



Original Article

Utilization of epilepsy surgery in the United States: A study of the National Inpatient Sample investigating the roles of race, socioeconomic status, and insurance

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ABSTRACT

Background: Epilepsy is estimated to affect 70 million people worldwide and is medically refractory in 30% of cases.

Methods: This is a retrospective cross-sectional study using a US database from 2012 to 2014 to identify patients aged ≥ 18 years admitted to the hospital with epilepsy as the primary diagnosis. The sampled population was weighted using Healthcare Cost and Utilization Project guidelines. Procedural ICD-9 codes were utilized to stratify the sampled population into two cohorts: resective surgery and implantation or stimulation procedure.

Results: Query of the database yielded 152,925 inpatients, of which 8535 patients underwent surgical intervention. The nonprocedural group consisted of 76,000 White patients (52.6%) and 28,390 Black patients (19.7%) while the procedural group comprised 5550 White patients (64%) and 730 Black patients (8.6%) ($P < 0.001$). Patients with Medicare were half as likely to receive a surgical procedure (14.8% vs. 28.4%) while patients with private insurance were twice as likely to receive a procedure (53.4% vs. 29.3%), both were statistically significant ($P < 0.01$). Those in the lowest median household income quartile by zip code ($< \$40,000$) were 68% less likely to receive a procedure (21.5% vs. 31.4%) while the highest income quartile was 133% more likely to receive a procedure (26.1% vs. 19.5%). Patients from rural and urban nonteaching hospitals were, by a wide margin, less likely to receive a surgical procedure.

Conclusion: We demonstrate an area of need and significant improvement at institutions that have the resources and capability to perform epilepsy surgery. The data show that institutions may not be performing enough epilepsy surgery as a result of racial and socioeconomic bias. Admissions for epilepsy continue to increase without a similar trend for epilepsy surgery despite its documented effectiveness. Race, socioeconomic status, and insurance all represent significant barriers in access to epilepsy surgery. The barriers can be remedied by improving referral patterns and implementing cost-effective measures to improve inpatient epilepsy services in rural and nonteaching hospitals.

Keywords: Deep brain stimulation, Epilepsy surgery, Functional neurosurgery, National database, Neuromodulation

INTRODUCTION

Epilepsy is estimated to affect 70 million people worldwide.^[32] Medically refractory epilepsy occurs when two adequate trials of appropriate antiepileptic drugs fail to control their

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seizures.^[13,32] This occurs in 30% of patients with epilepsy and significantly increases the risk of seizure related injuries and death.^[32] Health-care costs are significantly increased in these patients as well.^[32] Multiple randomized controlled clinical trials have shown that the different surgical modalities (i.e., lesionectomy, lobectomy, disconnection, vagal nerve stimulation, responsive nerve stimulation, and deep brain stimulation) are superior to medical management alone in patients with medically refractory epilepsy.^[32]

Epilepsy surgery in children and adults continues to be underutilized in the US.^[2,16,32] Despite the American Academy of Neurology practice parameter in 2003 recommending “referral to a surgical epilepsy center on failing appropriate trials of first-line antiepileptic drugs,” studies pre- and post-2003 show a median duration of seizures of 18 years before referral to epilepsy surgery centers.^[2,10,29] However, epilepsy surgery performed in children increased from 0.85 procedures per 1000 in 1997 to 1.44 per 1000 in 2009. In 1990, there were 100,000–300,000 patients with medically refractory epilepsy in the United States and only 1500 surgeries, or 0.5–1.5% of those needed, were performed.^[7] According to Englot *et al.*, there were approximately 112,026 hospitalizations and 6653 resective surgeries performed from 1990–1994 to 2004–2008 in the United States.^[7] From 1990–1994 to 2004–2008, a 100% increase in hospitalizations was observed for medically refractory epilepsy but with a decreased rate of resective surgery (6.9–4.3%).^[6] Part of this result was attributed to increased hospitalizations among low-volume epilepsy surgery centers who are less likely to perform resective surgery.^[6] Schiltz *et al.* demonstrated an increase in hospitalization rate for video electroencephalogram (EEG) monitoring from 1998 to 2009 but without an increase in intracranial electroencephalogram or surgery.^[25] Thus, the underutilization of epilepsy surgery has been attributed to multiple factors, including but not limited to, fear of complications, delays in referral, lack of knowledge of epilepsy surgery among neurologists, proximity to epilepsy centers, increased hospitalizations among low-volume centers, non-White race, and Medicaid and Medicare insurance.^[2,9,10,12,16,25,26,29]

Our study aims to characterize hospitalization and surgery rates from 2012 to 2014 in the United States using the national inpatient database and to further elucidate factors associated with utilization of epilepsy surgery as well as its associated complications.

MATERIALS AND METHODS

Study design and eligibility criteria

Institutional Review Board approval was obtained from Riverside University Health System for access to the National Inpatient Sample (NIS), Healthcare Cost and Utilization

Project (HCUP), Agency for Healthcare Research and Quality.^[19] This was a retrospective cross-sectional study using the NIS database from 2012 to 2014 to identify patients aged ≥ 18 years admitted to the hospital with epilepsy as the primary diagnosis [Table 1]. The sampled population was weighted using HCUP guidelines. Procedural and complication ICD-9 codes were utilized to identify the sampled population into two cohorts: resective surgery and implantation or stimulation procedure [Table 2]. Natural log was utilized to normalize nonparametric continuous variables, which were presented by medians and the respective interquartile ranges. Categorical variables were presented as counts and their respective percentages. All counts below 10 were suppressed. Complex sample analysis was utilized for univariate and multivariate regression analysis to measure outcomes of mortality and complications between the two procedural cohorts within the sampled epilepsy population. All extractions and analysis were performed using SPSS v.26. $P < 0.05$ was determined to be statistically significant.

RESULTS

Query of the database yielded 152,925 inpatients with an epilepsy-DRG from 2012 to 2014. Of these patients, 8535 patients underwent surgical intervention. The median age of those in the procedural group was 26 years compared to 33 years in the nonprocedural group ($P < 0.001$). The number of epilepsy-DRG admissions increased by 9.2% as the number of epilepsy surgeries decreased by 1.4% during the 3-year study period. There was a significant racial difference in the demographics of nonprocedural versus procedural groups. The nonprocedural group consisted

Table 1: ICD-9 codes, primary epilepsy diagnosis of those ≥ 18 y/o admitted to hospital, and complications codes used.

ICD-9 codes	Description
345.91	Epilepsy, unspecified, with intractable epilepsy
345.9	Epilepsy codes, epileptic seizures, seizure disorder NOS, recurrent seizure disorder
345.0/345.1	Petit mal/petit mal with intractable
345.1/345.11	Grand mal/Grand mal with intractable
345.2	Petit mal status
345.3	Grand mal status
345.4	Complex focal seizure
345.41	Partial epilepsy, with impairment of consciousness, with intractable epilepsy
345.5	Simple focal seizure
345.51	Partial epilepsy, without mention of impairment of consciousness, with intractable epilepsy
345.7/345.71	Epilepsia partialis continua/epilepsia partialis continua with intractable
345.8/345.81	Other forms of epilepsy/other forms of epilepsy with intractable

of 76,000 White patients (5.6%) and 28,390 Black patients (19.7%) while the procedural group comprised 5550 White patients (64%) and 730 Black patients (8.6%) ($P < 0.001$). There were no statistically significant differences between any other racial demographic between the two groups [Table 3]. In the nonprocedural group, patients with Medicare were half as likely to receive a surgical procedure (14.8% vs. 28.4%) while patients with private insurance were twice as likely to receive a procedure (53.4% vs. 29.3%), both were statistically significant ($P < 0.01$). Those in the lowest median household income quartile by zip code ($< \$40,000$) were 68% less likely to receive a procedure (21.5% vs. 31.4%) while the highest income quartile was 133% more likely to receive a procedure (26.1% vs. 19.5%). Patients from rural and urban nonteaching hospitals were, by a wide margin, less likely to receive a surgical procedure [Table 3]. Intrahospital mortality in both groups was low but higher in nonprocedural epilepsy-DRG admission than in surgery admissions (1.6% vs. 0.30%, $P < 0.001$).

There were no significant differences in comorbidities or complications between the resective surgery group and the implantation or stimulation surgery group. There were higher costs (median costs \$164,286 vs. \$108,782, $P < 0.001$) and greater hospital length of stay with the implantation or stimulation surgery group (9 vs. 4 days, < 0.001). Resective

surgeries saw a 7.4% increase from 2012 to 2014 (1490–1600) while implantation or stimulation surgeries saw a 10.9% decrease from 2012 to 2014 (1370–1220).

DISCUSSION

Medically refractory epilepsy is a condition unfamiliar to many patients and clinicians. In fact, one survey found nearly 49% of one group of neurologists were unfamiliar with the definition of medically refractory epilepsy.^[19] It is a significant source of disability that requires extensive medical resources. The literature increasingly demonstrates that epilepsy surgery can significantly reduce, if not completely eliminate, seizures and improve the quality of life in both children and adults albeit at a higher cost.^[4,7] Neurosurgeons, neurologists, and hospital administrators can utilize these data to better target patient outreach efforts to find patients who have not received optimal treatment options. Despite the evidence and new clinical practice guidelines recommending earlier referrals for epilepsy surgery, significant barriers remain resulting in delayed referral patterns and increased hospitalizations for epilepsy without a similar trend in the number of epilepsy surgeries performed.^[8,17,21] In our study of the NIS from 2012 to 2014, we found many statistically significant barriers that limit access to epilepsy surgery. The three most significant barriers were race (Black), income ($< \$40,000$), and location (rural).

Racial factors in utilization of epilepsy surgery

Our findings are in line with previous publications discussing racial disparities in access to epilepsy surgery. In a single institution retrospective cohort, Burneo *et al.* found that African-Americans were 60% less likely to undergo epilepsy surgery than non-Hispanic Whites.^[3] A retrospective review of a nationwide population cohort from 1988 to 2003 found that African-American race was a predictor of being less likely to receive anterior temporal lobectomy.^[13] In addition, in a review of the Kids' Inpatient Database and NIS, Sánchez Fernández *et al.* found that Black patients were significantly underrepresented even after stratifying for socioeconomic status.^[23] Another study by Jackson *et al.* found that non-White patients had longer duration to epilepsy surgery and underwent surgery at an older age despite having to travel shorter distances for care.^[11] The numbers for epilepsy surgery appear to be a microcosm of the racial disparities that exist in all facets of the health-care system.^[5,27,30]

Socioeconomic factors in utilization of epilepsy surgery

In our review, median income represented the second most significant barrier to receiving epilepsy surgery. Those in the lowest income quartile were the only subset of patients to have a lower percentage of patients to undergo a surgical

Table 2: ICD-9 codes, types of resective surgery, and implantation or stimulation procedure.

Resective surgery	Implantation/stimulation surgery
01.52 – Hemispherectomy	02.93 – Implantation or replacement of intracranial neurostimulator leads
01.53 – Lobectomy	04.92 – Implantation or replacement of peripheral neurostimulator leads
01.59 – Other excision or destruction of lesion or tissue of brain	01.20 – Craniotomy and craniectomy for implantation or replacement of neurostimulator pulse generator
01.32 – Lobotomy and tractotomy	01.22 – Removal of intracranial neurostimulator leads
01.41 – Operations on thalamus	01.26 – Insertion of catheters into cranial cavity or tissue
01.39 – Other incision of brain	01.27 – Removal of catheters from cranial cavity or tissue
01.51 – Excision of lesion or tissue of cerebral meninges	01.28 – Placement of intracerebral catheters via burr holes
	00.94 – Intraoperative neurophysiologic monitoring
	04.99 – Other operations on cranial and peripheral nerves – other

Table 3: Demographics of epilepsy patients undergoing epilepsy procedure.

	No procedure (n=144,390)		Procedure (n=8535)		P-value
	Median	IQR	Median	IQR	
Age	33	12.55	26	13.42	<0.001
Gender					
Male	74,025	51.30%	4340	51.80%	0.746
Female	70,355	48.70%	4195	49.20%	
Race (uniform)					
White	76,000	52.60%	5540	64.90%	<0.001
Black/African-American	28,390	19.70%	730	8.60%	<0.001
Hispanic	19,385	13.40%	1130	13.20%	
Asian or Pacific Islander	2805	1.90%	170	2.00%	
Native American	1045	0.70%	40	0.50%	
Other	6285	4.40%	365	4.30%	
Payor source					
Medicare	40,995	28.40%	1265	14.80%	<0.001
Medicaid	48,460	33.60%	2210	25.90%	
Private insurance	42,325	29.30%	4560	53.40%	<0.001
Self-pay	6220	4.30%	100	1.20%	
No charge	550	0.40%	20	0.20%	
Other	5580	3.90%	370	4.30%	
Median household income					
<\$40,000	45,285	31.40%	1835	21.50%	<0.001
\$40,000–\$50,999	35,270	24.40%	2135	25.00%	
\$51,000–\$65,999	32,160	22.30%	2150	25.20%	
\$66,000+	28,195	19.50%	2230	26.10%	<0.001
Hospital location/type					
Rural	5940	4.10%	55	0.60%	<0.001
Urban-nonteaching	26,385	18.30%	145	1.70%	
Urban teaching	112,065	77.60%	8335	97.70%	<0.001

procedure (31.4% vs. 21.5%). Recent studies demonstrate similar findings. In a retrospective review of 284 children receiving epilepsy surgery, those in the lowest income quintile had the longest time to receive epilepsy surgery and had significantly lower odds of improvement in seizure frequency.^[20] Non-White patients are more likely to have government-funded insurance such as Medicare and Medicaid and undergo epilepsy surgery at an older age.^[11,26] In a study of Medicare beneficiaries, there was an increased use of enzyme-inducing AEDs in patients despite Quality Indicator for Epilepsy Treatment 9 recommendations to avoid these as first-line agents in older patients.^[18] It can be inferred from our data as well as the literature that there is a significant socioeconomic bias in patient selection for epilepsy surgery.^[21]

Geographic barriers to epilepsy surgery

Patients residing in rural locations also underwent significantly fewer epilepsy procedures. This is likely because epilepsy providers are primarily located in urban centers and visiting these centers are not feasible for many patients.^[21] Lack of proximity to specialists may also

affect referral patterns or knowledge of specialists on the part of primary care providers.^[31] Forming collaborative relationships between community and tertiary centers are a proven method to increase the number of referrals for epilepsy surgery and patients whose cases are discussed in a multidisciplinary epilepsy conference.^[17,22]

Potential solutions

The above factors each play a unique role that affects access to epilepsy surgery. It is essential that primary care providers and neurologists be educated on the efficacy of epilepsy surgery and early referral to epilepsy centers is encouraged.^[6,15,17] Neurosurgeons who perform epilepsy procedures and epilepsy foundations can provide such education in this regard. The Connectors Project is a strong example of how educational outreach to providers and patients and their families can improve access to information and emerging trends in rural and underserved communities by connecting patients and providers.^[15] In addition, they can offer telemedicine appointments to patients with geographic or socioeconomic limitations so they may eliminate barriers to a subspecialty consultation.^[22] Nathan and Gutierrez established

FACETS, a framework to address specific factors that affect disparities in epilepsy surgery. The six factors are patient fear, access, communication barriers, education, trust, and social support and physician bias.^[14] The authors recommended interventions such as provider bias and cultural communication training, visual aids and handouts to explain procedures, community engagement, and social work involvement.^[14]

Schlitz *et al.* highlights the possibility of minimally-invasive epilepsy surgery for patients with disadvantaged patients but is not convinced that access will be broadened beyond large academic centers in the near future. They argue that behavioral and social strategies will be more effective to address the surgical access gap for medically refractory epilepsy.^[24]

In addition, epilepsy programs must make efforts to alleviate the financial burden on patient families. The multiple encounters required for preoperative planning can be a deterrent for families whose financial security may be threatened by taking time off work. Jackson *et al.* suggested having an epilepsy program coordinator schedule all of the patient's preoperative studies and appointments together to prevent delays to surgery and to ease the family's burden.^[11]

Remote EEG software provides a technological solution that can eliminate many existing barriers for patients with this condition. Multiple studies in Guinea found that a smartphone-based technology – Smartphone Brain Scanner – and tablet-based software provided the ability for low-income areas to receive specialist input using remote technologies and crowdsourcing.^[28,32] Further, advancements and implementation of these technologies will greatly expand access to treatment for those in geographic or financial barriers to epilepsy care. Incentivizing these technological advancements may also aid in the speed of their implementation.

Limitations

Retrospective reviews inherently have their own limitations on how long and what variables were collected in addition to selection bias. Having to search a database based on various diagnostic and procedure codes may leave out a significant number of patients due to incorrect coding. The sample data come from the years 2012 to 2014 which may not accurately reflect current trends in epilepsy surgery, however, the NIS only has data through 2018 and the largest database study previously performed on epilepsy surgery reported data through 2008.^[7] The NIS, although powerful as a population-level representative database, harbors limitations in data accuracy and comprehensiveness. This portends a risk for selection, sampling, and design biases. We also cannot adjust for institutional and physician quality, procedural nuances, or severity of illness beyond what is delineated by ICD characterization.^[1] Lack of long-term follow-up may

also impact the data accuracy in our study. Finally, the NIS describes hospital charges rather than true reimbursement.

CONCLUSION

Our review of the NIS data from 2012 to 2014 and epilepsy literature demonstrate an area of need and significant improvement at institutions that have the resources and capability to perform epilepsy surgery. Potential epilepsy surgery patients can be up to 30% in a hospital catchment area. The data show that institutions are not performing enough epilepsy surgery because of racial and socioeconomic bias. Admissions for epilepsy continue to increase without an increase in epilepsy surgery despite its documented effectiveness. Race, socioeconomic status, and insurance all represent significant barriers in access to epilepsy surgery. The barriers can be remedied by improving referral patterns and implementing cost-effective measures to improve inpatient epilepsy services in rural and nonteaching hospitals.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Conflicts of interest

There are no conflicts of interest.

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