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Epilepsy surgery in the United States: Analysis of data from the National Association of Epilepsy Centers

Kitti Kaiboriboon[a,b,1], Ayham M. Malkhachroum[a], Ahmad Zrik[a], Ahmad Daif[a], Nicholas M. Schiltz[c,d], David M. Labiner[e], Samden D. Lhatoo[a,*]

[a] Epilepsy Center, Department of Neurology, University Hospitals Case Medical Center, Cleveland, OH, United States
[b] Neurological and Behavioral Outcome Center, Neurological Institute, University Hospitals Case Medical Center, Cleveland, OH, United States
[c] Population Health and Outcomes Research Core, Clinical & Translational Science Collaborative, Department of Epidemiology & Biostatistics, Case Western Reserve University, Cleveland, OH, United States
[d] The Center for Child Health & Policy, Rainbow Babies and Children's Hospital, Cleveland, OH, United States
[e] Arizona Comprehensive Epilepsy Program, Department of Neurology, University of Arizona, Tucson, AZ, United States

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ABSTRACT

Objective: To examine trends in epilepsy-related surgical procedures performed at major epilepsy centers in the US between 2003 and 2012, and in the service provision infrastructure of epilepsy centers over the same time period.
Methods: We analyzed data from the National Association of Epilepsy Centers' (NAEC) annual surveys. The total annual figures, annual average figures per center and annual rates of each surgical procedure based on US population numbers for that year were calculated. Additional information on center infrastructure and manpower was also examined.
Results: The number of the NAEC's level 3 and level 4 epilepsy centers submitting annual survey reports increased from 37 centers in 2003 to 189 centers in 2012. The average reported number of Epilepsy Monitoring Unit (EMU) beds per center increased from 7 beds in 2008 to 8 beds in 2012. Overall annual EMU admission rates doubled between 2008 and 2012 but the average number of EMU admissions and epilepsy surgeries performed per center declined over the same period. The annual rate of anterior temporal lobectomies (ATL) for mesial temporal sclerosis (MTS) declined by >65% between 2006 and 2010. The annual rate of extratemporal surgery exceeded that of ATL for MTS from 2008 onwards, doubled between 2007 and 2012 and comprised 38% of all resective surgeries in 2012. Vagus nerve stimulator implant rates consistently increased year on year and exceeded resective surgeries in 2011 and 2012.
Conclusion: The last decade has seen a major change in the US epilepsy surgery landscape. Temporal lobectomies, particularly for MTS, have declined despite an increase in EMU admissions. On the other hands, case complexity correspondingly increased as evidenced by more extratemporal surgery, intracranial recordings and palliative procedures.

Introduction

The benefit of epilepsy surgery, particularly temporal lobectomy has been well documented (Wiebe et al., 2001; Engel et al., 2012) and published estimates have emphasized the under-utilization of this important treatment option (Lhatoo et al., 2003; Berg et al., 2009). However, rather than the expected increase in surgical numbers effected by the impact of peer reviewed literature (Wiebe et al., 2001), physician education and the establishment of guidelines and practice parameters (Engel et al., 2003), surveys in the UK (Neligan et al., 2013) and Sweden (Kumlien and Mattsson, 2010) suggest that the number of resective surgeries have in fact declined over the past decade. Recent studies in the US analyzing the Nationwide Inpatient Sample (NIS) also suggest similar trends (Englot et al., 2012; Schiltz et al., 2013). Nonetheless, there is concern about the limited accuracy and interpretability of the NIS data, which have mainly relied on the International Classification of Diseases 9th Revision

Abbreviations: AAN, American Academy of Neurology; ATL, anterior temporal lobectomy; EMU, epilepsy monitoring Unit; MTLE, mesial temporal lobe epilepsy; MTS, mesial temporal sclerosis; NAEC, National Association of Epilepsy Centers; NIS, Nationwide Inpatient Sample; VNS, vagus nerve stimulation.

* Corresponding author. Tel.: +1 216 844 5855; fax: +1 216 844 3160.
E-mail address: Samden.Lhatoo@UHhospitals.org (S.D. Lhatoo).
[1] Currently at Epilepsy Center, Swedish Neuroscience Institute, Seattle, WA, USA.

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Clinical Modification (ICD-9-CM) codes (Kaiboriboon et al., 2011; Cardenas et al., 2014). In addition, identification of specific surgical procedures (e.g., temporal lobectomy, or extratemporal resection) is impossible to carry out using the NIS dataset. Hence, the true picture of epilepsy surgery volumes and time trends in the US, particularly for temporal lobectomy, remains largely unknown. A recent Q-PULSE survey of US epileptologists, assumed to be mostly representing academic medical centers, has shown a broad, but not universal, perception that there is an overall increase in case complexity and fewer cases of mesial temporal lobe epilepsy over the past 10 years (Carlson, 2013). This article provides direct evidence of epilepsy surgery expansion or lack thereof, in the US between 2003 and 2012 using data from the National Association of Epilepsy Centers (NAEC).

Material and methods

The NAEC is a non-profit organization that has more than 190 members across the US (National Association of Epilepsy Centers, 2007). Every year the NAEC asks its members to provide information on the level of care that they provide including epilepsy surgery volumes, and to indicate whether their epilepsy center meets criteria for level 3 or level 4 epilepsy center designations (Labiner et al., 2010).

The NAEC's level 3 epilepsy centers provide basic diagnostic and treatment for patients with refractory epilepsy including non-invasive evaluations for epilepsy surgery, straightforward resective epilepsy surgery (e.g., lesionectomy, anterior temporal lobectomy in a clear-cut mesial temporal sclerosis (MTS)), and implantation of devices such as vagus nerve stimulators (VNS). Level 4 epilepsy centers serve as regional and/or national referral facilities and therefore provide more complex diagnostic and treatment facilities including intracranial electrode placement, functional cortical mapping, evoked potential recording, electrocorticography (ECoG), and a broad range of surgical procedures for epilepsy (Labiner et al., 2010).

The NAEC's annual designation survey is based on the NAEC's guidelines for essential services, personnel, and facilities in specialized epilepsy centers (Labiner et al., 2010). Over time, there have been several modifications to the annual survey.

We analyzed total as well as annual averaged figures per center for essential services, personnel, facilities and procedures. We also calculated annual rates of EMU admissions and surgical procedures. Since US population numbers have increased over the study period as has membership of the NAEC, we estimated annual surgical numbers based on the prevalent population with epilepsy in the US. We used yearly data from the US Census population estimates (US Census Bureau, 2011) and the previously published prevalence rate of 7.1/1000 persons (Hirtz et al., 2007) to calculate the total number of persons with epilepsy in the US for each year of our study period.

We estimated the number of people with refractory epilepsy to be about 30% of the entire epilepsy population (Kwan and Sander, 2004). Since up to 20% of persons with refractory epilepsy turn out to have non-epileptic seizures (Binnie et al., 1981), only 80% of the total number of persons with refractory epilepsy was used as a denominator to calculate rates for comparison over time. Mann–Kendall trend test was used to test for changes in the rates of surgeries. Since multiple comparisons could lead to false positive findings, false discovery rate control was performed using Benjamini–Hochberg procedure (Benjamini and Hochberg, 1995). Statistical analysis was conducted using R version 2.15.1 for Windows. All *P*-values were two-sided and values of <0.05 were considered statistically significant.

Results

The number of epilepsy centers that responded to the survey increased from 37 centers in 2003 to 189 centers in 2012. Table 1 shows the average annual expansion of Epilepsy Center facilities over time. The number of epilepsy monitoring unit (EMU) beds increased from approximately 7 beds in 2008 to approximately 8 in 2012. Average personnel numbers including those of epileptologists, neurosurgeons, neuropsychologists, and nurses all increased. In 2012, each epilepsy center had approximately 5 epileptologists, 2 neurosurgeons, 1–2 neuropsychologists, and 3 nurses. In contrast, the average number of EMU admissions and every epilepsy surgery category per center declined over the years (Table 1).

Table 2 shows the rates of EMU admissions and epilepsy-related surgical procedures calculated per 100,000 persons with refractory epilepsy for each calendar year. Adjusting for changes in population numbers over the years, there was an overall increase in EMU admission and intracranial monitoring rates. Rates of both temporal and extratemporal resections also increased to reach a peak in 2009, approximately 6 years after the publication of practice guidelines for epilepsy surgery referrals by the American Academy of Neurology (AAN) (Engel et al., 2003), and then declined thereafter. The rates of ATL for MTS, and non-lesional temporal lobectomy rose and dropped much earlier. In 2010, the rates of ATL for MTS and non-lesional resection were less than half of those in 2006. Temporal lobectomy rates continued to decline over the last few survey years, but rates of extratemporal

Table 1
Averaged annual numbers of essential services, personnel, facilities and procedures per epilepsy center.

	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Number of epilepsy centers	37	55	72	84	87	98	117	129	163	189
EMU beds	–	–	–	–	6.82	6.38	7.11	6.26	7.31	7.71
EMU admission	–	–	–	–	–	387.17	425.32	418.13	403.88	363.33
Epileptologists	3.70	3.58	3.64	3.89	4.80	4.87	4.98	5.01	4.96	5.10
Neurosurgeons	1.70	0.95	1.76	1.73	1.90	1.88	2.04	2.10	1.87	1.88
Neuropsychologists	0.16	0.45	1.35	1.32	1.44	1.52	1.52	1.47	1.45	1.43
Nurses	0.62	0.64	1.17	1.15	1.91	2.59	1.89	1.93	1.76	2.72
Intracranial EEG recording	28.84	7.96	15.42	18.90	14.78	12.21	12.26	10.80	8.22	8.17
Temporal lobe resection	–	–	–	–	–	18.64	17.54	14.70	8.75	8.10
Extratemporal resection	–	–	–	–	5.33	7.44	8.14	7.26	5.61	5.11
Hemispherectomy	–	–	–	–	–	1.20	1.33	1.11	–	–
Corpus callosotomy	–	–	–	–	–	1.44	1.26	1.23	1.10	1.01
VNS	26.30	8.93	18.72	–	–	17.56	17.34	19.27	16.67	14.86
Neurostimulator implantation	–	–	–	–	–	2.92	4.21	3.71	–	–
Radiofrequency surgery	–	–	–	–	–	0.77	1.18	0.53	0.41	0.22

Abbreviations: EMU, epilepsy monitoring unit; EEG, electroencephalography; VNS, vagus nerve stimulation; NB. Blank boxes indicate that data was not collected for these categories.