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Measuring the Barriers to Adherence With Neurology Clinic Appointments for Children With Epilepsy: A Pilot Study

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Abstract

Introduction: Epilepsy is one of the most common neurological disorders in children. Missed appointments reflect missed opportunity to provide care for children with epilepsy. The objective of this study was to identify social determinants of health (SDH) and other factors associated with missed appointments in children with epilepsy and measure the relation between missed appointments and frequency of emergency room (ER) visits and inpatient admissions. **Methods:** This was a prospective study conducted in the neurology division at a level 4 epilepsy center. Children (0 to < 18 years of age) with a diagnosis of epilepsy were included and a semi-structured questionnaire was provided to the families. Patients with 2 or more missed neurology clinic appointments in the previous year ("study group", n = 36) were compared to those with 1 or zero missed appointments ("control group", n = 49). A comparison of the clinical characteristics, emergency room visits and hospitalizations in the past year as well as SDH was performed. Statistical analysis was performed using SPSS and $p < 0.05$ was considered significant. **Results:** The mean age, gender distribution and presence of medical refractoriness were comparable between the 2 groups. Families in the study group reported a higher likelihood of having to make special work arrangements for clinic appointments. Children in the study group were noted to have a significantly higher frequency of single mother households, presence of public insurance, father not graduating from high school and household income less than 50,000 dollars. Within the preceding year, children in the study group were noted to have a higher frequency of visits to the emergency department as well as 6 times higher likelihood of inpatient hospitalization for seizures. **Conclusions:** Social determinants of health play an important role in determining adherence with neurology clinic visits in children with epilepsy. Children with more missed appointments are likely to have a higher frequency of visits to the emergency department as well as a higher incidence of hospitalization for seizures. Identification of high-risk families and implementation of early interventions may improve adherence to office visits and decrease emergency room visits and hospitalization for seizures.

Keywords

children, epilepsy, outcome, pediatric, quality of life, risk factors

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Rationale

Epilepsy is one of the most common neurological disorders in children, with a higher prevalence in those with lower socio-economic status (SES).[1–3] Childhood onset epilepsy has long term consequences and impacts several aspects of the child's life including school, employment, marriage, and parenthood.[4–6] Long term cognitive outcomes in childhood onset epilepsy are worse in those with poorly controlled epilepsy.[7] Children with epilepsy are also at a higher risk of mortality[8,9] specifically children with symptomatic epilepsy having a 20-fold greater mortality than the general population.[10]

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Long-term management of epilepsy requires close clinical monitoring to achieve the best clinical outcomes. Depending on the seizure frequency as well as the complexity of the child's epilepsy, children may be seen in the neurology clinic multiple times a year. The clinic visits create opportunities to manage recurring seizures, optimize the drug doses based on child's weight, review adherence to medication, evaluate for co-morbid conditions, monitor cognitive development and review seizure action plans. A missed clinic appointment reflects missed opportunity to provide comprehensive care for these children. Repetitive non-adherence to neurology clinic appointments can lead to non-adherence to anti-epileptic drug therapy which is associated with a higher recurrence rate of seizures,[11] more frequent emergency room visits,[12] a misdiagnosis of drug resistant epilepsy as well as diminished quality of life for both the child and the family. Children with epilepsy who have a high rate of missed appointments and more calls to triage nursing are at high risk for ED visits.[12] Repetitive missed clinic appointments can thus potentially have a significant impact on the cost of care.[13,14]

Additionally, continuity of physician/provider exerts a positive effect on staff and patient attitudes and behaviors, improved efficiency, better appointment keeping, and greater disclosure of personal problems to the physician/provider.[15]

Many interventions have been shown to be effective to decrease non-adherence to clinic appointments in patients with chronic conditions. However, these are implemented once the patient has been identified as someone who is likely to not adhere to the recommended follow up schedule and prescribed therapy based on their history. Our goal is to identify the socioeconomic variables that can place a child and the family at risk for non-adherence to clinic appointments at the time of diagnosis of epilepsy. Our hypothesis is that if we institute preemptive measures to prevent missed appointments to neurology clinic in children with epilepsy when they are first diagnosed, we can prevent unnecessary ED visits and inpatient admissions. This would also ensure continuity of care, opportunities for education by the same team of caregivers promoting trust and have a potential impact on the clinical outcome.

Methods

This was a prospective pilot study conducted from June 2019 to April 2020 in the neurology division at Dayton Children's Hospital. The study was terminated prematurely due to the COVID 19 pandemic as we transitioned to tele-health visits. We are a level IV epilepsy center serving Western and Southern Ohio. At our center, epilepsy patients are seen in the neurology clinic as well as in a dedicated multidisciplinary intractable epilepsy clinic. For the study, patients were recruited during their regularly scheduled neurology clinic appointment. Inclusion criteria for the study group included children (0 to $\leq$ 18 years of age) with a diagnosis of epilepsy who had 2 or more missed appointments in the previous year. Missed appointments were defined as patients not showing up to the clinic visit or cancelling it within 24 hours of the appointment. A "control group" was recruited and the inclusion criteria consisted of children with epilepsy who had 1 or 0 missed appointment in the same year. Epilepsy was defined according to the 2014 ILAE definition of epilepsy.[16]

The study and control group patients were identified by screening daily patient schedules during the study period. Out of 46 patients who were approached to be included in the study group, only 36 agreed to participate. Patients in the control group were selected randomly during the study period. Out of 59 patients identified as controls, 49 families agreed to participate.

During the clinic visit, face to face semi-structured interviews were conducted by the first 2 authors (JB, MW) of this study, based on a questionnaire (attached) to identify the barriers perceived by the family in attending neurology outpatient clinic visits. The survey questions were based on previous studies examining missed appointments in the clinic setting[3,17–19] as well as feedback from 2 of the study investigators who are social workers (JB, MW).

We also collected data about the age, gender, epilepsy classification, presence of intractable epilepsy defined according to the ILAE,[20] Emergency Department (ED) visits in the 1 year prior to the visit, hospitalizations in the last 1 year, insurance type, household income, education and profession of the biological parents and the primary caregiver (if different from the biological parents).

The outcomes measures included emergency room visits for all reasons as well as for seizures and admissions to the hospital for all reasons as well as for seizures in the last 1 year prior to the encounter with the family. Study outcomes and patient age were summarized with mean (standard deviation, SD), median (interquartile range [IQR], which is the middle 50% of the observations), and range. Comparisons of study outcomes and patient age between the study and control groups were made with Mann-Whitney U tests. Categorical variables were summarized with frequency (percent of non-missing responses), and compared between the study and control groups with chi-square tests or Fisher's exact tests. For statistically significant comparisons of categorical variables with 3 or more levels, multiple paired comparisons were made among the levels, with P values adjusted using Bonferroni corrections. Statistical analysis was performed using IBM SPSS v26.0 for Windows, and $P < .05$ was considered significant. The study was reviewed by the Dayton Children's Hospital IRB and approved.

Results

There were 36 patients in the study group and 49 patients in the control group. The mean age, gender distribution and presence of medical refractoriness were comparable between the 2 groups. A significantly higher number of study group patients had public health insurance compared to the control group. Within the preceding year, children in the study group were also noted to have more visits to the emergency department, emergency department visits to hospitalizations, and 6 times

Table 1. Demographic and Clinical Characteristics of Patients in the Study and Control Groups.

Variable	Study Group n = 36	Control Group n = 49	*P* value
Gender, n (%) male	19 (52.8)	25 (51.0)	0.873
Health insurance type, n (%)			
Public	30 (83.3)	21 (43.8)	**<0.001**
Private	6 (16.7)	27 (56.3) (n = 48)	
Presence of medical refractoriness, n (%) yes	17 (47.2)	20 (40.8)	0.556
Age (years)			
Median (IQR)	10 (8)	9 (7)	0.456
Mean (SD)	9.0 (4.3)	9.6 (4.4)	
Range	Feb-17	Jan-16	
Missed neurology clinic appointments			
Median (IQR)	2 (1)	0 (1)	na
Mean (SD)	2.5 (0.8)	0.3 (0.5)	
Range	02-Jun	0-1	
All ED visits in past year			**0.042**
Median (IQR)	2 (6)	1 (2)	
Mean (SD)	3.1 (3.6)	1.6 (2.5)	
Range	0-12	0-14	
Seizure/epilepsy related ED visits in past year			
Median (IQR)	0 (2)	0 (1)	0.107
Mean (SD)	1.1 (2.0)	0.4 (0.7)	
Range	0-9	0-3	
All ED to hospitalizations in past year			
Median (IQR)	0 (2)	0 (0)	**0.01**
Mean (SD)	1.2 (2.0)	0.4 (1.2)	
Range	0-9	0-8	
Seizure/epilepsy related ED to hospitalizations in past year			
Median (IQR)	0 (1)	0 (0)	**0.014**
Mean (SD)	0.6 (1.0)	0.1 (0.4)	
Range	0-4	0-2	

Abbreviations: ED, emergency department; IQR, interquartile range (the middle 50% of the observations); na, not analyzed (grouping variable); SD, standard deviation. N = 36 for the study group and n = 49 for the control group unless otherwise specified in the table. *P* values for gender, health insurance type, and presence of medical refractoriness are from chi-square tests; *P* values for all other variables are from Mann-Whitney U tests, comparing the medians between the study and control groups. Statistically significant *P* values are bolded.

Table 2. Number of ED Visits and Hospitalizations in Previous Year for Study and Control Group Patients.

Variable	Study Group n (%)	Control Group n (%)
All ED visits in past year		
0	13 (36.1)	23 (46.9)
1	1 (2.8)	8 (16.3)
2	8 (22.2)	8 (16.3)
3	2 (5.6)	3 (6.1)
4	2 (5.6)	4 (8.2)
≥5	10 (27.8)	3 (6.1)
Seizure/epilepsy related ED visits in past year		
0	22 (61.1)	36 (73.5)
1	5 (13.9)	9 (18.4)
2	3 (8.3)	3 (6.1)
3	2 (5.6)	1 (2.0)
4	1 (2.8)	0 (0.0)
≥5	3 (8.3)	0 (0.0)
All ED to hospitalizations in past year		
0	21 (58.3)	40 (81.6)
1	5 (13.9)	6 (12.2)
2	3 (8.3)	2 (4.1)
3	4 (11.1)	0 (0.0)
4	0 (0.0)	0 (0.0)
≥5	3 (8.3)	1 (2.0)
Seizure/epilepsy related ED to hospitalizations in past year		
0	24 (66.7)	43 (87.8)
1	7 (19.4)	5 (10.2)
2	2 (5.6)	1 (2.0)
3	2 (5.6)	0 (0.0)
4	1 (2.8)	0 (0.0)

Abbreviations: ED, emergency department. N = 36 for the study group and n = 49 for the control group.

higher likelihood of inpatient hospitalization for seizures (Table 1). Table 2 shows the number of patients in each group who had 0, 1, 2, 3, 4, or ≥5 ED visits or hospitalizations in the previous year. A higher percent of patients in the study group vs. the control group had at least 1 ED visit (63.9% vs. 53.1%) or seizure/epilepsy related ED visit (38.9% vs. 26.5%), but the differences were not statistically significant ($P = .318$ and $P = .227$ respectively). A significantly higher percent of patients in the study group had at least 1 ED visit to hospitalization (41.7% vs. 18.4%, $P = .018$), and seizure/epilepsy related ED visit to hospitalization (33.3% vs. 12.2%, $P = .019$).

Table 3 summarizes the family's perceptions and difficulties about the neurology clinic appointments. There was no significant difference in the perceived difficulty in keeping neurology appointments or scheduled frequency of neurology visits between the study and control groups. There was no significant difference reported in the need for special arrangements for transportation, lodging and childcare.

Families in the study group reported a higher likelihood of having to make special work arrangements for clinic appointments (Table 3). Children in the study group were noted to have a statistically significant higher frequency of single mother household, father not graduating from high school and household income less than 50,000 dollars (Table 4).

Qualitative data obtained was informative in understanding some specific factors unique to the 2 groups. Given the heterogeneity of this information and the small sample size, this data was not analyzed statistically, however, it did identify a few themes.

In response to how we could help families come to the appointment, in the study group, the majority of responses involved transportation assistance such as gas cards, which was a theme not found within the control group. The largest obstacles noted by the control group revolved around scheduling

Table 3. Responses to Questions Regarding Family's Perceptions About Their Clinic Appointments.

Questionnaire Item	Study Group n (%)	Control Group n (%)	*P* value
Q1. How difficult to attend neurology appointments			
1 (Not difficult)	16 (45.7)	26 (53.1)	0.867
2	7 (20.0)	11 (22.4)	
3	9 (25.7)	8 (16.3)	
4	2 (5.7)	3 (6.1)	
5 (Extremely difficult)	1 (2.9)	1 (2.0)	
	(n = 35)		
Q2. Special arrangements needed to attend appointments (select all that apply)	9 (25.0)	6 (12.2)	0.127
Transportation, n (%) yes	2 (5.6)	0 (0.0)	0.176
Lodging, n (%) yes	5 (13.9)	11 (22.4)	0.318
Childcare, n (%) yes	3 (8.3)	5 (10.2)	0.999
Insurance, n (%) yes	8 (22.2)	21 (42.9)	**0.047**
Work-related issues, n (%) yes	5 (13.9)	6 (12.2)	0.999
Other, n (%) yes			
Q3. How difficult to be on time for neurology appointments			
1 (Not difficult)	20 (57.1)	26 (53.1)	0.814
2	10 (28.6)	15 (30.6)	
3	5 (14.3)	5 (10.2)	
4	0 (0.0)	2 (4.1)	
5 (Extremely difficult)	0 (0.0)	1 (2.0)	
	(n = 35)		
Q4.1. Does child see another specialist? n (%) yes	23 (63.9)	25 (51.0)	0.237
Q4.2. Other specialists seen by child			
Gastroenterology	5 (21.7)	7 (28.0)	0.676
Physical Medicine/Rehabilitation	5 (21.7)	6 (24.0)	
Pulmonary	3 (13.0)	5 (20.0)	
Orthopedics	3 (13.0)	1 (4.0)	
Developmental	1 (4.3)	1 (4.0)	
Psychiatry	3 (13.0)	3 (12.0)	
Psychology	0 (0.0)	2 (8.0)	
Endocrinology	2 (8.7)	0 (0.0)	
Nephrology	1 (4.3)	0 (0.0)	
	(n = 23)	(n = 25)	
Q5. How do you feel about frequency of neurology appointments?			
Frequency matches needs	31 (86.1)	45 (91.8)	0.643
Very frequent, and would prefer fewer	2 (5.6)	1 (2.0)	
Child needs more frequent appointments	3 (8.3)	3 (6.1)	
Q8. What emotion best matches how you feel about child seeing neurologist?			
Neutral	12 (33.3)	24 (49.0)	0.262
Happy	18 (50.0)	21 (42.9)	
Other	6 (16.7)	4 (8.1)	
Q9. How did you decide on choosing this clinic?			
Physician recommendation	15 (41.7)	30 (61.2)	0.114
Family/friend recommendations	5 (13.9)	1 (2.0)	
Convenience	4 (11.1)	4 (8.2)	
Other	12 (33.3)	14 (28.6)	

For all questions, n = 36 for the study group and n = 49 for the control group unless otherwise specified in the table. *P* values are from chi-square tests, or Fisher's exact tests if one or more expected cell frequencies was ≤5. Statistically significant *P* values are bolded.

whether it was scheduling around work or around school which was also found in the study group to some extent (Table 3).

The control group had 13 parents who work as either a supervisor, manager, or business owner whereas the study group did not have any parents in these roles. The parents in the control group worked as teachers, office workers and contractors whereas the majority of study group parents had occupations in either the service industry or involving manual labor.

Discussion

Our study revealed that social determinants of health strongly correlated with adherence to neurology clinic visits in children with epilepsy. In our study, children with repetitive no-shows to the neurology clinic appointments were more likely to have public insurance, belong to a single-mother household and have an annual household income of less than 50,000 dollars. We also noted that the level of parental education was low in these families with paternal education having a significant impact. Children with ≥2 missed neurology clinic visits had a higher frequency of visits to the emergency department as well as a higher incidence of hospitalization for seizures as well as other medical reasons within the past year.

Previous studies investigating the reasons for missed appointments across various settings including clinic visits, follow up after hospitalization as well as elective procedures[21–23] have shown higher rates of missed appointments in pediatric patients with Medicaid.[17] Public health insurance has been related to a higher chance of having epilepsy, decreased access to genetic testing[24] less access to effective rescue medications,[25] less access to epilepsy surgery[26,27] and higher noncompliance rate with medication leading to higher utilization of health care resources.[28] These children are also more likely to visit the ED, even after controlling for prior ED use and number of anti-seizure medications.[12] Identifying public insurance as a risk factor for missed appointments may be helpful in identifying at risk children with epilepsy and removing barriers to adherence to clinic appointments.

Parental education has been associated with many facets of epilepsy care in children. Lower parental education has been correlated with higher rates of non-adherence in pediatric epilepsy and is an overall significant predictor of missed anti-seizure medication dose and seizure frequency,[29] and adverse psychosocial outcomes.[30] Higher parental educational achievement may lead to more positive levels of self-perception in children with epilepsy.[31] In our study, paternal education had a significant influence on the rate of adherence to clinic appointments. It is unclear why maternal education did not have a similar impact, but it is possible that paternal education is more closely correlated with resourcefulness of a family as men remain the primary breadwinners at present in USA.

Children and adolescents with seizures are significantly more likely to live in poverty and low-income households and

Table 4. Family and Caregiver Characteristics as Reported in the Questionnaire.

Questionnaire item	Study Group n (%)	Control Group n (%)	*P* value
Q10. Primary caregiver			
Mother (only)	24 (66.7)	17 (34.7)	**.010**[b]
Mother and father	7 (19.4)	27 (55.1)	
Other[a]	5 (13.9)	5 (10.9)	
Q11. One parent or both parents in household:			
One parent	22 (62.9)	20 (44.4)	0.102
Both parents	13 (37.1)	25 (55.6)	
	(n = 35)	(n = 45)	
Q12A. Employment status of mother			
Employed	16 (51.6)	32 (68.1)	0.232
Unemployed	13 (41.9)	11 (23.4)	
Not applicable/not known	2 (6.5)	4 (8.5)	
	(n = 31)	(n = 47)	
Q12A. Employment status of father			0.369
Employed	18 (62.1)	35 (76.1)	
Unemployed	5 (17.2)	4 (8.7)	
Not applicable/not known	6 (20.7)	7 (15.2)	
	(n = 29)	(n = 46)	
Q13A. Is mother Hispanic/Latino? n (%) yes	2 (5.6)	2 (4.1)	0.999
Q13B. Is father Hispanic/Latino? n (%) yes	2 (5.9)	1 (2.1)	0.567
	(n = 34)	(n = 48)	
Q14A. Mother's race			
African-American	11 (32.4)	7 (14.3)	0.144
Caucasian	22 (64.7)	40 (81.6)	
Other	1 (2.9)	2 (4.1)	
	(n = 34)		
Q14B. Father's race			
African-American	11 (33.3)	8 (16.7)	0.145
Caucasian	20 (60.6)	36 (75.0)	
Asian	1 (3.0)	0 (0.0)	
Other	1 (3.0)	4 (8.3)	
	(n = 33)	(n = 48)	
Q14C. Primary caregiver's race (if not mother/father)			0.4
Caucasian	3 (100)	1 (50.0)	
Other	0 (0.0)	1 (50.0)	
	(n = 3)	(n = 2)	
Q16A. Did mother graduate high school/GED? n (%) yes	32 (88.9)	45 (91.8)	0.717
Q16B. Did father graduate high school/GED? n (%) yes	17 (58.6)	39 (92.9)	**0.001**
	(n = 29)	(n = 42)	
Q16C. Did primary caregiver (if not mother/father) graduate high school/GED? n (%) yes			
	2 (100)	2 (100)	na
	(n = 2)	(n = 2)	
Q17. Annual household income			
≤ $50,000	28 (90.3)	24 (57.1)	**0.002**
> $50,000	3 (9.7)	18 (42.9)	
	(n = 31)	(n = 42)	

Abbreviations: GED, General Educational Development Test; na, not analyzed (n = 2 for both groups and all 4 responses = yes). For questions, n = 36 for the study group and n = 49 for the control group unless otherwise specified in the table. *P* values are from chi-square tests, or Fisher's exact tests if one or more expected cell frequencies was ≤5. Statistically significant *P* values are bolded.

[a]For primary caregiver = other, 3 were father only (1 in study group, 2 in control group), 3 were other only (1 in study group, 2 in control group), 2 were mother and other (both in study group), and 2 were mother, father, and other (1 in study group, 1 in control group).

[b]For primary caregiver, the comparison between groups for mother only versus mother and father was statistically significant ($P < .05$); comparisons for mother only versus other, and for mother and father versus other were not statistically significant ($P > .05$, Bonferroni adjustments for multiple comparisons).

the prevalence of epilepsy is higher in populations with low income.[2,32]

Low household income has been associated with higher use of the hospital emergency rooms and hospitalizations, poor psychosocial outcomes and poor health related quality of life in children and adolescents with epilepsy[33,34] Our study found that lower household income was also associated with a statistically significant incidence of non-adherence to clinic appointments.

We additionally found that single mother households were more likely to not show for appointments. According to the US census bureau report, 23% of children live in single mother household in US.[35] Single-mother households tend to have lower family income compared to single father households, which may further increase the difficulties faced by these families.[36]

Single mother households have shown to have a higher percentage of children with unmet health needs and poorer control of their chronic health condition which is similar to the findings in our study.[18,19]

Other common reasons for missing appointments in previous studies have included forgetting the appointment, transportation problems and time off of work.[37] In our study, taking time off work was found to be a significant barrier for adherence to clinic appointments. Families in the study group reported a higher likelihood of having to make special work arrangements for clinic appointments. This can be addressed by early identification of this barrier and providing resources to the identified families.

Previous studies exploring barriers to appointment keeping in children with disabilities have proposed multiple interventions to prevent non-adherence to clinic including transportation support, multimethod scheduling options (e.g., open access scheduling, key contact, extended service hours, and automated appointment reminders[38]), and enhanced family-centered care delivery approaches to improve the experience and scheduling for children. A study looking at creation of an urgent clinic for children with established epilepsy found that this intervention was associated with a reduction in ED visits for seizures and improved adherence to outpatient clinic appointments for seizures.[39]

The identification of socio- economic variables in our study impacting non-adherence to clinic appointments in children with epilepsy may provide us an opportunity to provide safe, effective and high-quality care by carefully triaging patients and ensuring close follow up right when the child is diagnosed with epilepsy. This may prevent unnecessary ED visits and inpatient admissions.

We are in the process of implementing interventions that would include triaging patients with new onset epilepsy based on these variables and once identified at high risk for non-adherence to clinic appointments providing them resources including transportation, frequent reminders and help with child care. The assessment and interventions will be implemented by our social workers who are a part of our 'first seizure clinic' and also receive referral from the inpatient team for evaluation of families with children with new onset epilepsy.

Our pilot study is unique as this is the first study that addresses the impact of social and economic variables in children with epilepsy. Our assumption is that most parents want the best health care for their children and repeat missed appointments are a result of systemic failures rather than lack of internal motivation. We acknowledge that this is a small study overall and the sample in the study group was much smaller than the control group due to the study group families often missing appointments and due to premature termination of the study due to the COVID 19 lock down. We also acknowledge that we did not address language as a barrier for adherence to clinic appointment as having limited English proficiency in the United States can be a barrier to accessing health care services and understanding health information.[40]

Conclusion

Children with epilepsy who have frequent missed appointments in the pediatric neurology clinic have a higher rate of visits to the emergency department, have a higher rate of inpatient admissions due to all reasons as well as due to epilepsy. They belong to families with unfavorable socio-economic status including poverty, single mother households, lower level of parental education and public insurance. In order to ensure that optimal care is provided to children with epilepsy, we have to identify high risk families immediately after the diagnosis of epilepsy. We can attempt to prevent non-adherence to office visits by implementing interventions early on so that equitable care can be ensured.

Declaration of Conflicting Interests

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