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Increasing Utilization Of Pediatric Epilepsy Surgery In The United States Between 1997 and 2009

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SUMMARY

OBJECTIVE—To examine national trends of pediatric epilepsy surgery usage in the United States between 1997 and 2009.

METHODS—We performed a serial cross-sectional study of pediatric epilepsy surgery using triennial data from the Kids' Inpatient Database from 1997 to 2009. The rates of epilepsy surgery for lobectomies, partial lobectomies, and hemispherectomies in each study year were calculated based on the number of prevalent epilepsy cases in the corresponding year. The age-race-sex adjusted rates of surgeries were also estimated. Mann-Kendall trend test was used to test for changes in the rates of surgeries over time. Multivariable regression analysis was also performed to estimate the effect of time, age, race, and sex on the annual incidence of epilepsy surgery.

RESULTS—The rates of pediatric epilepsy surgery significantly increased from 0.85 epilepsy surgeries per 1,000 children with epilepsy in 1997 to 1.44 epilepsy surgeries per 1,000 children with epilepsy in 2009. An increment in the rates of epilepsy surgeries was noted across all age groups, in boys and girls, all races, and all payer types. The rate of increase was lowest in blacks and in children with public insurance. The overall number of surgical cases for each study year was lower than 35% of children who were expected to have surgery, based on the estimates from the Connecticut Study of Epilepsy.

SIGNIFICANCE—In contrast to adults, pediatric epilepsy surgery numbers have increased significantly in the past decade. However, epilepsy surgery remains an underutilized treatment for

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DISCLOSURE OF CONFLICTS OF INTEREST

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children with epilepsy. In addition, black children and those with public insurance continue to face disparities in the receipt of epilepsy surgery.

Keywords

Epilepsy surgery; Pediatrics; Trends

INTRODUCTION

Several studies have shown that the rate of epilepsy surgery in adults has either declined[1] or remained stable in the past decade.[2, 3] However, whether the utilization of epilepsy surgery in pediatric population has followed the same pattern is unclear. Our recent analysis of the Nationwide Inpatient Sample (NIS) suggested that there was an expansion of pediatric epilepsy surgery during 2004–2009 compared to 1998–2003.[3] Nonetheless, a detailed analysis particularly the annual rates of surgery in pediatric population was not performed. A recent study at a single pediatric epilepsy surgery center also found an increase in the number of surgical procedures performed in the last 25 years.[4] To date, there is a lack of national estimates of pediatric epilepsy surgery in the United States. This information is critically needed for planning appropriate actions and interventions to improve quality of care for children with refractory epilepsy.

This study aimed to examine national trends in epilepsy surgery utility in children using the Kids' Inpatient Database (KID). The KID, which is part of the Healthcare Cost and Utilization Project (HCUP), represents national estimates of all hospital discharges specific to children in the US. This dataset has been validated against other national databases including the American Hospital Association annual survey, and the National Hospital Discharge Survey (NHDS) to ensure the accuracy of estimates.[5, 6] The KID has been widely and successfully used to analyze patterns of hospitalizations in children with several disease entities.[7–9] Unlike the NIS, which is based on a random sample of only 20% of the entire hospital discharges,[10] the weighted analysis of KID is based on 80% of all non-birth pediatric discharges from community, non-rehabilitation hospitals in states participating in HCUP.[11] We hypothesized that rates of epilepsy surgery in the pediatric population have increased over time.

METHODS

The study protocol was approved by the Institutional Review Board at Case Western Reserve University.

Study design and data source

Epilepsy surgery cases were identified from a serial cross-sectional analysis of pediatric hospital discharges using the KID in 1997, 2000, 2003, 2006, and 2009. The number of participating states in the KID has increased from 22 states in 1997 to 27 states in 2000, 36 states in 2003, 38 states in 2006, and 44 states in 2009. The KID contains deidentified discharge information and includes weighted variables that can be used to derive national

estimates while accounting for differences in the sampling frame and/or oversampling of patient sub-populations that might have occurred over time.[5]

Study population

Children younger than 19, who underwent epilepsy surgery were identified by the presence of the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis codes for epilepsy or convulsion (ICD-9-CM: 345.XX or 780.39) and procedure codes for brain lobectomy (ICD-9-CM: 01.53), partial brain lobectomy (ICD-9-CM: 01.59), or hemispherectomy (ICD-9-CM: 01.52).

Independent variables

The frequency and rate of surgeries were compared across several covariates including age group, gender, race/ethnicity, primary payer, hospital characteristics, and types of surgery. Age was divided into <1 year, 1–4 years, 5–9 years, 10–14 years, and 15–17 years. Race/ethnicity was categorized as white, black, Hispanic, and other races. Payer types were classified as private, public (e.g., Medicaid, Children's Health Insurance Program [CHIP], other government programs), and "other" including the uninsured. A hospital was considered to be a teaching hospital if it had an AMA-approved residency program, was a member of the Council of Teaching Hospitals (COTH), or had a ratio of full-time equivalent interns and residents to beds of 0.25 or higher.[11] Hospital regions were classified as Northeast, Midwest, South, or West. Children's hospitals were defined by membership in the National Association of Children's Hospitals and Related Institutions (NACHRI).[11]

Data analysis

All statistical analysis was conducted using SAS/STAT software, version 9.2 of the SAS system for UNIX (SAS Institute Inc., Cary, NC, USA) except where stated otherwise. We used discharge weights created by the HCUP to produce national estimates for each sampling year. We also used the survey design procedures in SAS (SURVEYFREQ and SURVEYMEANS) to account for the stratified sampling design and clustering by hospital. The stratification variables were hospital region, bed size, ownership/control, and location/teaching status, and each individual hospital was a cluster unit. Due to significant modifications to the KID in 2000, we used KID Trend Supplemental File, which was developed to provide consistent data elements and discharge weights for 1997 HCUP KID. Since the unit of analysis in the KID was a hospital discharge rather than an individual, we estimated the number of children with epilepsy for each study year based on US Census estimates as reported in the AHRQ 2011 Population File[12] and a prevalence of 6.3 per 1,000 persons.[13] The age group of <1 year and 1–4 years were combined for rate of surgery analysis due to a very small number of surgeries performed in infants. The rate of surgeries for each study year was then calculated by dividing the weighted number of surgeries performed, by the number of children with epilepsy. In addition, the age-race-sex adjusted rates of surgeries were also calculated using direct adjustment with the 2000 US population ≤18 as the reference population. The prevalence of epilepsy for each age-race-sex and payer type category was obtained from the National Survey of Children's Health.[13] The number of children with epilepsy by payer type for each study year was calculated based on the US census estimates of insurance enrollment among children.[14] Mann-Kendall trend test was

used to test for changes in the rates of surgeries over time. To account for multiple comparisons in trend analysis, we used Benjamini-Hochberg method[15] to control for the false discovery rate. R version 3.1.1 for Windows[16] and the Kendall package were used for Mann-Kendall trend test and for calculating the P-values adjusted for multiple comparisons. We also performed multivariable negative binomial regression analysis to estimate the effect of time, age, race, and sex on the annual incidence of epilepsy surgery. Number of surgeries was the outcome variable, and age, race, sex, year, and all possible age-race-sex interaction terms were the covariates. The log-transformed population estimate of each year-age-race-sex combination was used as the offset term. Payer type was not included in the multivariate model because the US census did not have population estimates by insurance type for each age-race-sex category. All P-values were two-sided and values of ≤0.05 were considered statistically significant.

Sensitivity Analysis

Previous validation studies in the US have shown that the positive predictive value of ICD-9-CM code 345.xx or 780.39 for a clinical diagnosis of epilepsy ranges between 62%[17] and 94%.[18] Since a single appearance of 780.39 might not be specific to epilepsy, we performed a sensitivity analysis by including only children with ICD-9-CM codes for epilepsy (345.xx).

RESULTS

Over a period of 13 years, the number of epilepsy surgeries nearly doubled (Table 1). This increase was seen across all age groups, with the exception of infants. More boys underwent surgery than girls across the study period. The greatest number of surgeries was observed among whites, compared to blacks, Hispanics, or other minorities. Children with private insurance also had the highest number of surgeries performed compared to those who were on public insurance programs or had ‘other’ payer, which included the uninsured. A majority of pediatric epilepsy surgeries were performed at academic Children’s Hospitals.

The number of lobectomies, partial lobectomies, and hemispherectomies increased over time (Table 2). During the entire study period, the mean age was 10.8 years with standard deviation (SD) of 5.1 years for lobectomies, 10.4±5.3 years for partial lobectomies, and 6.8±5.2 years for hemispherectomies. The mean length of stay was 15.6±13.2 days for children undergoing hemispherectomies, 10.6±14.2 days for lobectomies, and 10.6±8.7 days for partial lobectomies.

As the population increased, the number of children with epilepsy also increased. Table 3 shows that the number of surgical cases for each study year is less than 35% of children who are expected to have surgery, based on the estimates from the Connecticut Study of Epilepsy.[19]

Adjusting for age-race-sex and changes in population distribution over the study period, the rates of pediatric epilepsy surgeries increased significantly from 0.85 epilepsy surgeries per 1,000 children with epilepsy in 1997 to 1.44 epilepsy surgeries per 1,000 children with epilepsy in 2009 (Table 4). In stratified analyses, there was an increase in the rates of

surgeries for all age groups, in boys and girls, all races, and all payer types. The increase of epilepsy surgeries, however, was lowest in black children (compared to other races) and in those with public insurance (compared to private insurance). Multivariate analysis confirmed an increase of epilepsy surgeries over time (Table 5). In addition, age, race, and sex were also independent predictors of surgery. An increased in annual trends of epilepsy surgery was also noted remained significant when using a more restrictive study population (sensitivity analysis).

DISCUSSION

This is the first study that provides national estimates of pediatric epilepsy surgery utilization in the US. In contrast to adults, epilepsy surgery rates in children underwent a steady increase from 1997 to 2009. This apparent dichotomy between burgeoning pediatric epilepsy surgery numbers and relatively stagnant if not shrinking adult epilepsy surgeries is striking. It is possible that earlier, proactive surgical intervention combined with a lower threshold for referral amongst pediatric neurologists is responsible for the plateauing of adult epilepsy surgeries. Nonetheless, the overall number of surgeries in children remained substantially low, less than 35% of expected (Table 3), suggesting that epilepsy surgery is significantly under-utilized in the pediatric population. The reasons for under-utilization of epilepsy surgery in children appear to be complex and likely related to several factors involving both patients and physicians.[20–22] What and how these factors influence decision to pursue (or not to pursue) surgical treatment in children with refractory epilepsy warrant further investigations.

The precise reasons for an increase in pediatric epilepsy surgery numbers are speculative but intriguing nevertheless. It may simply reflect a recent expansion in pediatric epilepsy surgery expertise.[23, 24] In addition, advances in structural and functional imaging, EEG monitoring and surgical techniques offer a more detailed understanding of the basis and expression of the epileptic focus in a variety of clinical settings, resulting in broader selection of surgical candidates, particularly those who have been considered as inoperable in the past.[25] Some etiologies of focal epilepsy in children such as cortical dysplasia and developmental tumors often lead to catastrophic epilepsy.[24] Given that clinical severity including a history of infantile spasms and frequent seizures (daily or more) are now associated with a shorter time from epilepsy onset to surgical referral,[26] this increase is perhaps to be expected. The reason for the lower surgical referral threshold in children probably relates to strong literature documenting excellent results from surgical intervention in well selected cases, especially those that are performed early, resulting in good seizure control and improvement of neurodevelopmental outcomes.[27, 28] Nonetheless, delays in referrals for surgical evaluation remain the central problem in the surgical management of children with intractable epilepsy.[29]

We found that children with private insurance had significant increases in their rates of epilepsy surgery compared to those with public insurance. A recent study showed that children who rely mainly on public insurance, like Medicaid and CHIP, often face significant barriers to specialists.[30] This particular group of patients, therefore, may not have been referred to an epileptologist for appropriate work up. Moreover, physicians who are not

specialized in the treatment of epilepsy are likely to have significantly higher thresholds for referral and their lack of familiarity with literature and practice may conceivably even lead them to recommend against surgical interventions.[21] On the other hand, the publicly insured who have access to specialists may simply refuse surgery due to insufficient insight into the benefits and risks of the procedures, as well as personal preference and uninformed cultural health behaviors.[20] An increasing trend of surgical rates in publicly insured children with epilepsy is a hopeful finding that access to specialized epilepsy care in low-income children and/or patient's and physician's perception and understanding of surgical treatment have improved. It remains to be further investigated whether recent health care reforms will expand access to specialized epilepsy care to cover more children with epilepsy.

Disparities in surgical treatment among minorities with epilepsy, especially blacks, have been well documented.[2, 3, 31–33] The reasons for racial disparities in the receipt of surgery are likely influenced by several factors including those that are related to patients (such as health beliefs and behavior, willingness to undergo surgery, and comorbidities), those that are related to providers (such as practice style and quality), and those that are systemic (such as inequitable access to health care, hospital quality, and facility availability).[34] Nonetheless, an increase in the rate of epilepsy surgery among black and particularly Hispanic children is intriguing. These findings are in line with a recent study, which showed that Hispanic patients had shorter time intervals to surgery than non-Hispanic whites.[26] In addition, our previous analysis in the NIS also detected similar trends in black and Hispanic population.[3] However, race and ethnicity findings in the KID should be interpreted with caution, since some hospitals and/or states do not provide data on race or ethnicity to HCUP.[11] Re-evaluation of race and ethnic disparities with regard to receipt of epilepsy surgery may provide new insights and is therefore warranted.

Inequalities in access to specialized epilepsy care among low income population and in racial and ethic minorities have been highlighted in the recent Institute of Medicine report.[29] Access to specialized epilepsy care is an important element of quality of care improvement for persons with epilepsy, particularly those with refractory epilepsy. Our findings emphasize that improving access to specialized epilepsy care for all children with epilepsy are as important as ever. A recent report of the Project Access, which is a national initiative to improve access to health care for children in rural and medically underserved areas, has shown that education, outreach, community support, and professional guide can lead to increased access to epilepsy care.[35] Similar strategies can be applied to all children. In addition, our results provide important information that is critical for health care provision such as an important of health insurance exchange program that subsidizes the purchase of private insurance for low-income people; and work force planning including an effective care coordination, particularly specialty referral and the development of the epilepsy care network to improve access to specialized epilepsy care for children with epilepsy.

Our study has several limitations, especially those common to studies using administrative data including coding errors.[3, 36] However, these types of errors are likely randomly distributed and should not affect the overall results. Importantly, KID does not contain any patient identifiers. A single patient who had several surgeries over the study period would be treated as different individuals in the analysis. Repeated surgeries are likely performed in

only a small number of subjects and therefore unlikely to bias the overall findings. The use of ICD-9-CM codes also poses significant challenges because specific epilepsy syndromes and/or indications of the procedures performed cannot be ascertained.[37] In addition, the accuracy of ICD-9-CM codes in identifying resective epilepsy surgery has never been investigated. Previous studies in other disease entities have shown that coding for procedures in administrative data is quite accurate, since the data are generally collected from claims submitted for payment.[38] In this study, we mainly focused on lobectomy and hemispherectomy, which had specific ICD-9-CM codes. These procedures represent the majority of epilepsy-related procedures performed in children. Other surgical procedures such as corpus callosotomy and vagus nerve stimulation were not included, and required further study. The lack of age-, race-, or sex-specific epilepsy prevalence estimates at national level for each time point in our study forced us to apply similar prevalence rates uniformly across the entire study period. Nevertheless, the prevalence rates by Russ and associates,[13] which were used in our analysis, were within range of estimates from other population based studies that were conducted in different time periods.[39, 40]

CONCLUSION

Our results indicate a significant expansion of pediatric epilepsy surgery in the US over the past decade. Nonetheless, epilepsy surgery appears to be an underutilized treatment in children with epilepsy. Continued emphasis on highlighting awareness of epilepsy surgery amongst pediatricians and pediatric neurologists is as important as ever, as they serve as the main gatekeepers for patients to access specialized epilepsy care.

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Table 1

Pediatric epilepsy surgery in the US.

	1997	2000	2003	2006	2009
Number of cases (weighted)	375	410	589	683	706
Age, n (%)					
<1	18 (5)	16 (4)	37 (6)	31 (4)	18 (3)
1 to 4	67 (18)	81 (20)	86 (15)	110 (16)	120 (17)
5 to 9	86 (23)	79 (19)	136 (23)	170 (25)	182 (26)
10 to 14	85 (23)	110 (27)	168 (29)	189 (28)	208 (29)
15 to 17	120 (32)	124 (30)	157 (27)	176 (26)	173 (25)
Sex, n (%)					
Boys	205 (55)	245 (60)	293 (50)	356 (52)	381 (54)
Girls	170 (45)	165 (40)	290 (49)	320 (47)	319 (45)
Race, n (%)					
White	197 (52)	267 (65)	294 (50)	371 (54)	385 (54)
Black	23 (6)	26 (6)	18 (3)	32 (5)	37 (5)
Hispanic	24 (6)	33 (8)	52 (9)	61 (9)	110 (16)
Other	26 (7)	27 (7)	29 (5)	44 (6)	50 (7)
Missing	105 (28)	57 (14)	196 (33)	175 (26)	706 (18)
Primary Payer, n (%)					
Public (Medicaid and CHIP)	64 (17)	88 (21)	133 (23)	196 (29)	196 (28)
Private	259 (69)	290 (71)	396 (67)	439 (64)	448 (63)
Others	52 (14)	29 (7)	50 (9)	48 (7)	63 (9)
Region, n (%)					
Northeast	99 (26)	139 (34)	103 (18)	104 (15)	113 (16)
Midwest	45 (12)	27 (7)	219 (37)	195 (29)	195 (28)
South	162 (43)	140 (34)	188 (32)	212 (31)	248 (35)
West	69 (18)	104 (25)	79 (13)	172 (25)	150 (21)
Children's Hospital, n (%)	285 (76)	345 (84)	530 (90)	642 (94)	672 (95)
Teaching Hospital, n (%)	304 (81)	397 (97)	561 (94)	639 (92)	611 (85)

Abbreviations: CHIP, Children's Health Insurance Program.

Table 2

The number of surgeries by procedures over time.

Type of procedures, n (%)[a]	1997	2000	2003	2006	2009
Number of cases (weighted)	375	410	589	683	706
Lobectomies, n (%)	145 (39)	135 (33)	197 (33)	194 (28)	205 (29)
Partial lobectomies, n (%)	177 (47)	223 (54)	287 (49)	376 (55)	404 (57)
Hemispherectomy, n (%)	53 (14)	57 (14)	117 (20)	130 (19)	120 (17)

[a]Procedures may not add up to 100% due to multiple procedures in one stay.

Table 3

Estimated percentage of children with refractory focal epilepsy who underwent epilepsy surgeries between 1997 and 2009.

	1997	2000	2003	2006	2009
Children who should have had some type of epilepsy-related surgical procedures[a]	1937.1	2010.0	2035.7	2044.3	2048.6
Percentage of children who actually had surgeries	19.4%	20.4%	28.9%	33.4%	34.5%

[a] Approximately 27 per 1,000,000 children are supposed to have some types of epilepsy-related surgical procedures performed.[19]

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Table 4

Rates of pediatric epilepsy surgeries in the US between 1997 and 2009, stratified by age, race, sex, and payer type.

	Rates of surgeries (per 1,000)[a]					Yearly increase in pediatric epilepsy surgeries per 1000 children with epilepsy (95% CI)[b]	P-value[f]
	1997	2000	2003	2006	2009		
Unadjusted	0.83	0.87	1.24	1.43	1.48	.062 (.029 – .095)	0.05
Age-race-sex adjusted[c]	0.85	0.87	1.21	1.42	1.44	.058 (.025 – .090)	0.05
Stratified by[d]							
Age							
4 and younger	1.17	1.34	1.68	1.91	1.85	.064 (.023 – .105)	0.11
5–9	0.86	0.79	1.43	1.80	1.89	.102 (.038 – .167)	0.11
10–14	0.51	0.62	0.91	1.03	1.15	.056 (.038 – .074)	0.05
15–17	1.07	1.05	1.30	1.41	1.37	.032 (.003 – .061)	0.22
Sex							
Male	0.72	0.82	0.97	1.18	1.26	.048 (.036 – .060)	0.05
Female	1.02	0.97	1.67	1.83	1.81	.081 (.008 – .154)	0.22
Race							
White	0.64	0.80	0.89	1.14	1.20	.049 (.033 – .064)	0.05
Black	0.33	0.45	0.32	0.54	0.62	.022 (−.007 – .052)	0.22
Hispanic	0.43	0.66	0.92	0.98	1.67	.093 (.036 – .151)	0.05
Payer type[e]							
Public (Medicaid and CHIP)	0.40	0.54	0.63	0.90	0.71	.033 (−.008 – .073)	0.11
Private	1.05	1.16	1.65	1.87	2.03	.089 (.054 – .124)	0.05

Abbreviations: CHIP, Children's Health Insurance Program. CI, Confidence interval.

[a] Rates of surgeries modeled using linear regression with time as an independent variable.

[b] Yearly increase in pediatric epilepsy surgeries was the regression beta coefficient over the study period.

[c] Direct adjustment for age, race, and sex using year 2000 as the reference population.

[d] Stratified analysis included the rates of surgeries among people with the characteristic of interest only.

[e] Uninsured children were not included in the analysis due to very small number of surgeries performed in this subgroup (n <10 for most of the study years).

[f] P-value were obtained from the Mann-Kendall trend test and were adjusted for multiple comparisons using Benjamini-Hochberg method.[15]

Table 5

Multivariable negative binomial regression model for all subjects and for subjects with ICD-9-CM codes for epilepsy (sensitivity analysis).

Predictor	Adjusted incidence rate ratio	
	All subjects (95% CI)	Sensitivity analysis (95% CI)
Year	1.06 (1.04 – 1.08)	1.07 (1.05 – 1.09)
Age		
4 and younger	1.57 (0.98 – 2.52)	1.47 (0.93 – 2.32)
5 – 9	1.00 (0.62 – 1.60)	0.92 (0.59 – 1.46)
10 – 14	0.91 (0.56 – 1.45)	0.88 (0.56 – 1.38)
15 – 17	Reference	Reference
Sex		
Female	1.70 (1.13 – 2.56)	1.63 (1.10 – 2.42)
Male	Reference	Reference
Race		
Black	0.33 (0.18 – 0.62)	0.43 (0.24 – 0.79)
Hispanic	2.20 (1.31 – 3.70)	2.24 (1.35 – 3.71)
Others	0.88 (0.55 – 1.41)	0.88 (0.56 – 1.38)
White	Reference	Reference

Abbreviations: CI, Confidence interval.

Since the US census did not have population estimates by insurance type within each age-race-sex category, payer types were not included in the model.