Health care charges for youth with newly diagnosed epilepsy

Jamie L. Ryan, PhD
 Meghan E. McGrady,
 PhD
 Shanna M. Guilfoyle,
 PhD
 Katherine Junger, PhD
 Alex D. Arnett, BS
 Avani C. Modi, PhD

Correspondence to
 Dr. Ryan:
jamie.ryan@cchmc.org

ABSTRACT

Objectives: To estimate first-year health care charges for youth with newly diagnosed epilepsy seen within an interdisciplinary pediatric epilepsy team and examine demographic, clinical, and psychosocial predictors of annual charges.

Methods: Retrospective chart review was conducted to extract medical, hospital, and physician billing data from the year following an epilepsy diagnosis for 258 patients (aged 2–18 years) seen in a New Onset Seizure Clinic between July 2011 and December 2012. Descriptive statistics were used to estimate per-patient total first-year charges and health care utilization patterns (e.g., hospitalizations, emergency department visits, outpatient visits). Univariate analyses examined differences in health care charges between demographic, clinical, and psychosocial factors. Predictors of health care charges were examined using hierarchical multiple regression analysis.

Results: The estimated per-patient total first-year health care charge was \$20,084 (95% confidence interval [CI] \$16,491–\$23,677). Charges were higher for patients who reported having seizures since diagnosis (\$25,509; 95% CI \$20,162–\$30,856) and were associated with more antiepileptic drug side effects ($r = 0.18$; 95% CI 0.03–0.32). Controlling for demographic and clinical factors, poorer baseline health-related quality of life was associated with higher per-patient health care charges ($B = -445.40$; 95% CI -865 to -25).

Conclusions: The economic impact of pediatric epilepsy in the year following diagnosis is substantial. Cost reduction efforts would be optimized by improving seizure control and targeting health-related quality of life, an outcome amenable to behavioral intervention. *Neurology*® 2015;85:490–497

GLOSSARY

AED = antiepileptic drug; **BASC-2** = Behavior Assessment System for Children, Second Edition; **CI** = confidence interval; **ED** = emergency department; **HRQOL** = health-related quality of life; **NOS** = New Onset Seizure; **PedsQL** = Pediatric Quality of Life Inventory; **PESQ** = Pediatric Epilepsy Side Effects Questionnaire; **PRS** = Parent Rating Scale.

Approximately 20%–40% of youth diagnosed with epilepsy do not successfully respond to antiepileptic drugs (AEDs)¹ and may require more expensive and invasive treatment options (e.g., epilepsy surgery).² Youth with epilepsy demonstrate greater psychosocial difficulties (e.g., disruptive behavior, depression, medication nonadherence, and poor health-related quality of life [HRQOL]) than youth with other pediatric chronic conditions,^{3–6} which can be the result of seizures, AED side effects, or developmental processes.^{7–9} The physical and psychosocial sequelae likely contribute to the significant economic burden faced by pediatric epilepsy patients. Annual per-patient pediatric epilepsy-related costs range from \$522 to \$9,713 and are primarily driven by AEDs, clinic visits, and diagnostic procedures.^{10,11} A large portion of these health care costs are unnecessary/excessive and are incurred in the first year following diagnosis.^{12,13}

Epilepsy-related factors, including polytherapy, therapeutic drug monitoring, newer AEDs, and seizure control,¹⁰ are often linked to higher health care costs.¹¹ Psychosocial comorbidities among pediatric patients have also been shown to predict increased health care charges,^{14,15} but to our knowledge these have not been examined in pediatric epilepsy. These psychosocial factors are ideal targets for investigation because they are amenable to behavioral intervention.

Editorial, page 486

Supplemental data
 at Neurology.org

From the Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, Cincinnati, OH.

Go to Neurology.org for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

Previous studies are limited by their inclusion of select etiologies¹¹ and costs¹⁶ during an unstandardized time period.¹⁰ Thus, we aimed to describe the health care utilization patterns and inpatient and outpatient charges in the 12 months following a pediatric epilepsy diagnosis, estimate average annual per-patient health care charges, and identify demographic, clinical, and psychosocial predictors of total health care charges. In line with previous studies, we hypothesized that seizure occurrence, AED nonadherence, and poor HRQOL among youth with newly diagnosed epilepsy would predict increased health care charges in the 12 months postdiagnosis.

METHODS The study included patients diagnosed between July 2011 and December 2012 who received 12 months of care in the New Onset Seizure (NOS) Clinic.

Standard protocol approvals, registrations, and patient consents. Data were extracted from a larger project approved by the hospital's institutional review board.¹⁷

Pediatric New Onset Seizure Clinic. The multidisciplinary NOS Clinic is part of the Comprehensive Epilepsy Center at a large pediatric hospital serving patients in the Midwestern United States. Patients with seizures are initially seen by an epileptologist for evaluation and complete a routine EEG and MRI. After patients receive an epilepsy diagnosis, they are typically prescribed an AED by an epileptologist (i.e., diagnosis visit) and followed by a specialist nurse practitioner. In addition to routine diagnostic procedures and the diagnosis visit, our recommended epilepsy treatment includes a follow-up clinic visit 1 month postdiagnosis and every 3 months thereafter with coinciding safety laboratory tests and biannual behavioral medicine visits with a clinical psychologist, totaling approximately 13 medical encounters in the first year.

The NOS Clinic's patient population is homogeneous, in that youth are 2–18 years old, typically developing, and do not have significant medical (e.g., diabetes), psychiatric (e.g., bipolar), or developmental (e.g., autism) comorbidities. At our institution, patients with identified comorbidities at the time of diagnosis are triaged to a general neurologist for epilepsy treatment. Patients with unidentified preexisting conditions or who develop comorbidities after starting treatment continue to receive care within the NOS Clinic.

Families complete the Behavior Assessment System for Children, Second Edition (BASC-2)^{18,19} and Pediatric Quality of Life Inventory (PedsQL)²⁰ at their diagnosis visit. At one month postdiagnosis, a behavioral medicine assessment is conducted¹⁷ and families complete the PedsQL again, the Pediatric Epilepsy Side Effects Questionnaire (PESQ),²¹ and other symptom-based measures (e.g., Children's Depression Inventory). Families reporting greater symptoms or need during the assessment may be evaluated more frequently or referred for outpatient treatment. The BASC-2 and PedsQL at diagnosis and the PESQ at the 1-month follow-up visit were examined because they allow us to proactively target psychosocial concerns at disease onset. AED adherence was also included in analyses given the high rates of nonadherence⁶ among youth with epilepsy and its negative impact on seizures²² and health care expenditures in adult epilepsy populations.²³

Measures. BASC-2 Parent Rating Scale. The BASC-2 Parent Rating Scale (PRS) is a 134- to 160-item parent report measure of behavior and personality in youth across 3 age groups: preschool (2–5 years), child (6–11 years), and adolescent (12–21 years).^{18,19} Depending on the age group, the BASC-2 PRS yields 4 to 5 composite scales (e.g., Internalizing Problems, Externalizing Problems, Behavioral Symptoms Index, School Problems, and Adaptive Skills). Standardized *T* scores based on individual responses relative to children of the same age and sex allow for comparisons across age groups, with higher *T* scores representing poorer baseline psychosocial functioning. Internal reliability for the BASC-2 PRS ranges from 0.58 to 0.89.^{18,19}

PedsQL version 4.0. The PedsQL is a 23-item measure assessing physical, emotional, social, and academic functioning.²⁰ Caregivers rate the frequency of their child's difficulties on a 5-point Likert scale. Items are summed and transformed into scores ranging from 0 to 100, with higher scores representing better HRQOL.²⁰ The total score was used in the current study. Internal consistency for the PedsQL ranges from 0.89 to 0.93.²⁴ Parent proxy-reported HRQOL is a reliable and valid estimate of child functioning.²⁵

PESQ. The PESQ is a 19-item parent report measure of AED side effects (cognitive, motor, and behavioral).²¹ Items are summed and transformed into a score ranging from 0 to 100, with higher scores representing more side effects. The total side effects score was used in the current study. The PESQ has excellent internal reliability (0.90).²¹

AED adherence. AED adherence was assessed by asking caregivers or unaccompanied patients, "In the past week, how many doses of medication were missed?" One week was used as a reference to maximize recall. The number of doses administered in the previous week was divided by the number of prescribed doses and multiplied by 100 to calculate each patient's adherence rate. Self- or caregiver-reported AED adherence has been associated with objective electronic monitoring ($r = 0.46, p < 0.001$),²⁶ and although it tends to be inflated, it is clinically feasible.

Medical chart review. Two trained research assistants collected demographics and first-year clinical and psychosocial data through retrospective chart review (table 1). Psychosocial variables included the number of behavioral medicine visits, HRQOL (PedsQL at diagnosis), psychosocial functioning (BASC-2 PRS at diagnosis), and AED side effects (PESQ at 1-month follow-up). Seizure occurrence was dichotomized since a single unprovoked seizure can contribute to increased health care charges²⁷ and poor HRQOL.²⁸

Health care charges. The hospital and physician billing records for the year following diagnosis for each patient were obtained from the institutional accounting database. These data do not reflect coverage by insurance companies, copays, or premiums but simply the health care charges related to ambulatory care, hospitalizations, emergency department (ED) visits, laboratory tests, and diagnostic procedures. Governmental and societal charges (i.e., transportation, caregiver missed work) were beyond the scope of the current study. Two research assistants classified encounters according to predefined criteria (see table e-1 on the *Neurology*[®] Web site at Neurology.org). Two authors independently reviewed 20% of patient health care encounters (99% agreement) and discussed any questions to resolve disagreements.

Total and per-patient first-year health care charges were calculated using a gross costing approach. Charge data spanning multiple years were first adjusted to 2014 US dollars according to the medical care component of the Consumer Price Index²⁹ to allow for comparison across participants enrolled at different time points.

Table 1 Descriptive statistics and univariate analysis for total first-year health care charges (n = 258)

				ANOVA	
Variables	n (%)	Mean, US \$ ^a	95% CI, US \$ ^a	F	p
Demographic characteristics					
Age at diagnosis, y				0.19	0.82
2-5	79 (30.6)	19,165	14,528-23,803		
6-12	122 (47.3)	21,299	14,681-27,916		
13-18	57 (22.1)	18,759	13,250-24,268		
Sex				0.17	0.68
Male	133 (51.6)	19,351	14,258-24,445		
Female	125 (48.4)	20,864	15,681-26,048		
Insurance status				0.48	0.62
Private	165 (64.0)	20,807	15,992-25,623		
Medicaid	84 (32.6)	19,630	13,763-25,497		
Self-pay	9 (3.5)	11,067	5,499-16,636		
Clinical characteristics					
Epilepsy etiology				1.15	0.29
Idiopathic	216 (83.7)	19,218	15,647-22,790		
Symptomatic/cryptogenic	42 (16.3)	24,537	11,721-37,354		
Presence of syndrome				0.37	0.54
No	192 (74.4)	20,741	16,191-25,291		
Yes	66 (25.6)	18,173	13,129-23,217		
Epilepsy type				0.08	0.92
Localization-related	98 (38.0)	19,883	12,978-26,787		
Generalized	95 (36.8)	20,955	15,471-26,439		
Unclassified	65 (25.2)	19,116	12,957-23,694		
Antiepileptic drug (brand name) ^b				0.52	0.67
Levetiracetam (Keppra)	84 (32.6)	20,229	14,836-25,622		
Carbamazepine (Carbatrol, Tegretol)	61 (23.6)	21,477	11,809-31,145		
Valproic acid (Depakote)	50 (19.4)	16,161	12,442-19,879		
Ethosuximide (Zarontin)	40 (15.5)	17,289	13,334-21,245		
Seizure since day of diagnosis (n = 254)				16.05	<0.001
Yes	167 (65.7)	25,509	20,162-30,856		
No	87 (34.3)	10,262	8,659-11,954		
Psychosocial characteristic					
Behavioral medicine visits				0.75	0.52
0 visits	30 (11.6)	20,303	7,999-32,607		
1 visit	92 (35.7)	1,832	12,039-24,606		
2 visits	84 (32.6)	18,619	12,572-24,667		
3 or more visits	52 (20.2)	25,442	17,532-33,352		

Abbreviations: ANOVA = analysis of variance; CI = confidence interval.

^aAdjusted to April 2014 US \$.

^bPercentages do not add to 100% because the 5 most commonly prescribed antiepileptic drugs were selected for univariate analysis.

Statistical analysis. First-year health care utilization patterns and per-patient health care charges following an epilepsy diagnosis were quantified with descriptive statistics. Univariate analyses examined differences in per-patient health care charges

between demographic (e.g., age at diagnosis, sex, insurance status), clinical (e.g., epilepsy etiology, epilepsy type, syndrome presence, AED, seizure since diagnosis), and psychosocial factors (e.g., number of behavioral medicine visits, BASC-2 PRS).

Predictors of health care charges, namely demographic and clinical variables significant in previous research (block 1)^{10,16,27,30} and psychosocial variables correlated with per-patient charges at the bivariate level (block 2), were examined using hierarchical multiple regression analyses. In the first regression, the outcome variable was total first-year per-patient health care charges.

The provision of behavioral medicine services within the NOS Clinic is a relatively unique model and may result in additional charges (i.e., epilepsy clinic-based intervention, outpatient therapy) not commonly incurred at other institutions. Thus, the second regression analysis excluded charges attributable to behavioral medicine services to enhance the generalizability of the study findings. Analyses were performed using SPSS version 22 software.³¹

RESULTS Patient characteristics. Demographic and clinical characteristics of 258 youth (mean age 8.85 ± 4.28 years) with newly diagnosed epilepsy are presented in table 1. Overall, 4% of data values were missing across all study variables. Reasons for

missing data included measures not completed during diagnosis visit (PESQ $n = 76$, PedsQL $n = 26$), no behavioral medicine visit to assess adherence ($n = 30$), PESQ not administered for patients not starting AED ($n = 13$), incomplete clinic-based measures (BASC-2 $n = 6$), adherence not assessed/quantified during behavioral medicine visit ($n = 4$), and unclear seizure occurrence postdiagnosis ($n = 4$).

One month after starting an AED, parent-reported side effects were 15.41 ± 16.46 ($n = 169$) and adherence was high (94.52 ± 15.00 , $n = 224$). Baseline HRQOL was 81.11 ± 14.48 ($n = 232$) and psychosocial functioning (i.e., BASC-2 PRS) was in the average range.

Health care utilization patterns and health care charges. Health care utilization patterns and average health care charges by medical service type are presented in table 2. There were 3,951 medical service visits

Table 2 Health care utilization patterns and medical service charges ($n = 258$)

Medical service	Service utilization				Charges ^a	
	n (% of visits)	Mean	95% CI	Median	Mean, US \$	95% CI
Behavioral medicine visits						
Epilepsy clinic visit	479 (12.1)	1.86	1.72-2.00	2.00	333	316-350
Other outpatient visit ^b	171 (4.3)	0.66	0.38-0.94	0.00	336	315-356
Neuropsychological testing ^c	81 (2.1)	0.31	0.21-0.41	0.00	1,326	1,195-1,456
Diagnostic procedures						
CT	2 (<0.1)	0.01	0.00-0.02	0.00	4,405	3,736-5,073
EEG	144 (3.6)	0.56	0.47-0.65	0.00	2,707	2,174-3,239
ECG	10 (0.3)	0.04	0.02-0.06	0.00	553	451-654
MRI	171 (4.3)	0.66	0.56-0.76	1.00	4,755	4,497-5,013
PERF	2 (<0.1)	0.01	0.00-0.02	0.00	5,769	5,569-5,969
PET	1 (<0.1)	0.00	0.00-0.01	0.00	5,728	NA
Emergency department visits						
Epilepsy-related	45 (1.1)	0.17	0.11-0.23	0.00	2,656	2,423-2,889
Other ^b	55 (1.4)	0.21	0.14-0.28	0.00	1,496	1,337-1,655
Hospital admissions						
Epilepsy-related	43 (1.1)	0.17	0.11-0.23	0.00	33,115	29,027-37,202
Other ^b	32 (0.8)	0.12	0.07-0.17	0.00	15,345	13,661-17,029
Laboratory tests	1,067 (27.0)	4.14	3.93-4.35	4.00	500	441-558
Outpatient clinic visits						
Neurology	1,095 (27.7)	4.25	4.07-4.43	4.00	679	567-790
Neurosurgery	19 (0.5)	0.07	0.02-0.12	0.00	604	544-665
Other ^b	534 (13.5)	2.07	1.36-2.78	0.00	428	359-497

Abbreviations: CI = confidence interval; NA = not applicable; PERF = CT/MR perfusion imaging with contrast.

^aAdjusted to April 2014 US \$.

^bExample medical services not related to epilepsy categorized as "other": behavioral medicine: outpatient treatment for anxiety or disruptive behavior; emergency department: orthopedic injury, asthma flare; hospital admission: tonsillectomy, polysomnography; outpatient clinic: endocrinology, occupational therapy.

^cOne neuropsychological evaluation includes 3 visits.

totaling nearly \$5.2 million in health care charges in the 12 months postdiagnosis. The most frequent epilepsy-related services included neurology clinic visits, laboratory tests, and epilepsy clinic-based behavioral medicine visits. During the study period, 14% ($n = 36$) of patients had at least one epilepsy-related ED visit, and 13% ($n = 34$) had at least one epilepsy-related hospital admission.

Hospital admissions in the first year were associated with the highest average health care charge (table 2) and accounted for a disproportionate 27% of the \$5.2 million in total accrued charges. Average charges for diagnostic procedures varied but accounted for 24% of the total charges. Remaining health care charges resulted from other lower cost health care services including neurology clinic visits (14%), laboratory tests (10%), and epilepsy clinic-based behavioral medicine visits (3%). ED visits had the third highest average charge but accounted for only 1% of total visits and 2% of the total health care charges. Charges for neuropsychological testing or neurosurgery clinic visits contributed to 3% of the total first-year charges.

Per-patient health care charges and individual differences. Patients with epilepsy accrued $\$20,084 \pm \$29,446$ in health care charges in the year following diagnosis. With regard to outpatient epilepsy treatment, patients had an average of 4 neurology clinic visits and laboratory tests, 2 epilepsy clinic-based behavioral medicine visits, and 1 diagnostic procedure (table 2).

Patients who reported the presence of at least 1 seizure since diagnosis incurred more than twice the charges than patients who reported being seizure-free. Greater AED side effects were associated with higher per-patient total charges ($r = 0.18$, 95% confidence interval [CI] 0.03–0.32, $p = 0.02$, $n = 169$). Charges did not differ across groups on any other demographic or clinical characteristics (table 1).

Total per-patient charges were not associated with baseline psychosocial functioning (BASC-2: Internalizing Problems $r = 0.04$, $p = 0.56$; Externalizing Problems $r = -0.03$, $p = 0.60$; Behavioral Symptoms Index $r = 0.01$, $p = 0.81$; Adaptive Skills $r = 0.07$, $p = 0.27$), AED adherence ($r = 0.09$, $p = 0.18$), or the number of behavioral medicine visits (table 1). Poorer baseline HRQOL was associated with higher first-year charges ($r = -0.22$, 95% CI -0.34 to -0.09 , $p = 0.001$, $n = 232$).

Predictors of health care charges. Results of the regression analyses are presented in table 3. Demographic and clinical variables accounted for 8% of the variance but were not associated with patient health care charges, except for seizure occurrence since diagnosis. HRQOL was the only psychosocial variable correlated with patient health care charges and thus included in the regression analyses. Nonsignificant psychosocial variables excluded from the regression analyses included psychosocial functioning, AED adherence, and number of behavioral medicine visits. Poorer HRQOL was associated with higher health

Table 3 Hierarchical multiple regression results predicting first-year charges ($n = 231$)

Predictor variables ^a	B	95% confidence interval	β^b	p	R^2	ΔR^2	p
Block 1					0.08	0.08	0.02
Insurance status	3,000.45	−5,642 to 11,643	0.05	0.49			
Epilepsy etiology	5,166.18	−6,861 to 17,193	0.06	0.40			
Epilepsy type	1,666.44	−4,518 to 7,851	0.04	0.59			
Seizure since diagnosis	14,178.86	4,086 to 24,272	0.23	0.006			
Antiepileptic drug side effects	199.78	−106 to 506	0.10	0.20			
Block 2					0.10	0.03	0.008
Insurance status	4,882.58	−3,853 to 13,618	0.09	0.27			
Epilepsy etiology	2,610.63	−9,533 to 14,754	0.03	0.67			
Epilepsy type	1,142.73	−4,997 to 7,283	0.03	0.71			
Seizure since diagnosis	14,338.71	4,349 to 24,328	0.23	0.005			
Antiepileptic drug side effects	−30.58	−403 to 342	−0.02	0.87			
Health-related quality of life ^c	−445.40	−865 to 25	−0.21	0.04			

^a Variable units: insurance status (0 = Medicaid, 1 = private, 2 = self-pay); epilepsy etiology (0 = idiopathic, 1 = symptomatic/cryptogenic); epilepsy type (0 = generalized, 1 = localization-related, 2 = unclassified); seizure since diagnosis (0 = no, 1 = yes); antiepileptic drug side effects (total score 0–100); health-related quality of life (total score 0–100).

^b β coefficients represent the amount of increase or decrease in per-patient charges for a 1-unit change in the predictor variable.

^c Baseline measured at diagnosis visit.

care charges after accounting for demographic and clinical variables and explained an additional 2% of the variance. Seizure occurrence and baseline HRQOL remained the only factors associated with health care charges in the second set of regressions excluding charges related to behavioral medicine services. These results are not included because β weights and R^2 values did not change.

DISCUSSION This study comprehensively examined the relationship between clinical and psychosocial factors and health care charges in youth with newly diagnosed epilepsy. Consistent with previous findings,¹⁰ total annual health care charges were nearly \$20,000, with epilepsy-related charges consisting primarily of neurology clinic visits, laboratory tests, and diagnostic procedures. Health care utilization patterns suggest that while the majority of patients followed providers' treatment recommendations, equaling roughly 13 medical encounters in the first year, a subset of patients contributed to a disproportionately high percentage of total first-year charges. Specifically, epilepsy-related hospital admissions and ED visits represented excessive medical encounters not part of standard clinical care. If intervention efforts could reduce hospitalizations or ED visits (e.g., improving adherence to reduce seizures), up to \$1 million a year could be saved in one epilepsy clinic alone.

Consistent with previous literature,^{10,27} variations in per-patient charges were partially attributable to clinical factors (e.g., seizure occurrence since diagnosis). As this trajectory of higher spending is likely to continue, patients at risk for uncontrolled seizures represent a crucial target for reducing costs. Greater AED side effects also predicted higher total first-year charges, which may be attributable to their negative impact on physical and emotional functioning³² and medication adherence.³³ For example, an adolescent who fears the possibility of weight gain as a side effect of her valproic acid may forgo doses, resulting in a seizure and utilization of ED services. These findings have significant clinical implications, as providers consider an AED's effectiveness and potential side effects when deciding which AED to initiate. Providing anticipatory guidance to families on what to expect and ways to manage side effects may prevent excessive health care utilization and reduce costs.³²

First-year health care charges did not differ across any other clinical or demographic factors. These findings are consistent with previous studies,^{10,11,27} with the exception of medication adherence.^{34,35} Discrepant findings are likely due to adherence measurement methods, which were prescription refill data in the adult studies and self or caregiver report, which is known to be inflated, in the current study.

Baseline HRQOL was the strongest predictor of first-year health care charges after controlling for demographic and clinical factors. Although this relationship has not been examined previously in pediatric epilepsy, findings are consistent with pediatric³⁶ and adult studies^{37,38} that demonstrate a direct impact of poor HRQOL on increased health care utilization. Poorer HRQOL predicted greater health care charges when charges related to behavioral medicine services were removed from the outcome variable, indicating that this relationship is not due to increased behavioral medicine service use. This suggests that establishing a behavioral medicine service to decrease impairment and optimize HRQOL, independent of other cost determinants, is not associated with higher health care charges. Future studies are needed to understand precisely how HRQOL affects health care utilization and costs.

Early work in cost containment focused predominantly on achieving seizure control. Our findings suggest that these efforts may be further enhanced by targeting HRQOL. Behavioral interventions targeting self-management, lifestyle, and exercise for children with asthma have successfully improved HRQOL and reduced health care utilization.³⁹ Adapting these and similar interventions for youth with epilepsy is likely to be an integral component of low-cost, high-quality health care that needs to be further tested.

Limitations of the study should be considered when interpreting the results. Our model of psychosocial care and patient population are relatively unique compared with other epilepsy clinics and centers. The magnitude of the relationship between HRQOL and health care charges may be different in clinics without interdisciplinary psychosocial care. Findings may not generalize to youth with more complex epilepsies, significant comorbid psychiatric/developmental disorders, or those receiving care outside a specialty epilepsy clinic. Furthermore, only baseline or early clinical/psychosocial variables, including AED type, psychosocial functioning, and adherence, were used, and our study did not account for changes in treatment or psychosocial functioning over time. Future research should examine time-varying factors from multiple respondents and use more objective electronic monitoring to assess adherence behaviors. Limited generalizability might also apply to different providers and regions of the country, with variations in health care practices and billing services. Finally, total health care charges are likely underestimated because we did not capture AEDs and any services received outside of our institution or prior to the epilepsy diagnosis (e.g., EEGs/MRIs). Predictors of health care charges at the societal level remain unknown, and future research should include

relevant societal expenditures (i.e., caregiver missed work days) to estimate the broad economic impact of pediatric epilepsy.

The current study quantifies the economic impact of pediatric epilepsy in the year following diagnosis and highlights potential avenues for cost savings. Efforts to improve seizure control and HRQOL may not only improve health outcomes but also reduce health care costs. Medical teams are encouraged to consider incorporating behavioral medicine services to target HRQOL into standard clinical care as one potential avenue.

AUTHOR CONTRIBUTIONS

Dr. Ryan contributed to conception and design of the study; collection, management, analysis, and interpretation of the data; and preparation of the final manuscript. Dr. McGrady contributed to conception and design of the study; collection, management, analysis, and interpretation of the data; and preparation of the final manuscript. Dr. Guilfoyle contributed to conception and design of the study, the acquisition of the data, and critical revision of the manuscript for important intellectual content. Dr. Junger contributed to conception and design of the study, the acquisition of the data, and critical revision of the manuscript for important intellectual content. Mr. Arnett contributed to the acquisition and analysis of the data and critical revision of the manuscript for important intellectual content. Dr. Modi contributed to conception and design of the study, acquisition and interpretation of the data, critical revision of the manuscript for important intellectual content, and supervision. All authors agreed to be accountable for all aspects of the work to ensure its accuracy and integrity and approved the final manuscript as submitted.

ACKNOWLEDGMENT

The authors are greatly appreciative of the children and adolescents with epilepsy and their families who participated in this study. The authors thank the research assistants and graduate students, including Demaree Bruck, Teana Gravel, and Shannon Ollier (Cincinnati Children's Hospital Medical Center), for helping with data collection. They also thank the NOS clinical team involved in the medical and psychosocial care of youth with epilepsy.

STUDY FUNDING

Supported in part by NIH (T32HD068223) for J.L.R. and M.E.M. and Cincinnati Children's Hospital Medical Center—Schmidlapp Women's Scholar Fund for A.C.M.

DISCLOSURE

The authors report no disclosures relevant to the manuscript. Go to Neurology.org for full disclosures.

Received January 5, 2015. Accepted in final form March 26, 2015.

REFERENCES

- French JA. Refractory epilepsy: clinical overview. *Epilepsia* 2007;48(suppl 1):3–7.
- Wilby J, Kainth A, Hawkins N, et al. Clinical effectiveness, tolerability and cost-effectiveness of newer drugs for epilepsy in adults: a systematic review and economic evaluation. *Health Technol Assess* 2005;9:1–157, iii–iv.
- Austin JK, Dunn DW. Progressive behavioral changes in children with epilepsy. *Prog Brain Res* 2002;135:419–427.
- Davies S, Heyman I, Goodman R. A population survey of mental health problems in children with epilepsy. *Dev Med Child Neurol* 2003;45:292–295.

- Ettinger AB, Good MB, Manjunath R, Edward Faught R, Bancroft T. The relationship of depression to antiepileptic drug adherence and quality of life in epilepsy. *Epilepsy Behav* 2014;36:138–143.
- Modi AC, Rausch JR, Glauser TA. Patterns of non-adherence to antiepileptic drug therapy in children with newly diagnosed epilepsy. *JAMA* 2011;305:1669–1676.
- Austin JK, Perkins SM, Johnson CS, et al. Behavior problems in children at time of first recognized seizure and changes over the following 3 years. *Epilepsy Behav* 2011;21:373–381.
- McCagh J, Fisk JE, Baker GA. Epilepsy, psychosocial and cognitive functioning. *Epilepsy Res* 2009;86:1–14.
- Zhao Q, Rathouz PJ, Jones JE, et al. Longitudinal trajectories of behavior problems and social competence in children with new onset epilepsy. *Dev Med Child Neurol* 2014;57:37–44.
- Cramer JA, Wang ZJ, Chang E, et al. Healthcare utilization and costs in children with stable and uncontrolled epilepsy. *Epilepsy Behav* 2014;32:135–141.
- Salih MR, Bahari MB, Shafie AA, et al. Medical care costs of newly diagnosed children with structural-metabolic epilepsy: a one year prevalence-based approach. *Seizure* 2012;21:764–769.
- Beghi E, Frigeni B, Beghi M, De Compadri P, Garattini L. A review of the costs of managing childhood epilepsy. *Pharmacoeconomics* 2005;23:27–45.
- Begley CE, Famulari M, Annegers JF, et al. The cost of epilepsy in the United States: an estimate from population-based clinical and survey data. *Epilepsia* 2000;41:342–351.
- Lee JL, Gilleland J, Campbell RM, et al. Health care utilization and psychosocial factors in pediatric noncardiac chest pain. *Health Psychol* 2013;32:320–327.
- Richardson LP, Russo JE, Lozano P, McCauley E, Katon W. The effect of comorbid anxiety and depressive disorders on health care utilization and costs among adolescents with asthma. *Gen Hosp Psychiatry* 2008;30:398–406.
- Widjaja E, Smith ML, Jette N, Payne E. Patient and hospital characteristics are associated with cost of hospitalizations in children with epilepsy. *Epilepsy Behav* 2013;28:335–342.
- Guilfoyle SM, Follansbee-Junger K, Modi AC. Development and preliminary implementation of a psychosocial service into standard medical care for pediatric epilepsy. *Clin Pract Pediatr Psychol* 2013;1:276–288.
- Reynolds CR, Kamphaus RW. Behavior Assessment System for Children. Circle Pines, MN: American Guidance Service; 1992.
- Reynolds CR, Kamphaus RW. Behavior Assessment System for Children, 2nd ed. Circle Pines, MN: AGS Publishing; 2004.
- Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. *Med Care* 1999;37:126–139.
- Morita DA, Glauser TA, Modi AC. Development and validation of the Pediatric Epilepsy Side Effects Questionnaire. *Neurology* 2012;79:1252–1258.
- Modi AC, Rausch JR, Glauser TA. Early pediatric antiepileptic drug nonadherence is related to lower long-term seizure freedom. *Neurology* 2014;82:671–673.
- Davis KL, Candrilli SD, Edin HM. Prevalence and cost of nonadherence with antiepileptic drugs in an adult managed care population. *Epilepsia* 2008;49:446–454.

24. Varni JW, Limbers CA, Burwinkle TM. Impaired health-related quality of life in children and adolescents with chronic conditions: a comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL 4.0 Generic Core Scales. *Health Qual Life Outcomes* 2007;5:43.
25. Haneef Z, Grant ML, Valencia I, et al. Correlation between child and parental perceptions of health-related quality of life in epilepsy using the PedsQL. v4.0 measurement model. *Epileptic Disord* 2010;12:275–282.
26. Modi AC, Guilfoyle SM, Morita DA, Glauser TA. Development and reliability of a correction factor for parent-reported adherence to pediatric antiepileptic drug therapy. *Epilepsia* 2011;52:370–376.
27. Begley CE, Lairson DR, Reynolds TF, Coan S. Early treatment cost in epilepsy and how it varies with seizure type and frequency. *Epilepsy Res* 2001;47:205–215.
28. Modi AC, King AS, Monahan SR, Koumoutsos JE, Morita DA, Glauser TA. Even a single seizure negatively impacts pediatric health-related quality of life. *Epilepsia* 2009;50:2110–2116.
29. United States Department of Labor, Bureau of Labor Statistics. Consumer price index: medical care. Available at: <http://data.bls.gov/timeseries/CUUR0000SAM>. Accessed July 8, 2014.
30. de Kinderen RJ, Evers SM, Rinkens R, et al. Side-effects of antiepileptic drugs: the economic burden. *Seizure* 2014; 23:184–190.
31. IBM SPSS Statistics for Windows. v. 22.0. Armonk, NY: IBM Corp.; 2013.
32. Modi AC, Ingerski LM, Rausch JR, Glauser TA. Treatment factors affecting longitudinal quality of life in new onset pediatric epilepsy. *J Pediatr Psychol* 2011;36:466–475.
33. Modi AC, Guilfoyle SM. Adherence to antiepileptic drug therapy across the developmental life-span. In: Pinikahana J, Walker C, editors. *Society, Behaviour and Epilepsy*. New York: Nova Science Publishers Inc; 2011:175–205.
34. Ettinger AB, Manjunath R, Candrilli SD, Davis KL. Prevalence and cost of nonadherence to antiepileptic drugs in elderly patients with epilepsy. *Epilepsy Behav* 2009;14: 324–329.
35. Fought RE, Weiner JR, Guerin A, Cunningham MC, Duh MS. Impact of nonadherence to antiepileptic drugs on health care utilization and costs: findings from the RANSOM study. *Epilepsia* 2009;50:501–509.
36. Ryan JL, Mellon MW, Junger KW, et al. The clinical utility of health-related quality of life screening in a pediatric inflammatory bowel disease clinic. *Inflamm Bowel Dis* 2013;19:2666–2672.
37. Creed F, Ratcliffe J, Fernandez L, et al. Health-related quality of life and health care costs in severe, refractory irritable bowel syndrome. *Ann Intern Med* 2001;134: 860–868.
38. Simon-Tuval T, Scharf SM, Maimon N, Bernhard-Scharf BJ, Reuveni H, Tarasiuk A. Determinants of elevated healthcare utilization in patients with COPD. *Respir Res* 2011;12:7.
39. Cicutto L, To T, Murphy S. A randomized controlled trial of a public health nurse-delivered asthma program to elementary schools. *J Sch Health* 2013;83:876–884.

New Payment and Delivery Models

How can you ensure your first value-based contract is a success? Check out the AAN's Top 5 tips to get on the right track!

Link to – <https://www.aan.com/practice/top-five/>

Save These Dates for AAN CME Opportunities!

Mark these dates on your calendar for exciting continuing education conferences by the American Academy of Neurology. Learn more at AAN.com/conferences.

AAN Fall Conference

- October 16–18, 2015, Las Vegas, NV, The Cosmopolitan of Las Vegas

AAN Annual Meeting

- April 15–21, 2016, Vancouver, BC, Canada, Vancouver Convention Centre