

Guidelines for Specialized Epilepsy Centers

Executive Summary of the Report of the National Association of Epilepsy Centers Guideline Panel

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Abstract

The National Association of Epilepsy Centers first published the guidelines for epilepsy centers in 1990, which were last updated in 2010. Since that update, epilepsy care and the science of guideline development have advanced significantly, including the importance of incorporating a diversity of stakeholder perspectives such as those of patients and their caregivers. Currently, despite extensive published data examining the efficacy of treatments and diagnostic testing for epilepsy, there remain significant gaps in data identifying the essential services needed for a comprehensive epilepsy center and the optimal manner for their delivery. The trustworthy consensus-based statements (TCBS) process produces unbiased, scientifically valid guidelines through a transparent process that incorporates available evidence and expert opinion. A systematic literature search returned 5937 relevant studies from which 197 articles were retained for data extraction. A panel of 41 stakeholders with diverse expertise evaluated this evidence and drafted recommendations following the TCBS process. The panel reached consensus on 52 recommendations covering services provided by specialized epilepsy centers in both the inpatient and outpatient settings in major topic areas including epilepsy monitoring unit care, surgery, neuroimaging, neuropsychology, genetics, and outpatient care. Recommendations were informed by the evidence review and reflect the consensus of a broad panel of expert opinions.

Introduction and Background

Epilepsy is one of the most common chronic neurologic conditions worldwide, with an estimated prevalence of 3.4 million persons in the United States.¹ Epilepsy is associated with increased morbidity and mortality, decreased quality of life, and far-reaching socioeconomic implications.² These risks are further elevated for approximately 30% of patients with epilepsy who have refractory seizures despite treatment with antiseizure medications (ASMs), categorized as drug-resistant epilepsy (DRE).³ As such, national and international professional

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Glossary

ASM = antiseizure medication; **COI** = conflicts of interest; **DRE** = drug-resistant epilepsy; **EMU** = epilepsy monitoring unit; **mDelphi** = modified Delphi; **MEG** = magnetoencephalography; **NAEC** = National Association of Epilepsy Centers; **PNEE** = psychogenic nonepileptic event; **PWE** = people with epilepsy; **SAP** = seizure action plan; **SUDEP** = sudden unexplained death in epilepsy; **TCBS** = trustworthy consensus-based statements; **VEEG** = video-EEG.

organizations advocate for comprehensive epilepsy centers to provide both routine and highly specialized care for people with epilepsy (PWE).⁴⁻⁶

Comprehensive epilepsy care requires infrastructure encompassing inpatient and outpatient settings, as well as organization of a multidisciplinary care team spanning both environments. Patient-centered care begins with accurate diagnosis and pharmacologic treatment of seizures, epilepsy-related education, screening and/or management of comorbid conditions, and provision of psychosocial resources for patients and caregivers.

The National Association of Epilepsy Centers (NAEC) is a nonprofit association in the United States with a current membership of more than 260 epilepsy centers. NAEC published its first guidelines in 1990 to provide a basic framework for services, personnel, and facilities for in-patient care. Each decade since then, updated guidelines have expanded content to include epilepsy surgery considerations, interdisciplinary care approaches, and safety and quality measures. The 2023 Guidelines, solely funded by NAEC, present a further evolution in this process as the first guidelines founded in an evidence-informed, consensus-based process, drawing on a broad cross-section of stakeholders including patients and caregivers. These guidelines also reflect a broader scope than previous iterations, including outpatient care, care coordination, and emphasis on the patient perspective. The full Guidelines for Specialized Epilepsy Centers: Report of the National Association of Epilepsy Centers Guideline Panel with discussion of supporting evidence can be found in eAppendix 1 (links.lww.com/WNL/D386).

In 2016, NAEC established an epilepsy center accreditation program built on the foundation of existing epilepsy center guidelines. Although accreditation criteria draw on NAEC epilepsy center guidelines for content, they are not synonymous. As the guidelines expand to new areas, it is recognized that many recommendations extend beyond current accreditation requirements and that center resources may limit implementation.

The 2023 guidelines outline optimal standards of care with an intent to elevate evidence-based science into standard practice. In the absence of strong evidence, recommendations were guided by consensus from the panel of experts and highlight the areas of need for additional research. These guidelines can be used to determine services that should be provided, identify gaps in resources, and help patients and families assess the quality of

care received. They will inform the direction of future accreditation criteria and provide epilepsy centers with an expanded framework to improve processes and infrastructure to continue to advance quality care for all patients with epilepsy.

Methodology for the Development of the Systematic Review and NAEC Guidelines for Specialized Epilepsy Centers

NAEC contracted with EBQ Consulting to develop evidence-based and trustworthy consensus-based statements (TCBS) that conform with established international standards.⁷ When evidence is not robust enough to support quantitative analyses for publication of evidence-based guidelines, physicians and other health care providers at epilepsy centers, PWE, and advocates still need guidance they can trust.^{7,8} The TCBS approach⁸ produces unbiased, scientifically valid, and trustworthy guidelines through a transparent process that incorporates any available evidence—identified through a systematic approach to reduce biases—and expert panelists' advice. In nonclinical areas, the TCBS process is especially useful because the evidence base has knowledge gaps, few high-quality study designs (e.g., randomized clinical trials), and small sample sizes.

Guideline users' trust begins with confidence that the panel represents key stakeholders and relevant conflicts of interest (COI) are minimized. The NAEC recruited experts from a variety of health care disciplines including epileptologists, neurosurgeons, neuroradiologists, epilepsy nurses, EEG technologists, neuropsychologists, social workers, advanced practice providers, and other health professionals, as well as PWE and caregivers (Table 1). The panel represents a diversity of demographics, geographic locations, clinical specialties, and socioeconomic contexts. All panelists were thoroughly screened for relevant COI, resulting in 10 (24%) of the 41 panelists with terms of management specifying topics for which they must recuse themselves.

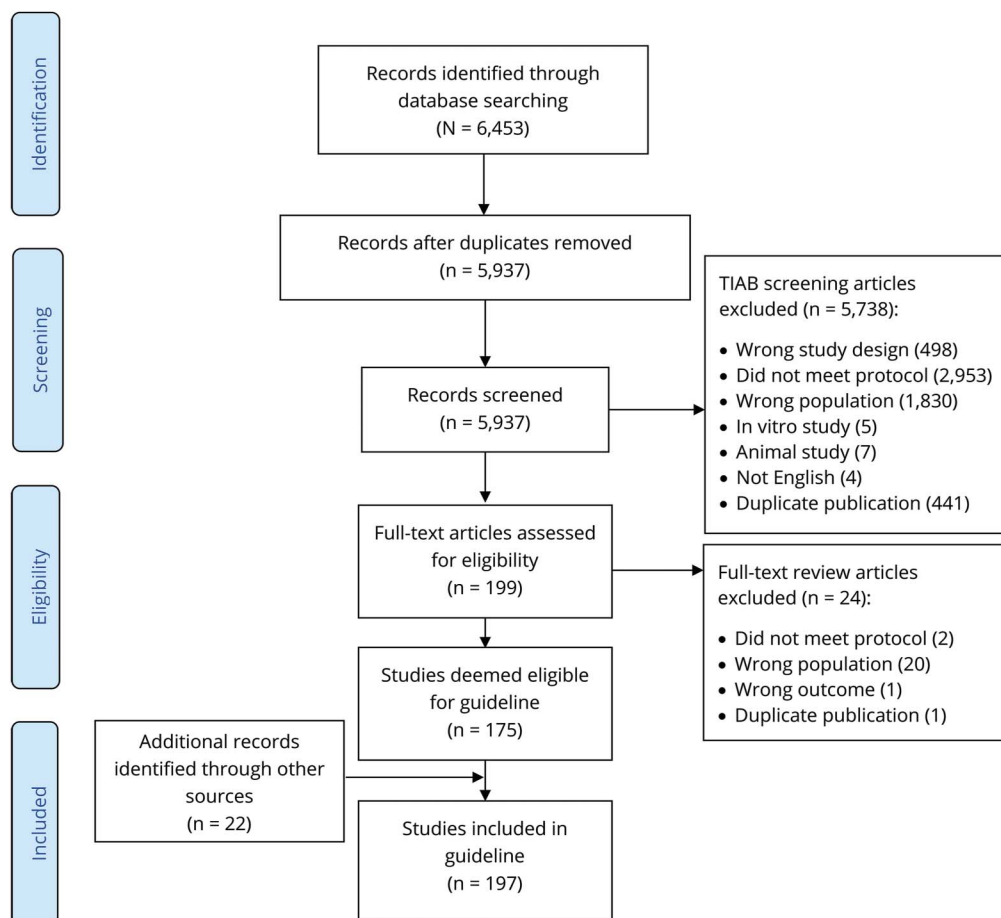
Topics of interest identified by the 2 chairs and panelists were sorted into PICO⁹ (Populations/Interventions/Comparators/Outcomes) elements to form the basis of the search strategies. A comprehensive and systematic search for relevant scientific literature was developed, peer-reviewed, and run in PubMed and Embase from January 1, 2000, to May 29, 2022, and updated on

Table 1 Panel Composition

2 epileptologists, panel co-chairs
14 additional adult and pediatric epileptologists
1 pediatric neurologist
4 neurosurgeons
2 neuroradiologists
1 neuropsychiatrist
2 neuropsychologists
3 EEG technologists
1 pediatric nurse practitioner
2 epilepsy nurse specialists
1 patient educator
1 epilepsy center administrator
7 persons living with epilepsy or caregivers (1 is also an epileptologist)
41 total panelists

March 19, 2023. Search strategies and limits are available in the accompanying supplement publication (eAppendix 1, links. [lww.com/WNL/D386](https://www.lww.com/WNL/D386)). The initial searches returned a total of 5,777 (deduplicated) studies, with an additional 160 articles identified in the second round of searches. The search and screening results are summarized in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram (Figure). The reasons for acceptance/rejection of studies during the dual phase screenings are listed in Table 2. Owing to the large number of articles identified and low rejection rate, the screening method was modified to identify “high interest” articles for full-text review. This process and how it was validated are detailed in the accompanying supplement. Other than the study design limitations placed on the literature search and screenings (case studies, case series, and studies with $n < 10$ were rejected), no formal quantitative analyses or additional exclusions were made based on methodologic quality of the research studies. Ultimately, 197 articles were retained for extraction.

Trained panelists, data analysts, and the senior methodologist extracted relevant data into evidence tables. A consulting data

Figure PRISMA Flow Diagram for NAEC Guidelines for Specialized Epilepsy Centers

NAEC = National Association of Epilepsy Centers; PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Table 2 PICO-Based Inclusion/Exclusion Criteria for Literature Screening

Participants	Among patients with: • Epilepsy (controlled or uncontrolled) • Recurrent seizure-like events • Suspected epilepsy based on multiple episodes Receiving treatment at epilepsy centers including a focus on: • Inpatient (EMU, exclude ICU monitoring for complex neurologic conditions other than epilepsy) • Outpatient (office-based clinic care, telehealth) • Accreditation level • Patient characteristic (adult, pediatric, mixed) • Geographic setting (rural medically underserved, urban medically underserved, suburban, rural not medically underserved, urban not medically underserved) Subgroups of interest: age 65+, pediatric patients, women, rare epilepsy syndromes/conditions
Interventions	Services including but not limited to: • Electrodiagnostic (e.g., 24-h video-EEG with either surface electrodes or sphenoidal electrodes, intracarotid amobarbital (Wada) testing, functional cortical mapping, evoked potential recording capable of being safely used with intracranial electrodes, electrode localization) • Neurosurgery (e.g., emergency or elective including biopsy and removal of incidental lesions, treatment of cerebral complications of epileptic seizures, stereotactic techniques, management of surgical complications, corpus callosotomy) • Imaging (e.g., computerized axial tomography, cerebral angiography, interictal positron emission tomography, fMRI) • Pharmacologic expertise (e.g., quality-assured anticonvulsant serum drug levels) • Neuropsychological (e.g., comprehensive test batteries for cerebral dysfunction) • Psychosocial services (e.g., inpatient and outpatient psychological services for assessment and treatment of chronic epilepsy) • Rehabilitation (e.g., physical, occupational, speech therapy) • Access to higher level care (e.g., ICU, anesthesia, emergency resuscitative equipment) • Care coordination (e.g., medication authorizations, home medical equipment, transition from inpatient to outpatient) • Genetic testing and counseling • Patient and caregiver education • Dietary management • Services for special populations (e.g., language interpretation services, rare epilepsies) Essential elements of the inpatient EMU including but not limited to: • The design and layout of the physical space to provide access, observation and monitoring needs of patients, and safety considerations • The equipment needed to perform services • Data collection protocols and management • Additional facility protocols (e.g., transportation, fall prevention, medication reduction, standard order set) Personnel including but not limited to: • Epilepsy specialists • Providers associated with neurosurgery • Providers associated with diagnostic testing • Psychosocial and care coordinators • Nursing • Advance practice providers
Comparators	Not applicable (include all)
Outcomes and outcome measures	Any center outcomes including but not limited to: - Center-wide clinical outcomes determined from data sets - Reduced hospitalizations, morbidity, or mortality (over a period of time) Nonclinical outcomes including but not limited to: - Patient volumes - Financial outcomes - Staff turnover rates - Number of times the center was sued - Patient complaints - Patients signing out or leaving prematurely due to dissatisfaction with care or requesting a new source of care - Patient satisfaction - Press Ganey scores, wait times for appointments, in-clinic wait, return of phone calls Patient outcomes including but not limited to: - Seizure frequency - Seizure freedom - Emergency department visits - Hospital readmission - Quality of life - Functional status - Behavioral health - Mortality - Education/employment status
Timing	Any
Study designs	Keep: • RCT (phase 1–4) • Non-RCTs (phase 1–4) • Observational, noncomparative • Observational studies, comparative • Cross-sectional • Prospective cohort

Continued

Table 2 PICO-Based Inclusion/Exclusion Criteria for Literature Screening (*continued*)

	• Retrospective cohort • Nonconcurrent cohort • Systematic reviews/meta-analyses • Pooled analyses • Case-control Reject (wrong study design): • Case reports/series • Prognostic course/factor studies • Modeling studies • Preclinical • Narrative reviews Reject (other reason for rejection): • In vitro • Not a clinical study • Not a treatment study • Animal studies • Non-English • Duplicate publication
Notes	Despite a long intervention list, any intervention/institution characteristic is acceptable Despite a long outcome list, any outcome reported is acceptable Hierarchy is to reject all nonepilepsy studies for wrong population > reject studies with no new data for not a clinical study > reject studies with no center information for wrong intervention
Abbreviations: ICU = intensive care unit; EMU = epilepsy monitoring unit; PICO = Populations/Interventions/Comparators/Outcomes; RCT = randomized clinical trial.	

analyst performed reliability checks on a random sample of 20% of the articles which demonstrated high accuracy for some extractors, while others missed important information or had other errors. Re-extractions were performed for all articles extracted by extractors of lower reliability.

The qualitative evidence summaries, along with the Evidence-to-Decision Framework¹⁰ questions, were used by work groups, formed with 1 co-chair and panelists with expertise in the topic area and 1 or more patient/caregiver representatives, to draft the initial recommendations. The evidence summaries were later shared with the entire panel, which convened through teleconference to review and discuss the evidence.

The modified Delphi (mDelphi) approach was used for all recommendations to bring precision and transparency to the consensus achievement process.⁸ The Guidelines Oversight Committee established several ground rules a priori to guide the mDelphi process, including:

- Up to 3 rounds of Delphi surveys to achieve consensus.
- An 85% minimum response rate for each survey round based on eligible voting panelists.
- An 80% threshold of voters indicating agreement or strong agreement for achieving consensus.
- Recommendations achieving consensus in the first or second round were not revoted on in subsequent rounds.
- No minority reports were permitted, although all panelists had the opportunity and were encouraged to express their opinions during each round of the mDelphi surveys for each recommendation.

All recommendations and their associated remarks achieved consensus in the first round. Based on the comments provided

by the survey respondents, however, the chairs made minor revisions to 7 recommendations and drafted 1 additional recommendation. The revised recommendations and the new recommendation underwent a second round of voting and all achieved consensus, resulting in 52 final recommendations. Survey tallies with the degree of consensus for each recommendation are available on request (info@naec-epilepsy.org).

The final manuscript underwent review by the panelists, chairs, medical writer, and staff, as well as the NAEC Board, Guidelines Oversight Committee, and monitoring organizations. These guidelines comply with current standards⁷ and guideline development using the TCBS approach.⁸ As additional research becomes available, practice standards become established, and clinical knowledge grows, published data should become more homogeneous and quantifiable, permitting evidence-based guideline updates in many of the content areas. NAEC will determine whether to use living guideline approaches for future recommendation updates.

NAEC Guidelines for Epilepsy Centers Recommendations

The 52 recommendations of the Guidelines are presented in Tables 3–6. All remarks are considered integral to the recommendations themselves and therefore are included as part of the recommendations. Most recommendations were informed by the evidence review, and the discussion of each topic in the Executive Summary highlights some of the relevant literature. Because the evidence base was extensive and comprised a wide range of sources, the panel chose not to grade the quality of individual studies. Consequently, all recommendations are considered consensus based.

Table 3 Recommendations: Inpatient Services/EMU

1. Recommendation: All epilepsy centers should have an EMU, which is a dedicated inpatient location for performing 24-h continuous video-EEG monitoring for seizure classification or localization. CB
Remark: The EMU should be staffed with epilepsy-trained nurses and nursing assistants. The nurse-to-patient ratio should be adequate to ensure safety and rapid response to seizures. CB
Remark: Patient rooms in the EMU should have remote control video cameras with 24/7 recording available that are movable by observers to keep the patient on video continuously. CB
Remark: Video and EEG data should be captured and sent to a central location and be readily available to the physician reviewer in real time. CB
Remark: All EMU rooms should have a patient-activated event button and alarm. CB
Remark: Centers should have registered EEG technologists on staff. CB
2. Recommendation: All epilepsy centers should have 24/7, continuous, real-time supervision of ongoing VEEG studies in the EMU. CB
Remark: Supervision should be performed by a trained observer watching VEEG studies with no other concurrent responsibilities. The trained observer may be an EEG technologist. CB
Remark: Trained observers must have direct access to nurses and physicians caring for the patient. If the observer is not an EEG technologist, trained observers must have direct access to a supervising EEG technologist. CB
Remark: Trained observers should be provided patient-specific seizure descriptions and considerations to assist them in seizure recognition. CB
Remark: The ratio of trained observers to VEEG studies being monitored should be adequate for timely recognition of seizures and patient-related events. CB
3. Recommendation: All epilepsy centers should have physicians with sufficient training and expertise to provide optimal care. CB
Remark: Center physicians should have board certification in epilepsy or clinical neurophysiology. CB
Remark: Centers treating children should have at least 1 pediatric epilepsy specialist on staff with board certification in epilepsy or clinical neurophysiology as well as neurology with special qualifications in child neurology. CB
4. Recommendation: All epilepsy centers should have sufficient volume of patients admitted to the EMU to maintain the expertise of the epilepsy care team. CB
5. Recommendation: All epilepsy centers should have EMUs that are equipped to handle epilepsy-related emergencies. CB
Remark: Emergency medications and equipment (such as supplemental oxygen, suction) for seizures or status epilepticus should be available in the EMU. CB
Remark: All centers should implement a written protocol for managing status epilepticus and acute repetitive or prolonged seizures. CB
Remark: Qualified providers or a rapid response team must be available in-house to manage seizure emergencies at all times. CB
6. Recommendation: All epilepsy centers should implement written protocols regarding response to events that occur in the EMU. CB
Remark: A trained observer must be present to identify seizures and initiate a medical response promptly. CB
Remark: Centers should have a written protocol for testing speech, memory, level of consciousness, and motor function during and following a seizure. CB
Remark: All epilepsy centers should take efforts to minimize risk due to injury and falls. CB
Remark: All epilepsy centers should have a protocol for responding to postictal agitation, including education for responders on how to work with these patients. CB
7. Recommendation: All epilepsy centers should have a standard set of admission orders and protocols for patients admitted to the EMU. CB
Remark: Centers should have a written protocol that addresses the number or duration of seizures over a given period that require physician notification and include measures to be taken if number, duration, or severity of seizures observed is excessive. These instructions should also be included in the admission orders. CB
Remark: All centers should have a written protocol that addresses safe medication reduction to increase seizure yield. CB
Remark: All EMU patients should have a documented plan for seizure response including rescue medications. CB
8. Recommendation: All epilepsy centers caring for children should have pediatric-specific protocols and resources. CB
Remark: Child life specialists play an important role in caring for children in the EMU and should be part of the epilepsy care team. CB
Remark: Centers with pediatric patients should modify all EMU protocols including, but not limited to, age-appropriate safety measures and medication dosage. CB
9. Recommendation: All epilepsy centers should provide EMU reports that meet ACNS standards. CB
Remark: Reports should use standard classification of seizure and epilepsy type. CB
Remark: Reports should be generated in a timely fashion. CB
10. Recommendation: Centers should provide patient and caregiver education in preparation for EMU admission. CB
11. Recommendation: Centers should regularly inform EMU patients and/or caregivers of important findings in their evaluation and changes in the care plan. CB
Remark: Patients and/or caregivers should be updated daily with interval results from VEEG and other diagnostic tests and changes in treatment. CB
Remark: Information in EMU reports should be shared with patients and caregivers, including a verbal conference with patient and caregiver to discuss preliminary findings before discharge. CB
12. Recommendation: Centers should provide EMU discharge planning and education that is shared with patients and caregivers, including safe medication resumption or guidance on new medication, follow-up care, and contact information. CB

Abbreviations: ACNS = American Clinical Neurophysiology Society; CB = consensus based; EMU = epilepsy monitoring unit; VEEG = video-EEG.

Inpatient Services

EMU/Electrodiagnostic Services

EMU Infrastructure and Personnel

A key component of an epilepsy center is an epilepsy monitoring unit (EMU) supported by a multidisciplinary team of specialty-

trained professionals and a comprehensive electrodiagnostic laboratory.^{4,11} Video-EEG (VEEG) monitoring is essential for managing patients with complex epilepsy, discriminating between epileptic and nonepileptic events, and evaluating candidates for epilepsy surgery.¹² For optimal patient safety and seizure recognition, an EMU must have continuous video recording¹³⁻¹⁵ and trained observers providing round-the-clock

patient monitoring.¹³⁻¹⁵ Studies performed under these conditions improve patient safety and are more likely to establish a diagnosis than those performed in a less structured setting.¹⁶ Seizure recognition and patient outcomes also improve with higher levels of staff training.¹⁴

Studies agree that EMU staff should have specialized training in seizure recognition and epilepsy care and the ability to closely monitor patients.^{4,11,13,15} However, there are no national standards for epilepsy nursing education and limited data regarding ideal nurse-to-patient ratios.¹⁵ Externally developed curricula such as the AES EMU Caring program or the American Association of Neuroscience Nurses' Certificate Program for the Seizure and Epilepsy Healthcare Professional in a Comprehensive Epilepsy Center can supplement local educational initiatives and improve consistency among centers.^{17,18}

For EEG technologists, certification by ABRET Neurodiagnostic Credentialing and Accreditation is a nationally recognized standard. ABRET has established the registered EEG technologist as a foundation credential for EEG technologists and also offers advanced credentials CLTM and NA-CLTM for technologists focused on continuous VEEG monitoring. Ideally, all technologists would have the highest level of training and certification; however, this goal is constrained by the limited availability of trained technologists.^{4,11} Although some data suggest that seizure detection is higher with trained EEG technologists and a low ratio of studies to observers,¹⁴ center practices vary. Some centers use trained observers to supplement technologists. Current evidence supports the need for continuous observation of VEEG monitoring studies^{13,15,19} but is insufficient to support recommendations regarding the type of observer or the ratio of studies to observer.

Expertise in interpretation of VEEG monitoring and in management of the diversity of epileptic disorders, comorbidities, and disorders mimicking epilepsy exceeds the training of most general neurologists. Epilepsy center physicians should have subspecialty fellowship education, for example, in clinical neurophysiology or epilepsy, and subspecialty board certification.^{4,11} Similarly, caring for children with epilepsy requires specialty pediatric training.

Care of patients in the EMU is a complex undertaking requiring coordinated efforts by team members and experience responding to convulsions and postictal agitation. To optimize outcomes, there should be an adequate yearly volume of EMU patients to ensure the team has regular daily experience caring for patients with epilepsy. Although, data on the impact of volume in EMU care are lacking, in other complex medical conditions, such as congestive heart failure, high volume centers achieve better outcomes compared with low-volume centers.

EMU Protocols and Safety

EMU patients often have poorly controlled epilepsy and are at increased risk for status epilepticus and other adverse events.¹⁹

EMUs must be prepared to manage epilepsy-related emergencies with immediately available medications, equipment, and bedside providers or emergency medical team.^{4,11,13} Centers with pediatric patients should have specific protocols addressing the medications and dosages used for children, and other pediatric resources including child life specialists.

The EMU should be designed with seizure precautions and safety in mind.^{4,11,13} Risks of seizure-related falls and injuries increase with medication withdrawal or postictal agitation. Implementation of standardized protocols to guide safe ASM reduction, mitigate adverse events, and anticipate acute seizure management are widely recommended as essential safety measures, yet many centers lack relevant protocols, and practice varies significantly. Standardized seizure response protocols also increase information gained through EMU studies by encouraging consistent testing of speech, memory, motor function, and level of awareness during and after a seizure. Standardized admission order sets ensure that protocols are consistently applied and should include seizure precautions and safety measures for all patients regardless of whether they suffer from epileptic seizures or nonepileptic events.^{12,15,19,20}

Communication and Reporting

Few epilepsy guidelines address the importance of communication and education. A 2012 expert consensus guideline from Schafer et al. recognized that communication with patients and caregivers was essential for safety and recommended preadmission and predischarge education as well as an assessment during admission to identify additional educational needs.¹³ A timely report of EMU findings, using standard classification and terminology, is also essential for communication with the referring provider and with additional specialists if needed in the future.²¹

Surgery

Approximately one-third of PWE continue having seizures despite trying multiple ASMs, experiencing increased morbidity and mortality and decreased autonomy. Epilepsy surgery is safe and effective yet remains underutilized^{22,23} despite abundant evidence that demonstrates its value.²⁴

Presurgical Screening and Candidate Selection

Identifying patients who may benefit from surgery requires concerted effort. Directing patients to epilepsy surgery can be fraught with delays and challenges.

Selecting among surgical options and planning of intracranial EEG studies requires integrating the results of electrophysiology and neuroimaging with surgical anatomy. It also requires an assessment of the whole patient, including an individual's neurocognitive function, psychiatric state, psychosocial stressors, and support network. A multidisciplinary surgical conference that fosters interaction

Table 4 Recommendations: Surgery

13. Recommendation: All epilepsy centers should regularly screen patients for drug-resistant epilepsy and refer such patients to multidisciplinary surgical conference for consideration of epilepsy surgery. CB Remark: Referrals for epilepsy surgery evaluation should be made in a timely manner. CB Remark: Epilepsy surgery includes resective, disconnection, ablative, intracranial and extracranial neurostimulation procedures, and placement of intracranial electrodes. CB Remark: Patients who were previously evaluated for epilepsy surgery but did not proceed to surgery should continue to be screened regularly. CB
14. Recommendation: All centers that perform epilepsy surgery should have a formal presurgical conference with the multidisciplinary team to evaluate and plan for each patient referred for epilepsy surgery. CB Remark: The surgical epilepsy care team includes neurosurgeons, neuropsychologists, epileptologists, EEG technologists, nurses, neuroanesthesiologists, psychiatrists, neurophysiologists, neuroradiologists, case managers, and/or patient advocates. The neurosurgeon, neuropsychologists, epileptologists, and neuroradiologists should attend the presurgical conferences consistently, with others attending as appropriate. CB
15. Recommendation: Multidisciplinary surgical conferences should be able to appropriately screen patients for all epilepsy surgery options and recommend the best procedure for controlling a patient's epilepsy without regard to whether it is performed at the center. Centers that do not perform specific epilepsy surgical procedures should refer patients to a center that performs those procedures, when appropriate. CB Remark: Centers that only perform extracranial neurostimulation procedures (e.g., VNS) should have a referral arrangement whereby candidates for these procedures are presented at a multidisciplinary conference at the partner center that performs the full range of epilepsy surgical procedures. CB Remark: Centers that lack experience in performing certain procedures in children should refer patients to a center that regularly performs those procedures. CB Remark: Centers that receive referrals from other programs should not replicate the evaluation unnecessarily and should involve the referring provider in decision-making. CB
16. Recommendation: All epilepsy centers that perform intracranial surgery should have the capability of performing 24-h video-EEG monitoring with intracranial electrodes, including stereo EEG and subdural electrodes. CB Remark: All centers that perform intracranial monitoring should have epileptologists with sufficient volume of cases to maintain expertise in interpretation of intracranial EEGs. CB Remark: All centers should have written protocols governing care for patients undergoing video-EEG monitoring with intracranial electrodes, including care of head dressings and measures to prevent postoperative infections or other complications. CB Remark: All centers that place intracranial electrodes should have capabilities for electrode localization, including the use of 3D reconstruction. CB
17. Recommendation: All centers that perform resective surgeries should have the ability to perform intraoperative electrocorticography to identify epileptogenic tissue. CB Remark: Electrocorticography should be interpreted by epileptologists or neurophysiologists with sufficient volume of cases to maintain expertise. CB
18. Recommendation: Centers that perform intracranial surgeries should have the ability to perform functional mapping, including motor, sensory, language, and behavioral modalities. CB Remark: Functional mapping procedures include cortical stimulation and evoked potential recording. CB Remark: Centers should have written protocols for functional mapping that address methodology, safety, and risk of provoking seizures during mapping. CB Remark: Center protocols for mapping language and behavioral modalities should be drafted in consultation with a neuropsychologist. When possible, a neuropsychologist should be present during the mapping procedure. CB Remark: Centers should have the capability of performing intraoperative functional mapping to maximize possibility of seizure freedom while mitigating the risk of iatrogenic injury. CB Remark: Centers that use intracranial electrodes should have the capability of performing extraoperative functional mapping for surgical planning. CB
19. Recommendation: All centers that perform surgery should have the ability to preoperatively assess language dominance and memory. CB
20. Recommendation: All centers that perform epilepsy surgery should have a neurosurgeon with specialized training and experience in epilepsy surgery. CB Remark: Center neurosurgeons should be board certified or tracking toward certification in neurosurgery. CB Remark: Centers that serve children should have a neurosurgeon with specialized training and experience in pediatric epilepsy surgery, including hemispherotomy. CB
21. Recommendation: All centers that perform epilepsy surgery should have sufficient volume of cases to maintain expertise of the multidisciplinary surgical epilepsy care team. CB
22. Recommendation: All epilepsy centers that perform resective surgery should have surgical specimens analyzed by a neuropathologist who generates a formal pathology report. CB

Abbreviation: CB = consensus based; VNS = vagus nerve stimulation.

among multiple specialists, including neurologists, neurosurgeons, neuropsychologists, and neuroradiologists, among others, effectively incorporates these diverse perspectives and results in effective consensus-based treatment recommendations.²⁵

Consistent with patient-centered care, multidisciplinary surgical conferences should weigh all surgeries most likely to benefit a patient, not only those available in a particular center, and facilitate referrals to other centers in

cases where a recommended surgery cannot be performed locally.

Intracranial Surgery

Optimal surgical outcomes require identification of seizure onset regions and key propagation pathways. Because epilepsy is heterogeneous and involved brain regions and circuits differ significantly between patients, individualized surgical planning, including intracranial recordings, is essential to

achieve best outcomes. International consensus criteria for pediatric epilepsy surgery identify the ability to perform invasive EEG recording as an integral function of the highest level of surgical epilepsy care.²⁶ Intracranial EEG differs significantly from scalp EEG, requiring analysis by clinicians with significant experience interpreting intracranial EEGs.

Minimizing the complications of intracranial electrodes requires meticulous postimplant care. Centers should have written protocols that govern the care of patients undergoing intracranial EEG to minimize risks inherent to intracranial monitoring. These protocols should address the surgical dressing care, fall risk mitigation, postoperative infection prevention, safe ASM withdrawal, management of stimulation mapping provoked seizures, and neurophysiologic equipment standards.^{11,19}

Because the localization of seizure onset using intracranial electrodes determines the targeting of therapeutic surgery, clinicians interpreting intracranial EEG must know the precise locations of intracranial electrodes in relation to each patient's individual brain anatomy.

Intraoperative electrocorticography allows recording additional brain regions using an electrode placed by the surgeon intraoperatively on the exposed brain. By moving the recording electrode, a surgeon can assess the presence of epileptic activity in brain regions that were not implanted with intracranial electrodes previously. The removal of regions where epileptic activity is identified intraoperatively improves surgical outcomes.^{27,28}

Identification of Eloquent Brain Regions

Surgical planning requires identification of cortical regions where surgery would produce unacceptable morbidity. With accurate functional mapping, a neurosurgeon may safely and maximally remove brain regions producing seizures while minimizing risk to functional cortex. Lateralization of language function may be determined preoperatively with fMRI, magnetoencephalography (MEG), or with intracarotid sedative administration, the Wada test. In patients undergoing surgery, intraoperative or extraoperative functional mapping can delineate brain regions performing critical motor, sensory, behavioral, and language functions.

Selecting appropriate tasks during functional mapping is essential for accurate results. Neuropsychologists are most experienced with designing questions, objects, and tasks that probe the functions distributed across cortex and should be involved in designing testing protocols. The presence of a neuropsychologist during functional mapping, when feasible, allows adjustment of test questions and tasks in response to patient performance.

Surgical Training and Experience

Successful epilepsy surgery requires mastery of specialized techniques and knowledge directed at disrupting circuits producing seizures while preserving critical brain functions. The importance

of specialized training for epilepsy neurosurgeons is increasingly recognized.^{29,30} Evidence indicates that adding a sub-specialty-trained functional neurosurgeon dedicated to epilepsy surgery improved the volume and outcomes of patients referred to surgery.³¹ In North America, board certification is an indicator of training and experience. Surgeons from outside North America may have equivalent training and experience without board certification. In centers serving children, pediatric neurosurgeons skilled in pediatric procedures, such as hemispherotomy, along with pediatric anesthesiologists and critical care intensivists, are essential for the treatment of high-risk cases in infants and toddlers.³²

Adequate case volume is essential for maintaining the expertise of the multidisciplinary team. Studies across surgical and medical areas have consistently shown improved outcomes associated with higher volume.³³ The International League Against Epilepsy has established minimum case volume standards for epilepsy centers.^{6,26} While good outcomes may be achieved at low-volume epilepsy centers, available data suggest higher risk of surgical complications and higher costs of care at low-volume centers.³⁴

Pathology Report

Epilepsy may arise from structural, genetic, infectious, metabolic, and immune-related etiologies. The specific causes of seizures can influence treatment strategies and prognosis. Surgically resected tissue, including the epileptogenic zone or suspected lesion, should be examined and reported by a neuropathologist, who may provide crucial information for determining the underlying cause of epilepsy, guiding treatment decisions, and ensuring optimal patient care.

Diagnostic Evaluation

Neuropsychology Services

Neuropsychological testing assesses cognitive functions to anticipate the long-term effects of seizures and assess the impact of treatments. Neuropsychological testing assumes special importance in epilepsy surgery planning providing insight into the cognitive burden of poorly controlled epilepsy, identifying regions most affected by epilepsy, and considering potential impacts of epilepsy surgery.^{11,35} Furthermore, such testing can identify treatable mood comorbidities and point to current or postsurgery rehabilitation needs.^{35,36} In children, testing assists in monitoring maturation and development. For neuropsychological assessment to be optimally informative and cost effective, standardization of testing frequency, testing protocols, and use of validated measure of performance should be encouraged.³⁶

Imaging Services

Brain imaging is essential for the evaluation of epilepsy. Structural imaging, especially high-resolution MRI, enables the detection of epileptogenic cortical malformations or lesions. Every epilepsy center should have good quality CT and MRI capabilities and should use MRI protocols optimized for epilepsy.³⁷

Table 5 Recommendations: Diagnostic Evaluation

23. Recommendation: All epilepsy centers should have neuropsychologist(s) with training in neuropsychometric evaluation on site or by referral to perform or supervise clinical neuropsychological evaluations for patients manifesting or expressing neurocognitive symptoms or being evaluated for epilepsy surgery. CB
Remark: The epilepsy center should have standard protocols that address which patients require neuropsychometric evaluations. CB
Remark: Clinical neuropsychologists should be board certified or pursuing board certification. CB
Remark: Centers with pediatric patients should have neuropsychologists with specific training and expertise in evaluating children. CB
Remark: Individual tests should be performed by neuropsychologists, qualified psychometricians, or clinical staff with formal training in the administration of these tests. CB
24. Recommendation: All epilepsy centers should have CT and MRI with optimized epilepsy-specific MRI protocols. CB
Remark: Centers that serve children should have the capability of performing studies, while the patient is under anesthesia with appropriate safety monitoring. CB
25. Recommendation: For centers that perform surgery, PET, SPECT, and/or MEG should be used when appropriate to increase the yield of presurgical localization of the seizure focus and assist in surgical decision-making. CB
Remark: The multidisciplinary surgical planning team should make the decision regarding which specific imaging modality to use. CB
Remark: Centers that perform surgery but do not have these imaging modalities should have the capability to arrange referrals for surgical patients. CB
Remark: Centers that serve children should have the capability of performing studies while the patient is under anesthesia with appropriate safety monitoring. CB
26. Recommendation: For centers that perform surgery, fMRI, MEG, other functional mapping modalities, and/or Wada tests with cerebral angiography should be available to assist in localization of eloquent functions. CB
Remark: Centers that perform surgery but do not have these imaging modalities should have the capability to arrange referrals for surgical patients as appropriate. CB
27. Recommendation: Centers that perform diagnostic imaging should have studies interpreted by personnel with appropriate specialty training and certification. CB
Remark: Centers that serve children should have studies interpreted by neuroimaging specialists with specific training and expertise in pediatric studies. CB
28. Recommendation: All epilepsy centers should use genetic testing as part of the diagnostic workup for patients with intractable epilepsy of unknown etiology. CB
Remark: Genetic testing is useful in evaluation of surgical candidates. CB
Remark: Testing can be performed by an external laboratory. CB
29. Recommendation: All epilepsy centers should have an established protocol to identify those patients who would most likely benefit from genetic testing, even if their seizures are well controlled. CB
Remark: Protocols should identify populations with a higher risk for genetic disorders, including early-onset epilepsy, developmental and epileptic encephalopathy, neurodevelopmental disabilities, and family history of epilepsy. CB
30. Recommendation: All epilepsy centers should offer genetic counseling from a certified genetic counselor either within the program or by referral. CB
Remark: All pediatric centers should have access to medical genetics consultation on site or by referral. CB

Abbreviations: CB = consensus based; MEG = magnetoencephalography.

Additional noninvasive functional imaging capability is necessary in centers performing surgery. Although class I outcome data comparing different functional imaging methods are lacking, there is consensus that functional imaging, including PET, SPECT, and MEG—techniques that localize the regions of abnormal metabolism, blood flow, or electromagnetic activity, respectively—help identify epileptogenic brain regions.³⁸ Functional imaging—particularly fMRI and MEG—can also localize brain regions critical for language, movement, tactile sensation, hearing, and vision, providing landmarks to guide the surgeon.³⁸

The Wada test, the intracarotid administration of sedative to anesthetize 1 hemisphere, is also used to lateralize language and memory and is currently the only method that can assess the potential impact of surgery on memory. As Wada testing is more invasive and carries more risk than functional imaging, it should be used selectively when the benefit of assessing memory outweigh the risks of testing.^{11,29}

Because brain development and epilepsy syndromes differ uniquely in young children, pediatric epilepsy centers should have neuroradiologists with training and expertise in

interpreting pediatric studies. Moreover, the behavioral needs of children require that pediatric centers follow pediatric safety measures, including pediatric anesthesia, if necessary.

Genetic Services

Genetic testing has an increasingly important role in the diagnostic evaluation of epilepsy demonstrating utility in children³⁹ and adults.^{40,41} Testing results may provide insight into mechanisms or prognosis that influence surgical³⁹ decision-making and inform medical management.³⁹⁻⁴¹ Because a genetic diagnosis may lead to more effective management and better outcome, testing should occur early in diagnostic evaluation.⁴¹

No consensus exists currently on the optimal genetic testing strategy. Diagnostic yield, age at testing, and cost-effectiveness all influence test choice. Diagnostic yield of genetic tests is higher with DRE,⁴⁰ earlier seizure onset age,^{40,41} and subpopulations such as individuals with developmental epileptic encephalopathy or neurodevelopmental disabilities.⁴⁰ Centers implementing a consistent testing strategy that reflects these factors are more likely to benefit patients than those lacking testing protocols.⁴¹

The growth of genetic testing has created a need for genetic counseling in epilepsy centers. Genetic counselors educate patients and families regarding test results, specific genetic syndromes, risk of recurrence, and the options for prenatal testing. Because genetic disorders often affect multiple organ systems, medical geneticist consultation may be helpful in the initial diagnosis and management of a genetic epilepsy syndrome.

Outpatient Services

Outpatient Care

Outpatient care is a core element of an epilepsy center's mission, often serving as the access point to specialized care, facilitating diagnosis and initiation of treatment. Longitudinal outpatient care is the main venue for ongoing management to mitigate seizure risks, manage medication side effects and common comorbidities, and provide psychosocial support and resources.

Early access to a comprehensive epilepsy clinic improves seizure control, developmental outcomes, and reduces the risk of premature mortality.⁴² Yet, there is a progressive decline in outpatient access, due in part to a shortage of neurologists.⁴² Working within the confines of immovable constraints, epilepsy centers should prioritize resources to optimize scheduling, including development of a triage system to identify patients who need urgent evaluation. Telemedicine is an important resource, providing earlier access to specialized care and improving patient satisfaction, especially in resource-limited areas.⁴³ For PWE who may not drive, telemedicine is already an essential tool for accessing medical care. Telemedicine has even greater potential to bring specialized care to underserved regions of the United States if regulators are able to update laws concerning state-based medical licensure and interstate prescribing of ASMs that are classified as controlled substances.

Medication Management

ASM management is required for nearly all patients with epilepsy. Nonadherence with ASM is associated with increased morbidity, mortality, and higher health care–associated costs.⁴⁴ Using a multidisciplinary team with pharmacologic expertise to provide medication counseling and to monitor for side effects can improve caregiver and patient adherence to ASM therapy.¹¹ Centers should also provide resources to help patients navigate financial barriers to medication adherence.

Care Coordination

Children and adults with epilepsy often have additional social, educational, and/or complex medical needs. Optimal management requires cooperation among medical providers, therapy and education specialists, school personnel, and social workers.⁴⁵ Care coordinators play an integral role in organizing and facilitating care for patients with high resource needs and improve family and care team satisfaction, clinical efficiencies, and patient outcomes.⁴⁶

Adolescents have unique needs in the transition period from pediatric to adult care. The American Academy of Pediatrics

has advocated for the standardization of early transition education and coordinated care among patients with complex, chronic health conditions, such as epilepsy. National and international task forces have developed epilepsy-specific transition recommendations.^{5,47}

Psychogenic Nonepileptic Events

Psychogenic nonepileptic seizures or psychogenic nonepileptic events (PNEEs), also called functional seizures, are a relatively common psychiatric disorder that presents challenges in diagnosis and treatment and often coexists with epilepsy. VEEG monitoring is the gold standard for establishing the diagnosis of PNEE which accounts for approximately 15%–20% of patients referred to an EMU. Anxiety and depression may contribute to PNEE symptoms.⁴⁸ Correct diagnosis and treatment requires psychological evaluation and psychotherapy and improves quality of life.⁴⁸ Epilepsy centers play a key role in the diagnosis of PNEE, disambiguating epileptic seizures from nonepileptic events and facilitating referral to mental health providers for treatment.¹¹ Centers should remain involved in the care of patients with PNEE following the initial diagnosis, to advise mental health providers who may be concerned about possible epileptic seizures and, when necessary, to re-evaluate patients where epileptic and nonepileptic events may both be present.

Patients With Special Needs

Children with developmental disabilities are at increased risk for developing epilepsy and its associated comorbidities, and constitute a special population that requires special attention. They require frequent follow-up visits and multispecialty care and may exhibit behaviors that can—if not appropriately addressed—interfere with optimal neurologic evaluation and treatment.⁴⁵ Epilepsy centers should consider the barriers to care faced by children with disabilities and develop a systematic approach to overcoming these obstacles.

PWE and Childbearing Potential

Seizures or the use of ASMs may affect fertility, contraception, pregnancy, or risk of developmental disabilities in offspring. PWE and childbearing potential constitute a special population that requires additional attention to mitigate these risks. Evidence is clear that intrauterine exposure of the fetus to some ASMs, such as valproate, significantly affects fetal and postnatal development, often profoundly.⁴⁹ Yet, the use of potentially teratogenic medications remains common. Because pregnancies may be unplanned, counseling must be part of routine care. The 2017 Epilepsy Quality Measures of the American Academy of Neurology endorsed the importance of counseling on pregnancy-related topics and folate supplementation for women with epilepsy of childbearing age.

Patient Education

Education for patients and caregivers is a cornerstone of quality epilepsy care.⁵⁰ Effective patient education leads to improved epilepsy knowledge, coping skills, sense of wellbeing, and ASM adherence.⁵⁰ Centers should ensure broad access by providing

Table 6 Recommendations: Outpatient Services

Outpatient care

31. Recommendation: All epilepsy centers should optimize scheduling to achieve timely appointments both for new and existing patients. This should include triaging patients with urgent need for evaluation. CB

32. Recommendation: All epilepsy centers should include telehealth services as an option for outpatient care. CB

Remark: The center should have the appropriate infrastructure to provide telehealth services and staff training on providing secure telehealth services. CB

33. Recommendation: All epilepsy centers should facilitate patient communication using both telephone and virtual health care access services with prompt response to patient concerns. CB

Medication management

34. Recommendation: All epilepsy centers should regularly assess patient medication adherence and side effects as part of routine outpatient care. CB

Remark: Centers should have a protocol that guides assessment and documentation of medication adherence and side effects. CB

Remark: Centers should have personnel with expertise in pharmacology (pharmacists, epileptologists) to address side effects and increase adherence. CB

35. Recommendation: All epilepsy centers should have strategies to assist patients with navigating barriers to medication access. CB

Remark: Centers need to recognize this problem for patients and take responsibility to connect patients with available resources. CB

Remark: Centers should have social workers able to assist patients whose needs cannot be met by available resources. CB

Care coordination

36. Recommendation: All epilepsy centers should have a care coordinator(s) assigned to facilitate referrals for services a center does not provide, to facilitate communication between center providers and outside specialists or agencies, to ensure smooth patient transitions between inpatient and outpatient care, and to assist in transitioning from pediatric to adult epilepsy care providers. CB

Remark: Care coordinators may also take a direct role or assist in securing medication and treatment authorizations, home health care services, and obtaining medical equipment for outpatient use. CB

Remark: Some of the responsibilities of care coordination could be met by an epilepsy nurse, nurse navigator, advanced practice provider (APP), social worker, or other personnel. However, this does not replace the need for a designated care coordinator. CB

37. Recommendation: Epilepsy centers that serve children should have a well-defined protocol to facilitate transition between pediatric and adult care. CB

Remark: Transition of care includes pretransition planning, transfer, and integration into adult care. CB

Remark: Transition education for persons with epilepsy and caregivers should begin in early adolescence. CB

Psychogenic Nonepileptic Events

38. Recommendation: All epilepsy centers should be able to provide comprehensive care for PNEEs. CB

Remark: Centers should have psychologists or psychiatrists with experience managing PNEE on staff or available via an established referral relationship. CB

Remark: Epileptologists and mental health providers should discuss the diagnosis with the patient during the initial assessment period. CB

Remark: Center care providers should remain active in the ongoing care of patients with PNEE to minimize recurrent hospitalization and avoid confusion regarding diagnosis. CB

Patients with special needs

39. Recommendation: All epilepsy centers should be prepared to care for patients with special needs including those with motor, sensory, and behavioral disorders, and intellectual and developmental disabilities. CB

Remark: Centers should have policies guiding the accommodation of patients with intellectual and developmental disabilities, including preparation for and administration of epilepsy-related procedures. CB

Remark: Pediatric epilepsy centers should have trained child life specialists to help children and their caregivers in preparation for and administration of epilepsy-related procedures. CB

PWE and childbearing potential

40. Recommendation: All epilepsy centers should provide counseling to PWE and childbearing potential on the impact of epilepsy and antiseizure medications on contraception and pregnancy. CB

Remark: Counseling should include the importance of folate supplementation for PWE and childbearing potential. CB

Patient education

41. Recommendation: All epilepsy centers should provide epilepsy-specific patient educational materials and referrals to support groups and community resources. CB

Remark: Educational materials should cover the broad spectrum of needs and include materials for people with new-onset epilepsy, people affected by common comorbidities of epilepsy, and people with complex needs including those contemplating epilepsy surgery. CB

42. Recommendation: All epilepsy centers should provide patients with individualized written seizure safety management plans including seizure precautions, recognition, triggers, first aid, and rescue medications. CB

43. Recommendation: All epilepsy centers should provide PWE and caregivers with information on the risks of SUDEP and life-threatening events related to epilepsy. CB

Social determinants of health and interpretation services

44. Recommendation: All epilepsy centers should assess the impact of social determinants of health on patients and offer referral for support services when necessary. CB

45. Recommendation: Centers should offer interpretation services and written translation for patients and caregivers with language barriers. CB

Remark: Educational materials should be available in English and in other frequently used languages in the center's community. CB

Remark: Patient-specific materials, such as patient care instructions and seizure action plans, should be written in the patient's preferred language, or if not available, interpreter services should be used to verbally communicate information to patients. CB

Psychosocial services

46. Recommendation: All centers should regularly screen patients for behavioral health comorbidities and offer referrals for treatment when necessary. CB

Remark: All centers should screen for depression and anxiety and utilize standardized screening tools if appropriate. CB

Remark: All centers should have established referral processes for behavioral health counseling and psychiatric services. CB

Continued

Table 6 Recommendations: Outpatient Services (*continued*)

Remark: Centers serving children should screen for learning and behavioral concerns and attention deficit disorders. CB
Remark: Centers serving children should have trained child life specialists to help children and their caregivers cope with the stress of chronic illness. CB
47. Recommendation: All epilepsy centers should have a licensed clinical social worker on staff to assess and address, as appropriate, the disproportionate impact epilepsy has on educational, social, emotional, and vocational needs. CB
Remark: Although primary assessment of educational needs is usually performed by the school system or by a neuropsychologist, a social worker plays an important role in addressing how children and their caregivers can access school services. CB
Dietary therapy services
48. Recommendation: All epilepsy centers that offer dietary therapy should have a registered dietitian with expertise in managing dietary therapies. CB
49. Recommendation: Pediatric epilepsy centers should have a ketogenic diet program for treatment of epilepsy within the center or by referral, which must include both an epileptologist and a registered dietitian. CB
Remark: Centers need a protocol for initiation of the ketogenic diet and for monitoring for adverse events. CB
Remark: Centers may utilize advanced practice providers and nurses trained in the ketogenic diet to manage patients. CB
Rehabilitation services
50. Recommendation: All centers should have a protocol addressing regular screening for neurodevelopmental and cognitive comorbidities in patients with epilepsy, with referrals for appropriate rehabilitation services. CB
Remark: Pediatric epilepsy centers should screen for developmental disorders and speech and language disorders for patients of all ages; they should screen school-aged children for learning and attention disorders. CB
Remark: Adult epilepsy centers should screen all patients for cognitive and vocational issues. CB
51. Recommendation: All centers should provide physical, occupational, and speech therapy services within the center or by referral. CB
Remark: All centers should provide services for cognitive and language disorders, common comorbidities of epilepsy, as part of comprehensive care. CB
Remark: Centers should offer referrals for physical medicine and rehabilitation consultation when needed. CB
52. Recommendation: All epilepsy centers should anticipate potential rehabilitative needs for patients undergoing epilepsy surgery and include appropriate preoperative assessment to plan for presurgical and postsurgical therapy services. CB
Remark: For patients undergoing epilepsy surgery, centers should provide physical, occupational, and speech therapy services as part of their presurgical and postsurgical care. CB
Remark: Centers should utilize presurgical neuropsychological testing to direct or guide planning for presurgical and postsurgical therapy services. CB
Abbreviations: CB = consensus based; PNEE = psychogenic nonepileptic event; PWE = people with epilepsy; SUDEP = sudden unexplained death in epilepsy.

written materials in English and other frequently used languages in their communities.

Seizure action plans (SAP) are a self-management tool providing timely instruction for seizure emergencies, increasing patient/caregiver comfort level with acute seizure care. Although studies have not documented a decrease in health care utilization, this remains a postulated benefit and SAPs are recommended for all PWE.⁵¹

Sudden unexplained death in epilepsy (SUDEP) is a rare but catastrophic risk among PWE, with known risk factors and well-established preventative interventions. The literature strongly demonstrates that patients and caregivers want their neurologist to discuss SUDEP, preferably at the time of diagnosis and in person.⁵² Joint clinical guidelines from the American Academy of Neurology and American Epilepsy Society recommend SUDEP counseling for all PWE and caregivers.

Social Determinants of Health and Interpretation Services

Social determinants of health are nonmedical factors that influence health outcomes. Delays in access to care are seen in PWE with lower educational attainment, limited health literacy, and lower rates of employment or insurance, as well as those who live in rural areas or far from an epilepsy center.⁵³ Historical health disparities, discrepancies, and inequities experienced by African Americans, Hispanics, non-English speakers, Asian/Pacific Islanders, and Native Americans have persisted in PWE and are

likely multifactorial.⁵⁴ These affect time to diagnosis, syndrome-specific ASM management, medication adherence, and time to presurgical evaluation and surgery.⁵³ Epilepsy surgery is less prevalent among African Americans, Hispanics, and non-English speakers compared with their White, English-speaking counterparts. Fortunately, studies have shown that once patients get to epilepsy centers, treatment gaps may be lessened.⁵⁵

Psychosocial Services

Psychosocial services encompass a range of medical and psychological support that contributes to comprehensive care for PWE. Skilled mental health clinicians are essential components of the epilepsy care team, and incorporating psychosocial services into epilepsy care may improve outcomes and quality of life.⁵⁶

Dietary Therapy Services

Dietary therapy has a long history of use in the management of childhood epilepsy, with well-documented evidence for efficacy.⁵⁷ It is a treatment of choice for certain genetic syndromes and has a role in managing refractory epilepsy in infants.⁵⁸ More recently, dietary therapy has also been shown to be effective in adults with epilepsy.^{58,59} Registered dietitians play an important role in initiation and subsequent management of all forms of dietary therapy.⁵⁷

Rehabilitation Services

Rehabilitation services are an essential component of comprehensive epilepsy care to address common neurodevelopmental and neuropsychiatric comorbidities in PWE. Recognition of their importance and recommendations for screening and treatment

have been highlighted in previous national and international epilepsy guidelines.¹¹

Current literature also supports consideration of rehabilitative needs for patients undergoing epilepsy surgery evaluation and treatment. Cognitive “prehabilitation” programs before epilepsy surgery can prepare patients for predicted postoperative changes and help tailor postsurgical rehabilitation planning.

Conclusion

These guideline recommendations are the product of a diverse panel, comprising a broad spectrum of epilepsy center stakeholders, including patients and caregivers, which led to a new focus on outpatient care, education, and communication topics that were outside the scope of prior NAEC guidelines.

The 2023 guidelines also reflect the first time that the NAEC has gone beyond the field of neurology to seek input from other medical specialists and allied health personnel. This is exhibited in a greater emphasis on multidisciplinary care conferences, screening for comorbidities of epilepsy, and providing access to other specialty services in addition to the core epilepsy center components of outpatient care, diagnostic procedures, and epilepsy surgery. Consensus opinion from a diversity of stakeholders strengthens the weight of the guideline recommendations in areas where the evidence base is limited.

Greater participation of epilepsy centers in data collection and outcomes reporting is needed to advance research into optimal epilepsy care. Connecting outcomes to the implementation of the recommendations in these guidelines will be especially valuable. The National Association of Epilepsy Centers is considering adopting a living guidelines model as a means for updating individual recommendations as new relevant evidence becomes available.^{7,8,60}

The fundamental purpose of these guidelines is to advance the quality of epilepsy care by outlining the essential services needed for a comprehensive epilepsy center and the optimal manner for their delivery. The current recommendations reflect the contributions from a broad panel of expert opinions and a comprehensive review of existing data. They are designed to facilitate incorporation of future advances and research. As a result, this information will provide ongoing support for epilepsy centers to obtain adequate resources for their programs and for PWE and their caregivers to assess the quality of care they receive.

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