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The State of Specialized Epilepsy Care in the States: Increased Access, New Tools, but the Same Dismal Underutilization of Epilepsy Surgery

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United States Epilepsy Center Characteristics: A Data Analysis From the National Association of Epilepsy Centers

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Background and objectives: Patients with drug-resistant epilepsy (DRE) may benefit from specialized testing and treatments to better control seizures and improve quality of life. Most evaluations and procedures for DRE in the United States are performed at epilepsy centers accredited by the National Association of Epilepsy Centers (NAEC). On an annual basis, the NAEC collects data from accredited epilepsy centers on hospital-based epilepsy monitoring unit (EMU) size and admissions, diagnostic testing, surgeries, and other services. This article highlights trends in epilepsy center services from 2012 through 2019. Methods: We analyzed data reported in 2012, 2016, and 2019 from all level 3 and level 4 NAEC accredited epilepsy centers. Data were described using frequency for categorical variables and median for continuous variables and were analyzed by center level and center population category. EMU beds, EMU admissions, epileptologists, and aggregate procedure volumes were also described using rates per population per year. Results: During the period studied, the number of NAEC accredited centers increased from 161 to 256, with the largest increases in adult- and pediatric-only centers. Growth in EMU admissions (41%), EMU beds (26%), and epileptologists (109%) per population occurred. Access to specialized testing and services broadly expanded. The largest growth in procedure volumes occurred in laser interstitial thermal therapy (LiTT) (61%), responsive neurostimulation (RNS) implantations (114%), and intracranial monitoring without resection (152%) over the study period. Corpus callosotomies and vagus nerve stimulator (VNS) implantations decreased (−12.8% and −2.4%, respectively), while growth in temporal lobectomies (5.9%), extratemporal resections (11.9%), and hemispherectomies/otomies (13.1%) lagged center growth (59%), leading to a decrease in median volumes of these procedures per center. Discussion: During the study period, the availability of specialty epilepsy care in the United States improved as the NAEC implemented its accreditation program. Surgical case complexity increased while aggregate surgical volume remained stable or declined across most procedure types, with a corresponding decline in cases per center. This article describes recent data trends and current state of resources and practice across NAEC member centers and identifies several future directions for driving systematic improvements in epilepsy care.

Commentary

People with drug-resistant epilepsy (DRE) should undergo evaluation at specialized epilepsy centers (SEC) because they offer the next steps in therapy, the foremost of which is epilepsy surgery. The National Association of Epilepsy Centers (NAEC) accredits SECs in the United States as level 3 or level 4, primarily distinguished based on the availability of intracranial EEG monitoring. Apart from proposing guidelines on essential services, personnel, and facilities, the other primary purpose of NAEC's accreditation is to annually collect self-reported SEC data on the types and volume of services provided. This data represents almost the entirety of specialized care available to people with DRE in the US, outside the veterans affairs system. Therefore, any scientific analysis of this data deserves our close attention. The major themes that emerge from the latest such analysis by Ostendorf et al,[1] reviewed here, at three times points – 2012, 2016, and 2019, are:

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a) Improved access to care: The number of reporting NAEC member centers, pediatrics, and adults, increased from 161 in 2012 to 256 in 2019 (+59%). It translated into growth in EMU admissions and beds per 1 million people, which was led by level 3 centers (+159%, +200%, respectively) compared to level 4 (+34%, +47%, respectively).
b) Increased number of care providers and technologists: Epileptologists per 1 million people increased in adult and pediatric centers. There was also a significant increase in the hiring of EEG technologists over time.
c) Increased access to novel testing and non-pharmacological therapies: Increasing number of level 3 and 4 SECs are offering alternative/complementary medicine (33% and 52%, respectively, in 2019), ketogenic diet ($\sim$50% and $\sim$80%, respectively, in 2019), and genetic testing/counseling ($\sim$80% and $\sim$90%, respectively, in 2019). Non-resective surgical options like laser ablation and RNS implantation are offered by a significantly higher number of SECs, and the total volume of the procedures saw a sharp increase of 61% and 114%, respectively, in 2019 compared to 2016. However, the median number of both procedures performed at each SEC did not significantly increase over time. The increase in the total volume, therefore, likely represents more level 4 SECs performing these new procedures (around 40% in 2016 to 60 - 65% in 2019; $\leq$10% in level 3 SECs) along with few high-volume SECs that skew the total volume without significantly altering the median SEC volumes.
d) Use of resective epilepsy surgery is declining: Temporal lobectomies and extratemporal resections fell in the second half of the study period (2016 to 2019) at the per 1 million population level (−3.8% and −15%, respectively), and in terms of median volume performed at the level 4 SECs. Corpus callosotomies and vagus nerve stimulator (VNS) implantations significantly declined. The trend showing the sharpest increase over the years is intracranial monitoring without resection (+152%).

Before delving into the significance of declining surgeries, it is vital to recognize the bright side of the latest trends: the increase in access to care, and experts at a population level, availability of genetic testing at almost all SECs, and availability of non-pharmacological, and non-resective therapy options at an increasing number of SECs. These trends are very encouraging but do not bring any unexpectedly good news. The improvement in access to specialized care is an uptrend that continues from the prior decade. NAEC data analysis from 2003 to 2012 also found an increase in the number of SECs, EMU beds, and admissions.[2] In contrast, the growth and improved access in the last decade is primarily due to the increasing number of centers getting NAEC accreditation and not due to the expansion of these SECs. The median size of EMU beds and admissions at the SECs remained unchanged. The increased hiring of epileptologists, a trend that continues from the prior decade, and technologists coincides with an explosive increase in the practice of continuous EEG (cEEG) monitoring.[3] cEEG monitoring is a resource-intensive diagnostic modality that has revolutionized the care of critically ill patients but minimally impacts DRE patients, except in status epilepticus. Therefore, the increased investment in human resources at SECs may not have directly impacted the care of patients with DRE. In contrast, hiring and integrating advanced practice providers (APPs) improves access and quality of care to people with epilepsy.[4] Empirically, APPs are becoming a critical component of outpatient and EMU care, and future NAEC surveys should consider gathering these data.

Although every patient with DRE should get an epilepsy surgery evaluation at SECs, some estimates show that less than 1% of the approximately 1 million people with DRE in the US are referred there.[5] Further, using the data provided in the manuscript, only .67% of them underwent a surgical procedure in 2019. Serious research investment in investigating the methods and strategies that facilitate the implementation of evidence-based practice into regular use by practitioners is urgently needed. With epilepsy surgery's number needed to treat being two, and its demonstrated cost-effectiveness,[6] it is a tragedy that its use is declining, despite an improvement in access to SECs, which is often considered a significant factor in the lackluster use of epilepsy surgery.[7] This discrepancy likely stems from the fact that level 3 centers primarily drove the growth in access to SECs. However, an overwhelming majority of epilepsy surgeries were performed at level 4 centers (VNS implantation being an exception). The decline in resective surgeries is not compensated by the use of newer tools like RNS and laser ablation, which help overcome the limitation of surgical resection and patient hesitation, respectively, because they lacked a significant increase in median volume at level 4 SECs. The number of level 4 SECs performing these procedures increased by 20 – 25% between 2016 and 2019, while the total volume of laser ablation and RNS implantation increased by 61% and 114%, respectively. This difference suggests that the use of these procedures is possibly shifting to a few high volume level 4 SECs, which drive their total volume but are not affecting the median volume at SECs by remaining as outliers. The trend of underutilization especially unnerving in the context of findings from the 2003 to 2012 NAEC survey that also showed a declining average number of epilepsy surgery per SEC.[2]

The staggering increase in no resections after intracranial electrode use is likely multifactorial. SECs are evaluating an increasing number of complex, non-lesional cases.[8] Additionally, stereoEEG has become the predominant intracranial EEG monitoring modality in the US in the last decade.[9] Being safer and better tolerable[10] but requiring major upfront investment by SECs, it may incentivize lowering the threshold for performing intracranial EEGs. It is nonetheless an invasive brain surgery with associated morbidity and high costs. Hopefully, the fast learning curve with a new technique will lead to a matured use of stereoEEG in the next decade. On the contrary, if this current

uptrend continues, it may lead to disuse and disrepute for the technique in the long run.

It is critical to remember that the NAEC survey indicates the 'quantity' but not the 'quality' of specialized care available at SECs. We lack data to compare surgical outcomes or selection criteria for VNS implantation between level 3 and 4 centers or low-volume and high-volume centers, which shows differences in complication rates.[11] We are far from establishing national benchmarks for epilepsy surgery outcomes, akin to cancer and cardiac surgery fields. Such benchmarking and outcomes reporting will improve the quality of care and help alleviate concerns about epilepsy surgery among PWE by assisting them to make more informed decisions. In contrast to epilepsy surgery, a proven therapy with decades of experience in most SECs, a newly FDA-approved anti-seizure medication (ASM) goes from being completely unknown to being used in thousands of patients in a matter of 1 to 2 years. One major difference between these two therapies is that adoption of the latter is typically facilitated by coordinated marketing efforts of the pharmaceutical industry. Increasing the utilization of epilepsy surgery has clear financial incentives at a population level because DRE patients account for a large proportion of direct epilepsy healthcare costs, and epilepsy surgery is cost-effective compared to medical management across different healthcare systems.[6,12,13] In the absence of national stewardship for epilepsy surgery, the findings of Ostendorf et al should be a call to action for us, the epilepsy care providers. The ongoing underutilization of resective epilepsy surgery underscores the need to understand and resolve barriers to adoption of this potentially curative intervention. With growing availability of new technologies, it is an ethical imperative to generate robust comparative effectiveness and societal cost effectiveness data to objectively guide adoption and public health impact.

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