

# Factors associated with reported challenging behavior in young people with epilepsy and neurodevelopmental problems: Data from a specialist epilepsy center

\*Colin Reilly, and †‡§Rod C. Scott

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Colin Reilly is a psychologist working in the research department at Young Epilepsy, United Kingdom.

## SUMMARY

Reported incidents of challenging behavior over a 6-month period (December 2011–May 2012) were systematically recorded in young people (8–23 years) with epilepsy ( $n = 125$ ), and a comparison group of young people without epilepsy ( $n = 64$ ) at a specialist epilepsy center in the United Kingdom. Factors associated with such incidents were analyzed via regression analysis. The presence of epilepsy was not a significant predictor of recorded challenging behavior. Factors associated with increases in recorded challenging behavior on multivariable analysis in the epilepsy sample were the use of medication for behavioral/psychiatric conditions ( $p < 0.05$ ) and attending the center on a residential basis ( $p < 0.001$ ). In the total sample, use of medication for behavioral/psychiatric conditions ( $p < 0.05$ ), younger age ( $p < 0.01$ ),  $IQ < 50$  ( $p < 0.01$ ), and residential status ( $p < 0.001$ ) were associated with increases in recorded challenging behavior. The presence of depression was associated with reduced challenging behavior in the total sample ( $p < 0.05$ ). The association between the use of psychopharmacology and increased challenging behavior in those with epilepsy and nonepilepsy could indicate a difficult to treat behavioral/psychiatric burden, lack of treatment efficacy, and/or an increased side effect profile and needs further examination.

**KEY WORDS:** Epilepsy, Behavior, Attention deficit hyperactivity disorder.

Epilepsy in young people is associated with a range of neurobehavioral difficulties,<sup>1</sup> including Intellectual Development Disorder (IDD, also known as Intellectual Disability),<sup>1</sup> Attention Deficit Hyperactivity Disorder (ADHD),<sup>2</sup> Autism Spectrum Disorder (ASD),<sup>1</sup> thought disorder/schizophrenia-like symptoms,<sup>3</sup> and anxiety/depression.<sup>4</sup>

These difficulties are often underrecognized<sup>1</sup> and can have a greater impact on quality of life than the seizures.<sup>5</sup>

Challenging behavior is associated with increases in receipt of antipsychotic medication, service use, hospitalization, restrictive care practices, and deprivation.<sup>6</sup> In relation to potential contributors to challenging behavior in individuals with epilepsy, comorbid psychopathology was associated with violence in a meta-analysis of violence in epilepsy.<sup>7</sup> However, few studies examine reported incidents of challenging behavior in epilepsy or factors associated with such incidents.

The aim of the current study was to examine the relationship between a range of possible factors and recorded challenging behavior. Recorded challenging behavior (including aggressive and destructive behavior) was considered in young people with epilepsy and neurobehavioral difficulties and a comparison group of young people without epilepsy. Factors considered included demographic factors (i.e., age, gender), epilepsy-related factors (i.e., age of

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\*Research Department, Young Epilepsy, Lingfield, Surrey, United Kingdom; †Great Ormond Street Hospital for Children NHS Trust, London, United Kingdom; ‡Neurosciences Unit, Institute of Child Health, University College London, London, United Kingdom; and §College of Medicine, University of Vermont, Burlington, Vermont, U.S.A.

Address correspondence to Colin Reilly, Research Department, Young Epilepsy, Lingfield, Surrey RH7 6PW, U.K. E-mail: creilly@youngepilepsy.org.uk

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epilepsy onset, use of antiepileptic drugs [AEDs]), neurobehavioral factors (i.e., presence of ASD, ADHD, IDD, psychiatric disorders), and use of psychopharmacology.

## METHODS

### Setting

Young Epilepsy, a national charity for young people with epilepsy, has a school for children and adolescents and a college for young adults. Provision can be day only, 39 weeks a year (residential), or 52 weeks a year (residential). The center provides specialist care (including educational, psychological, and medical) for young people with complex epilepsy (epilepsy plus neurodevelopmental difficulty) but also for young people without epilepsy who have other neurodevelopmental disorders (e.g., IDD, ASD, and ADHD).

The incident report database at Young Epilepsy is a computerized database that contains information on staff reports of challenging behavior. An incident deemed to have involved challenging behavior must be logged on the incident report system the same day it occurs, and logged under at least one category of behavior, although more categories than one can be selected for each incident. The categories are hitting, grabbing, kicking, throwing objects, damaging property, biting, swearing, scratching, spitting, pushing over objects, pinching, self-harm, bullying, absconding, head butting, pulling over objects, and stealing. Staff receive comprehensive training on how to identify and record incidents, and reports are monitored by unit managers to ensure consistency.

### Characteristics of the young people

Data on the clinical characteristics of the young people were extracted from medical notes at Young Epilepsy using a standardized proforma between December 2011 and May 2012. Data extracted included epilepsy status (lifetime epilepsy vs. never had epilepsy), ADHD status, ASD status, depression status, anxiety status, psychosis status, cognitive functioning, age, and gender. For those with epilepsy, characteristics of the young person's condition were extracted, including number of current epilepsy medications and age of seizure onset. Lifetime epilepsy was defined as having a history of two or more unprovoked seizures separated by at least 24 h.

Cognitive functioning ( $IQ \geq 50$  or  $IQ < 50$ ) was determined by available results of assessments using standardized cognitive instruments in the young peoples' medical files (see assessment protocol in Data S1). Where these instruments did not provide valid information for children and young people, results from other assessment instruments were used to determine cognitive status (see Data S1). A psychologist (C.R.) subsequently classified these children as  $\geq IQ50$  or  $< IQ50$ . Diagnoses of ASD, ADHD, anxiety, depression, or psychosis were based on recorded

*DSM-IV-TR*<sup>8</sup> diagnoses in medical notes. Psychiatric and behavioral diagnoses at the center are made following referral to a child and adolescent psychiatrist and a team comprising a psychologist, a pediatric neurologist, an epilepsy nurse specialist, and an educator.

### Analysis

Chi-square analyses were used to compare the characteristics of the young people with epilepsy with those of young people who did not have epilepsy. ANOVA analyses were used to compare the mean age and the mean number of the 17 behaviors included in the incident report system in both groups.

Univariable and multivariable regression analyses were carried out using negative binomial regression for count data (to account for overdispersion of the outcome variable) to identify factors associated with total number of reported incidents. Analyses were carried out on the epilepsy sample ( $n = 125$ ) and on the total sample ( $n = 189$ ). Factors included in the regression analysis in the epilepsy sample were gender (male vs. female), age (in years), cognitive ability ( $IQ \geq 50$  vs.  $IQ < 50$ ), ASD status (Present vs. Absent), ADHD status (Present vs. Absent), psychopharmacology (i.e., medication for behavioral/psychiatric difficulties) (Present vs. Absent), and time adjustment (Day Pupil (reference)/39 week/52 week). AED usage (monotherapy vs. polytherapy) and age of seizure onset (in years) were included only in the analysis of the epilepsy sample. Epilepsy status (yes vs. no) was included only in the analysis of the total sample. Depression, anxiety, and psychosis were also only included in analysis of the total sample. They were originally included in the epilepsy sample but did not yield useful data, possibly because of the small number with each diagnosis, and were subsequently removed. Analyses were conducted using IBM SPSS version 2 (Chicago, IL, U.S.A.).

## RESULTS

The characteristics of the young people in both groups are in Table 1.

One hundred eighty-two of 189 (96%) individuals had an IQ score or adaptive behavior score in the IDD range. One hundred twenty-five young people had a lifetime diagnosis of epilepsy, and 64 did not have epilepsy. Based on ANOVA analysis, the mean age in the nonepilepsy group was significantly greater than in the epilepsy group ( $p = 0.001$ ). There were also significantly more children with  $IQ < 50$  in the epilepsy group ( $p = 0.006$ ), but significantly more children with ASD in the nonepilepsy group ( $p = 0.013$ ).

The mean number of each category of challenging behavior for young people with epilepsy and nonepilepsy is in Table S1. Based on ANOVA analysis, there was not a significant difference between the epilepsy and nonepilepsy

**Table 1. Characteristics of young people with epilepsy and young people without epilepsy who have neurodevelopmental difficulties**

	Epilepsy (n = 125)	Nonepilepsy (n = 64)	p	$\chi^2$
Male/Female	81/44	44/20	0.587	0.295
Age in years (Mean/range)	(18.6/8–23)	20.2 (12–22)	0.001	10.915 <sup>a</sup>
Educational setting				
School	61	51	0.000	14.419
College	64	14		
Day/Residential	23/102	18/46	0.125	2.357
39-week residential	75	43		
52-week residential	27	3		
Epilepsy ever	125	64	n/a	n/a
Current	113	n/a	n/a	n/a
Past	12	n/a	n/a	n/a
Epilepsy etiology				
Idiopathic	14	n/a	n/a	n/a
Symptomatic	81	n/a	n/a	n/a
Cryptogenic	1	n/a	n/a	n/a
Unknown/not recorded	29	n/a	n/a	n/a
Age of onset of epilepsy				
<3	62	n/a	n/a	n/a
3+	60	n/a	n/a	n/a
Monotherapy	28	n/a	n/a	n/a
Polytherapy	84	n/a	n/a	n/a
IQ < 50/IQ ≥ 50 <sup>b</sup>	86/39	31/33	0.006	7.442
ADHD	19	10	0.939	0.006
ASD	34	30	0.013	6.147
Psychiatric yes/no	9/116	8/56	0.242	1.367
Depression	4/121	3/61		
Anxiety	3/122	5/59		
Psychosis	2/123	2/62		

ADHD, Attention Deficit Hyperactivity Disorder; ASD, Autism Spectrum Disorder.  
<sup>a</sup>Based on ANOVA analysis,  $F = 10.915$ .  
<sup>b</sup>Of those classified as  $IQ \geq 50$ , 7 had  $IQ$  or adaptive behavior score  $\geq 70$ .

groups with regard to the mean number of any of the 17 behaviors on the incident reporting system over the 6-month period.

The factors associated with total incidents of challenging behavior based on regression analysis in the epilepsy sample are in Table S2.

Factors significantly associated with increased incidents of challenging behavior in the epilepsy sample on univariable analysis were the presence of ADHD, use of psychopharmacology, and time adjustment. On multivariable analysis, the factors that remained significant were use of psychopharmacology ( $p = 0.034$ ) and attendance for 52 and 39 weeks (compared to reference attendance as a day pupil) (both  $p < 0.001$ ).

The factors associated with total incidents of challenging behavior based on regression analysis in the total sample are in Table 2.

Factors significantly associated with increased total incidents in the total sample were younger age, lower cognitive functioning, ADHD, use of psychopharmacology, and time adjustment. On multivariable analysis, the factors that remained significantly associated with increased incidents

were younger age ( $p = 0.001$ ), lower level of cognition ( $p = 0.005$ ), use of psychopharmacology ( $p = 0.004$ ), and attendance for 52 and 39 weeks (compared to attendance as a day pupil) (both  $p < 0.001$ ). The presence of depression was associated with reduced incidents of challenging behavior ( $p = 0.035$ ).

## DISCUSSION

The results of the current study indicate that young people with epilepsy and additional neurobehavioral difficulties did not display more incidents of challenging behavior than a similar group of young people without epilepsy.

A previous study showed that the presence of epilepsy was not associated with increased self-injurious behavior in a sample of individuals with IDD.<sup>9</sup> One study did suggest a significant association between epilepsy and behavioral difficulties in children with IDD in South Africa.<sup>10</sup> However, in both studies behavior was based on parent/teacher report of behavior. The current study thus gives an indication of the frequency of challenging behavior using real-world measures and indicates that epilepsy does not

Table 2. Factors associated with total incidents of challenging behavior based on univariable and multivariable regression in total sample (n = 189)

Factor	Univariable			Multivariable		
	B (95% CI)	P	Exp B (95% CI)	B (95% CI)	P	Exp B (95% CI)
Gender	0.170 (-0.563 to 0.598)	0.954	1.017 (0.568 to 1.818)	-0.430 (-0.987 to -0.126)	0.130	0.650 (0.373 to 1.135)
Age	-0.142 (-0.239 to -0.046)	0.004	0.867 (0.787 to 0.955)	-0.160 (-0.257 to -0.063)	0.001	0.852 (0.774 to 0.939)
Epilepsy	-0.214 (-0.791 to 0.364)	0.469	0.808 (0.453 to 1.440)	0.233 (-0.326 to 0.771)	0.426	1.249 (0.722 to 2.161)
IQ	-0.781 (-1.337 to -0.225)	0.006	0.458 (0.263 to 0.799)	-0.739 (-1.253 to -0.225)	0.005	0.478 (0.286 to 0.798)
ASD	-0.249 (-0.806 to 0.307)	0.380	0.779 (0.447 to 1.360)	0.009 (-0.569 to 0.586)	0.976	1.009 (0.566 to 1.797)
ADHD	-1.119 (-1.875 to -0.362)	0.004	0.327 (0.153 to 0.696)	-0.682 (-1.404 to 0.040)	0.064	0.506 (0.246 to 1.040)
Depression	1.474 (-0.015 to 2.964)	0.052	4.369 (0.985 to 19.372)	1.454 (0.104 to 2.803)	0.035	4.278 (1.110 to 16.491)
Anxiety	0.714 (-0.616 to 2.043)	0.293	2.042 (0.540 to 7.717)	-0.924 (-2.086 to 0.239)	0.119	0.397 (0.124 to 1.269)
Psychosis	-1.042 (-2.968 to 0.883)	0.289	0.353 (0.051 to 2.419)	1.302 (-0.576 to 3.179)	0.174	3.675 (0.562 to 24.031)
Psychopharmacology	1.207 (0.560 to 1.854)	<0.001	3.343 (1.750 to 6.386)	-0.973 (-1.640 to -0.306)	0.004	0.378 (0.194 to 0.736)
Time adj.						
52 week	1.176 (1.144 to 2.331)	0.009	3.243 (1.339 to 7.854)	1.751 (0.894 to 2.607)	<0.001	5.760 (2.446 to 13.564)
39 week	0.314 (-0.368 to 0.997)	0.367	1.369 (0.692 to 2.710)	1.714 (0.956 to 2.473)	<0.001	5.553 (2.601 to 11.856)
Day pupil	Reference		Reference			

Analysis based on negative binomial regression with log link. Parameter set to estimate value. Goodness of fit value/d.f. 1.135. ADHD, Attention Deficit Hyperactivity Disorder; ASD, Autism Spectrum Disorder; CI, confidence interval.

confer an increased risk for the display of challenging behavior.

In the epilepsy group, none of the included epilepsy factors were associated with increases in challenging behavior. This is in line with studies suggesting that epilepsy factors per se are not associated with behavioral difficulties<sup>1</sup> and in agreement with a previous study of “aggressive” behavior at a residential epilepsy center.<sup>11</sup> The association between use of psychopharmacology and increased incidents of challenging behavior in both the epilepsy group and total sample could mean that these young people had significant behavioral/psychiatric difficulties that contributed to challenging behavior despite the use of psychopharmacology. The association could also be due to side effects of such medications or lack of effectiveness of some medications in this population, which has been noted in the IDD population.<sup>12</sup>

In the total sample, lower cognitive functioning was independently associated with increased challenging behavior. It has been shown that those with mild/moderate IDD were more likely to show verbal aggression, whereas those with severe/profound IDD were more likely to display physical aggression, self-harm, and property destruction.<sup>13</sup> Therefore, the relationship between cognitive ability and displays of challenging behavior is likely to depend on the nature of incidents. A significant association between younger age and increased incidents of challenging behavior was noted in the total sample. The literature regarding the impact of age and display of challenging behavior is inconsistent. A review of relevant literature suggests that challenging behavior and aggression increase from childhood into the teenage years but may decrease in later adulthood.<sup>14</sup> The association between depression and reduced incidents of challenging behavior suggests that depressive symptoms are likely to be associated with internalizing behaviors and not with overt challenging behaviors.

The relationship between incidents of challenging behavior and 39/52-week attendance could be attributed to the fact that young people who stay on the campus on a residential basis have behavior that would be more difficult to manage in the home setting, as well as related to being on campus for a longer time compared with those who attend on a day basis.

### Limitations

The setting is a specialist center for young people with epilepsy and neurobehavioral difficulties, and findings may not be generalizable beyond this setting. Although all young people underwent psychological evaluation, all were not screened for the specific neurobehavioral difficulties, and some children with these difficulties may have been missed. Although all staff who work at the center receive training on the identification/recording of challenging behavior, the system has not been subject to independent validation, and reliability has not been established. We were not able to consider seizure frequency or type, extent and nature of

psychological inputs, or types of medication as possible contributors to challenging behavior.

## CONCLUSION

Epilepsy did not confer an increased risk for the display of challenging behavior at a specialist center for young people with epilepsy and neurobehavioral disabilities. Use of psychopharmacology conferred an increased risk in those with epilepsy. These data support the view that behavioral impairments in children with epilepsy are unlikely to be modified significantly with the use of AEDs and that therapies directly targeting behavior are more likely to have important clinical benefits.

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## DISCLOSURE

None of the authors has any conflict of interest to disclose. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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## SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

**Data S1.** Assessment protocol at Young Epilepsy.

**Table S1.** Number of each category of recorded challenging behavior in the epilepsy and nonepilepsy groups over a 6-month period.

**Table S2.** Factors associated with total incidents of challenging behavior based on univariable and multivariable regression in epilepsy group (n = 125).