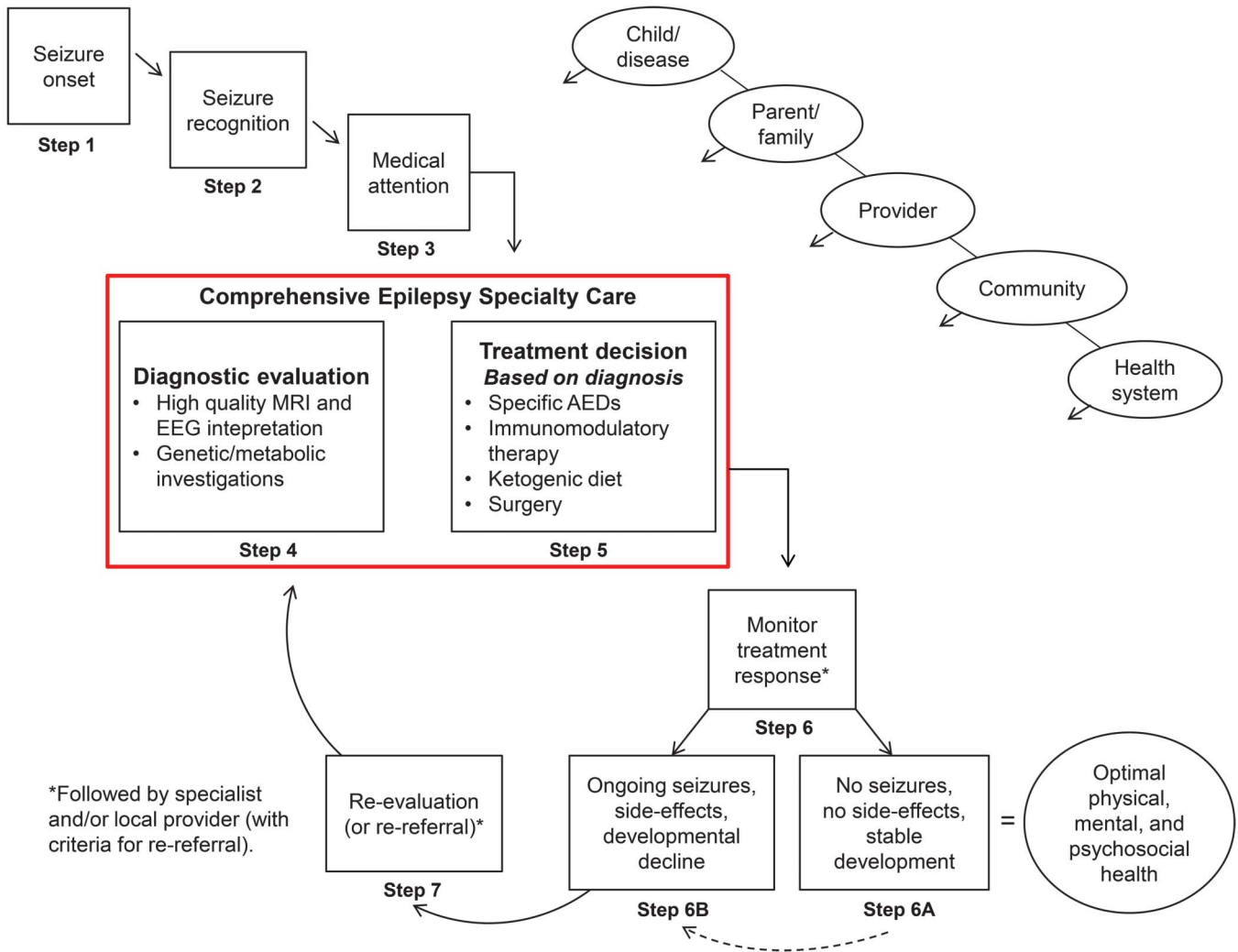
consultative mode. Alternatively, some children may be kept in specialty care for longer periods of time. This was proposed as part of a triaging system for epilepsy care in general⁴⁰ and is partially reflected in the National Institute for Health and Care Excellence guidelines.^{37,41}

KNOWLEDGE GAPS Several examples were discussed in which specialty-first care might have avoided years of uncontrolled seizures and developmental disability (see table 1) and provide compelling reasons for a specialty-first model for early-onset epilepsy. Implementing such a model could be resource-intensive. Two large considerations must first be addressed.

Accurate early diagnosis and “optimal” treatment: Impact on outcomes. There are few data regarding the relative yield of specific diagnoses (brain lesions, metabolic disorders, genetic disorders) in children with newly presenting early-onset epilepsy. Epidemiologic data are out of date and do not reflect the use of advanced neuroimaging, genetic testing, immunologic assays, or high-quality EEG. While there are guidelines recommending the use of EEG⁴² and neuroimaging⁴³ for evaluating children with epilepsy, details of how these tests should be performed are sometimes lacking. For MRI, guidelines specify a 1.5-tesla MRI with age-appropriate seizure protocol⁴³ whereas 3-tesla is rapidly becoming the standard in epilepsy evaluations.⁴⁴ EEG is important, but there are different protocols, not addressed by guidelines, for how EEG can be performed. Perhaps most important today is genetic testing. There is no information about the use of genetic testing in patients with new-onset epilepsy and no guidelines regarding use of metabolic and genetic testing or testing for inflammatory markers. There is little information about how these testing modalities are currently used and their impact on patient care and outcome. A set of performance indicators proposed for pediatric epilepsy care did not even mention genetic testing.⁴⁵

The impact of the diagnosis on the selection of treatment and on patient outcomes has not been studied in the modern context. US guidelines exist for infantile spasms,^{30,31} but not for other common early-onset epilepsies. Most experts would likely agree on the value of the ketogenic diet for GLUT1 deficiency syndrome.⁴⁶ Specific treatments for Dravet syndrome, however, while discussed in opinion pieces, do not have a general consensus. A systematic review of treatment for Lennox-Gastaut syndrome concluded that there was inadequate data for strong recommendations.⁴⁷ This lack of definitive evidence is understandable as early-onset epilepsies comprise numerous rare conditions, and there are 30 or more medications available for use. The typical evidence standard of head-to-head randomized clinical trials has generally been unobtainable given the rarity of each of the many

Figure 2 Comprehensive epilepsy specialty care first



An alternative model to pediatric epilepsy care in which specialty-comprehensive care is sought right from the outset to optimize patient care and outcomes. Children, particularly the very young, receive a full diagnostic evaluation. Disorders that can be identified and that have specific treatment implications are diagnosed and appropriately treated. More intensive treatments (surgery and diet) are considered early in the course of the epilepsy. AEDs = antiepileptic drugs.

conditions and the large number of available treatments. Consequently, individual providers vary considerably in their practices, and insurers may not always provide access to the expensive diagnostic and therapeutic modalities. The treatment of early-onset epilepsy is, in many regards, an evidence-free practice zone. The schism between hard evidence and the strongly expressed opinion that diagnosis should matter represents an opportunity for research and new methods.⁴⁸

Despite the lack of formal guidelines, the value of accurate early diagnosis and treatment can be appreciated in a few reports. In one study, both parents and providers reported substantial benefits of *SCN1A* gene testing in children with suspected Dravet syndrome. Benefits included changing treatment, better seizure control, and, if done early, better developmental outcomes.⁴⁹ A preliminary report examined the impact of

early diagnosis and optimal treatment in children with Doose syndrome.⁵⁰ Children who initially received certain drugs that experts “feel” are contraindicated for this form of epilepsy did substantially worse in terms of seizure control and development than did children who initially received more optimal treatments. These studies only scratch the surface of the many issues that must be adequately addressed in order to influence practice.

An important role of a comprehensive epilepsy program is to provide nonpharmacologic treatments. Dietary and surgical therapies are key alternatives to traditional pharmacotherapy. They are more difficult either because of the time-intensiveness (ketogenic diet) or the inherent invasiveness (surgery). Optimal use of such therapies requires a team approach and considerable support and expertise that generally

can only be provided at a comprehensive center. Notably, these therapies, because of their complexities, are utilized and administered very differently depending on the center; the therapy, as a “package,” is potentially quite different from one center to another. Immunomodulatory therapies are receiving increased attention although there is still much that is not known about when to use them, in whom, and the likely impact. Most studies represent series from individual centers, thereby limiting their value for assisting individuals in making informed decisions for their children. Limited knowledge about effectiveness of these therapies in specific clinical situations adds to the difficulty in developing a solid evidence base for individual decision-making.

Comprehensive/specialty epilepsy care. Although there was general enthusiasm for the idea of comprehensive or specialty care, there is no single definition of what that constitutes. The NAEC has standards for level 3 and 4 epilepsy centers, which emphasize surgical therapy.³⁶ Little is discussed regarding other therapies (diet, immunomodulatory), the collaborative team environment, or the speed with which diagnosis and interventions must occur. For young children, comprehensive care encompasses diagnostic and therapeutic resources and expertise, but also evaluation, referral, and intervention beyond seizures themselves. It requires a *multidisciplinary, collaborative, and coordinated* approach. Pediatric epileptologists attending the meeting outlined their own multidisciplinary comprehensive epilepsy programs; all involved a range of specialties including social work, psychiatry, neuropsychology, educational liaisons, nursing staff, advanced practice nurses, ketogenic dieticians, pharmacologists, genetic counselors, neurosurgeons, neuroimaging and nuclear medicine specialists, as well as hospital and community-based parent support groups, schools, and others. Although the models varied, each involved a systematic, coordinated approach and was likely influenced by resources available at each center as well as personal characteristics of the providers.

The role of and the impact on parents is rarely a major focus in “comprehensive” pediatric care. There was great enthusiasm for approaches to create better communication and information for parents and involve parents more explicitly as part of the decision-making and treatment team. There was also no information regarding how best to do this, what the actual impact is, and whether there are different approaches that would be more beneficial to different parents as a function of cultural, linguistic, and socioeconomic characteristics, or individual preference.

CHALLENGES TO PROGRESS Evidence. Without good evidence demonstrating the value to patient care and outcomes, it is arguably unjustifiable to

recommend time- and resource-intensive care approaches. Overcoming these limitations requires systematic assessment of the value of various diagnostic modalities and treatments, overall and in specific clinical situations, to provide the necessary information to all parties to make informed decisions and develop responsible policies. Questions were generated during discussions that could guide research to improve aspects of pediatric epilepsy care (table 2).

Barriers and access. Comprehensive care is also not readily available to large segments of the population because of geographic or economic access. A staged approach that prioritizes certain types of patients may need consideration. Other factors such as attitudes and personal preferences of both the parents and providers may influence the decision to seek specialty evaluation and care. Information needs to be communicated effectively to the parent to permit shared decision-making.

Implementation. Even strong evidence and well-supported guidelines do not always influence practice.⁵¹ Basic quality indicators for adult epilepsy care were recently published in a major journal,⁵² but they have not been fully adopted, especially by nonepileptologists to whom they were particularly targeted.^{53,54} A guideline on surgery for refractory temporal lobe epilepsy⁵⁵ did not appear to alter referral practices 7 years after publication.^{20,56} A recent survey regarding treatment for infantile spasms reported many respondents using non-first line treatments as initial therapies.⁵⁷ Reasons for and the impact of this variation on patient outcomes are unknown, but there is extensive literature on the role of implementation science in linking evidence to improved population outcomes.⁵⁸

CONCLUSIONS Early-onset pediatric epilepsy is a high-stakes condition. Early seizure control is of supreme importance to parents and is an overriding goal for clinicians. While early seizure control is a goal in itself, it also contributes to achieving other critical goals such as better cognitive and behavioral outcomes and decreased mortality. Ultimately, research must provide evidence that directly contributes to changes in care delivery and results in measurable improvements in patient outcomes. Collaboration of all concerned parties including clinical and health services researchers, parents, providers, other allied health professionals, insurers, administrators, health economists, and policy-makers is therefore needed and is consistent with recent announcements from the Patient-Centered Outcomes Research Institute.^{59,60} The priorities identified in the workshop are also highly consistent with the recommendations in the recent Institute of Medicine report.¹ Pediatric epilepsy care is an ideal candidate area for this type of endeavor because there is

Table 2 Examples of questions generated during the workshop deliberations regarding the steps in care and the interactions among different participants in the care process; answers to these questions could support changes in how care is delivered

Before the child's initial contact with the medical system
How long does it take for children to come to medical attention for seizures?
What are the reasons for delays in seeking care, and are there opportunities to shorten that delay?
Evaluation and diagnosis
Are current imaging guidelines followed?
Who interprets the EEG?
In what proportion of children is an accurate, specific diagnosis made and how does that vary based on the provider's training and experience?
Treatments and treatment decisions
What information do parents need and want in order to make the best decisions for their child about the use of the diet or surgery?
In what proportion of children are there no specific guidelines to aid in treatment selection?
When should the ketogenic diet or surgery be considered according to parents? Providers? Insurers?
Interaction with parents and members of the medical care system
What information are parents initially given about their child's diagnosis, by whom, and in what form?
What information are parents given about potential cognitive and behavioral difficulties their child may encounter?
What information are they given about the risks of seizures, including seizure-related death and SUDEP in particular?
Do parents receive adequate information and support to understand and adhere to treatment recommendations? What informational/educational measures could be taken to improve parents' effectiveness in participating in the child's care?
Are parents given a treatment plan and an understanding of how treatment success will be assessed and treatments changed if necessary?
Outcomes
What do parents and providers understand about the seriousness of seizures and the need to control them as soon as possible?
In difficult-to-control epilepsy, do providers and parents develop treatment goals together to achieve better if not perfect seizure outcomes?
Comprehensive care
What are the respective roles of the pediatric neurologist, pediatrician, and educators in addressing the cognitive or behavioral difficulties of a child with epilepsy?
How often do neurologic care providers screen for delays and autism or other behavioral problems?
Barriers and delays
How quickly are children with poorly controlled seizures referred for comprehensive evaluation? How quickly should they be referred and seen?
What factors (child, parent, provider, system) influence delays?

Abbreviation: SUDEP = sudden unexpected death in epilepsy.

much at stake and much that could be done, but so little, currently, to guide improvements.

CONTRIBUTORS

In addition to the authors, the following individuals spoke at and (or) participated in the discussions during the workshop. Their contributions form the basis for the workshop summary. Susan Axelrod (Citizens United for Research in Epilepsy, speaker and participant), Brent Allen (Chicago, participant), Terry Biagi, MD (New York, participant), Bogdan Ewendt (Citizens United for Research in Epilepsy, participant), Tracy Dixon-Salazar, PhD (University of California San Diego, speaker and participant), Leon Epstein, MD (Ann & Robert H. Lurie Children's Hospital of Chicago, speaker and participant), Kathy Evans (Glut1 Deficiency Foundation, participant), William Gaillard, MD (National Children's Medical Center, speaker and participant), Phillip Gattone, MEd (Epilepsy Foundation, speaker and participant), Alicia Goldman, MD (Baylor School of Medicine, speaker and participant), Lisa Gorschels, MA (DeKalb School District, Special Education Coordinator, speaker and participant), Lorie Hamivka, MD (Nationwide Children's Hospital, speaker and participant), Jouku Isojarvi, MD, PhD (Lundbeck LLC, participant), Sucheta Joshi, MD, MS (University of Michigan, participant), Christine Karam, PharmD (Questcor Pharmaceuticals, participant), Warren Kibbe, PhD (Northwestern University, participant), Sookyoung Koh, MD, PhD (Ann & Robert H. Lurie Children's Hospital

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AUTHOR CONTRIBUTIONS

Dr. Berg drafted the original manuscript and participated in revising the manuscript and producing the final draft. Dr. Baca, Dr. Lodenkemper, Dr. Vickrey, and Dr. Dlugos participated in critical review and revision of the manuscript and in producing the final draft.

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