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Behavioral Predictors of Medication Adherence Trajectories among Youth with Newly Diagnosed Epilepsy

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Abstract

Objective—This study aimed to identify psychosocial predictors of two-year antiepileptic drug (AED) adherence trajectories among youth with newly diagnosed epilepsy, controlling for known demographic and medical factors.

Method—This study is part of a large, prospective, longitudinal observational study of AED adherence and medical outcomes in youth with newly diagnosed epilepsy. Parents completed questionnaires of psychosocial and family functioning at one-month and one-year following diagnosis. Chart review and questionnaires were used to collect medical variables and seizure outcomes. Previously established two-year AED adherence trajectories (Severe Early Non-Adherence, Variable Non-Adherence, Moderate Non-Adherence, High Adherence) were used as the outcome variable.

Results—Participants were 91 parents of youth with epilepsy (7.3 ± 2.8 years of age; 60% male) and their families. Early (one-month following diagnosis) predictors of two-year adherence trajectories included socioeconomic status, epilepsy knowledge, family problem-solving, and family communication. Significant predictors one-year following diagnosis included socioeconomic status, parent fears and concerns, and parent life stress.

Conclusion—There are modifiable parent and family variables that predict two-year adherence trajectories above and beyond known medical (e.g., seizures, side effects) factors. Psychosocial interventions delivered at key points during the course of epilepsy treatment could have a positive impact on adherence outcomes.

Keywords

epilepsy; adherence; psychological factors; pediatric

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Conflict of Interest

The authors have no conflicts of interest to disclose.

1. Introduction

Past research has shown that children with epilepsy have difficulties taking antiepileptic drugs (AEDs) as prescribed[1, 2]. There are significant health and economic impacts of nonadherence to AEDs, such as poor seizure control[2], uninformed clinical decision making[3], and increased health care costs in adults[4].

In an effort to better understand reasons for nonadherence, past research has identified demographic, medical, and psychosocial factors associated with adherence behaviors (e.g., taking medication, clinic attendance). Lower socioeconomic status (SES) is consistently related to[5] and predicts[1] nonadherence across the disease course. Additional demographic and medical predictors of adherence include family composition, family history of epilepsy[6], and seizure control[2, 7]. While these factors may help clinicians classify patients most at-risk for non-adherence, the identification of modifiable psychosocial factors would more easily lend themselves to intervention and ultimately, improved adherence. Prior cross-sectional studies have demonstrated that less disease knowledge[8], higher barriers to the medication regimen[9], poorer parent psychosocial status, and poorer family functioning[10] negatively predict AED adherence. However, these studies have methodological limitations which limit generalizability of findings. Specifically, these studies lack an operational definition or evidence-based measure of adherence[6–8, 10–12], have small sample sizes[5–7], or assessed patients with chronic epilepsy[10, 12]. Additionally, most of the research has identified correlates, rather than predictors, of adherence over the course of epilepsy treatment[7, 8, 11, 12]. Identifying predictors that are amenable to intervention is essential for the prevention or reduction of nonadherence over the course of epilepsy treatment.

This study, which is a secondary data analysis[1], aimed to identify demographic, medical, and psychosocial predictors of previously established adherence trajectories among young children newly diagnosed with epilepsy at two different points in the course of epilepsy treatment. Factors that predict adherence may change over time as the family adjusts to the diagnosis and associated medical management[13]. For example, AED side effects may be highest during the acute period but often dissipate as the patient moves further from diagnosis and treatment initiation[14]. Further, a patient's tolerance for various AED side effects changes over time[15]. However, as the patient and family become more familiar with the condition and AED regimen, other factors, such as lack of resources and parental distress, may contribute to adherence difficulties. These trajectories were initially established to understand the influence of AED adherence on seizure outcomes. The next crucial step is to identify predictors of these trajectories to improve adherence following diagnosis. It was hypothesized that a more favorable (better) adherence trajectory would be predicted by fewer perceived barriers to the medication regimen, greater parent epilepsy knowledge, less perceived social stigma, decreased parent stress, and better family functioning, after controlling for SES, seizure trajectories, and AED side effects both early (one month following diagnosis) and later (one year following diagnosis) in the course of treatment.

2. Methods and materials

2.1. Participants

Participants were recruited from a New Onset Seizure (NOS) Clinic at a Midwestern United States children's hospital from November 2006 through March 2009. Eligibility criteria included: 1) new diagnosis of epilepsy; 2) 2–12 years old; 3) no parent-reported comorbid chronic illnesses requiring routine medications (e.g., diabetes) or significant developmental disorders (e.g., autism); 4) no prior AED treatment; and 5) initiation of carbamazepine or valproic acid monotherapy (which represented standard clinical practice within the NOS Clinic at the time of the study). There were 111 eligible families (children with epilepsy and a parent) that were approached for study participation. Five families declined participation due to time constraints (95% recruitment rate). One participant was found to be ineligible after informed consent was obtained (due to simultaneous diagnosis of a pervasive developmental disorder). Fourteen participants were excluded due to lack of follow-up data after their initial or one-month visit or significant missing adherence data (<90% complete data for all visits; see[16]). Thus, 91 participants were in this study cohort (82% of those initially eligible). The sample size for the one-year analyses was reduced to 73 due to missing adherence data or attrition (e.g., never returned to clinic, family relocated, withdrew) from the study. Participants who withdrew between the one-month and one-year predictor analyses were from lower SES households ($t = 2.51, p = .014$). There were no differences in age, sex, epilepsy type, adherence trajectory group, or seizure trajectory group.

2.2. Measures

2.2.1. Demographic and medical characteristics—A demographics questionnaire that assessed child and parent race, sex, age, and SES was obtained at recruitment. Socioeconomic status was assessed with the Revised Duncan, an occupation-based measure ranging from 15 to 97, where higher scores reflect higher occupational attainment[17]. For two-parent households, the higher Duncan score was used. Medical chart review was used to collect epilepsy-related information (e.g., date of diagnosis, epilepsy type, syndrome status, prescribed AED). Previously established seizure trajectories demonstrating the probability of having seizures over a two year period, including High (26% of participants) and Low (74% of participants)[16] were used as the seizure outcome variable. These trajectories are consistent with the broader pediatric literature, which suggests that approximately 30% of children will have intractable seizures[18–20].

2.2.2. Side effects—AED side effects were assessed with the 19-item Pediatric Epilepsy Side Effects Questionnaire (PESQ)[21] which consists of five subscales (i.e., cognitive, motor, behavioral, general neurological, weight). Each side effect was rated based on degree of severity on a 6-point Likert scale from “not present/not applicable or unable to assess” to “high severity”. The PESQ has excellent internal consistency ($\alpha = .90$), test-retest reliability (.91), and construct validity[21].

2.2.3. Barriers to medication adherence—The Barriers subscale (8-items) of the Pediatric Epilepsy Medication Self-Management Questionnaire (PEMSQ)[9], was used to

evaluate a parent's perception of factors that interfere with the child's treatment regimen (e.g., forgetting, disliking taste). Items were rated on a 5-point Likert scale from "strongly disagree" to "strongly agree". Internal consistency for the Barriers subscale was adequate ($\alpha = .59$).

2.2.4. Epilepsy knowledge—Knowledge about medical and social aspects of epilepsy was assessed using a modified version of the Epilepsy Knowledge Questionnaire (EKQ) [22]. Items were modified to be consistent with language and medical practice in the United States. The revised 47-item (True/False) version had a reliability coefficient of .58.

2.2.5. Parent functioning and stress—The Concerns and Fears subscale of the Parent Report of Psychosocial Care[23] consists of five items that assess parent concerns regarding whether the child's seizures will result in negative cognitive and health outcomes. Reliability for the current sample was good ($\alpha = .85$). The Family Stress Scale-Seizure Version (FSS-Seizure)[24] is a 14-item epilepsy-specific measure of parenting stress. Responses were provided on a 5-point Likert scale, ranging from "not at all stressful" to "extremely stressful," with higher scores indicating greater perceived stress. Reliability for the current sample was good ($\alpha = .87$). The Parenting Stress Index (PSI)[25] is a well-established, evidence-based measure of the degree to which stress is related to parent functioning, the behavioral and temperamental qualities of the child, and the parent-child relationship[26].

2.2.6. Social stigma—Parents' perception of stigma toward his/her child with epilepsy was measured with the Social Stigma Scale[27]. Responses were made on a 5-point Likert scale ranging from "strongly disagree" to "strongly agree", with higher scores indicating greater perceived stigma. Internal consistency for the current sample was .66.

2.2.7. Family functioning—The McMaster Family Assessment Device (FAD)[28] is a 60-item well-established measure of family functioning[26]. Based on a priori hypotheses, we examined the general functioning (overall functioning of family) scale, as well as the problem-solving (ability to resolve problems), communication (exchange of clear and direct verbal information), and behavior control (manner used to express and maintain standards of behavior) subscales. Internal consistencies were excellent for the general functioning scale ($\alpha = .95$) and acceptable for the subscales ($\alpha = .74 - .77$).

2.2.8. Medication adherence—Adherence to AEDs was assessed on a daily basis with electronic monitors (i.e., MEMS™ TrackCap, Aardex, Sion, Switzerland). This continuous data was used to identify four long-term adherence trajectory groups over the course of two years using latent class growth modeling [16], which include: Severe Early Non-adherence (9%), Variable Non-Adherence (15%), Moderate Non-Adherence (37%), and High Adherence (39%). These trajectory groups capture patterns of adherence during the two years following epilepsy diagnosis.

2.3. Procedure

This study was approved by the hospital's Institutional Review Board. Written parental consent and verbal assent was obtained during the child's first scheduled clinic visit. The current study is part of a larger investigation and details regarding study procedures have been described elsewhere [1, 2, 16]. Broadly, families were given an electronic monitor to measure AED adherence on the day of diagnosis. Children and their families completed ten study visits, which coincided with routine NOS clinic visits, over the course of two years. Data from the electronic monitors were downloaded at each visit; however, only parent-reported questionnaires at one month and one year post-diagnosis were used for the current study. Families were compensated with gift cards for completion of questionnaires and for bringing electronic monitors back to clinic for study visits.

2.4. Approach to statistical analysis

Adherence trajectory group status was the primary outcome variable used in ordinal logistic regression models implemented in SAS (version 9.3; SAS Institute, Cary, NC). Individual and family factors were all entered simultaneously as predictors of adherence trajectory group status in these models. Two models were estimated at two different important time points: initial diagnosis and one-year following diagnosis. Statistical significance was defined as $p < 0.05$. For statistically significant predictors, odds ratios with 95% confidence intervals and partial r^2 values were calculated to provide a better understanding of effect size. Partial r^2 values were calculated using max-rescaled r^2 values for logistic regression models to account for the fact that standard r^2 measures generally have an upper limit of less than 1.0 for discrete outcome variables [29, 30].

3. Results

3.1. Participants

Children in the study cohort were 7.3 ± 2.8 years of age, 60% male, and 98% non-Hispanic. Additional participant characteristics are described in Table 1.

3.2. Initial predictors of adherence trajectories

Initial predictors (e.g., individual and family factors) of the two-year adherence trajectories (Severe Early Non-adherence, Variable Non-adherence, Moderate Non-adherence, and High Adherence) were evaluated. Four significant predictors were identified, including SES ($\chi^2 = 12.2$ [$n = 79$]; $p < .001$; partial $r^2 = .093$), epilepsy knowledge ($\chi^2 = 4.0$ [$n = 79$]; $p = .04$; partial $r^2 = .029$), Problem Solving ($\chi^2 = 10.6$ [$n = 79$]; $p = .001$; partial $r^2 = .092$), and Communication ($\chi^2 = 9.8$ [$n = 79$]; $p = .002$; partial $r^2 = .083$). The result of the overall multinomial logistic regression model for predicting adherence trajectories is shown in Table 2.

3.3. Predictors of adherence trajectories at one-year following diagnosis

One-year post-diagnosis predictors of the two-year adherence trajectories were also examined. Three significant predictors were identified, including SES ($\chi^2 = 10.1$ [$n = 67$]; $p = .002$; partial $r^2 = .115$), parent fears and concerns ($\chi^2 = 6.3$ [$n = 67$]; $p = .01$; partial $r^2 = .$

053), and parent life stress ($\chi^2 = 4.4$ [$n = 67$]; $p = .04$; partial $r^2 = .042$). The result of the overall multinomial logistic regression model is shown in Table 3.

4. Discussion

To our knowledge, this is the first study to identify modifiable predictors of adherence trajectories in young children with newly diagnosed epilepsy using evidence-based adherence assessment[31]. Modifiable predictors of adherence trajectories included family-based problem solving, family communication, parent life stress, parent fears and concerns, and parent epilepsy knowledge, while SES was a significant nonmodifiable predictor. Surprisingly, family and parent predictors were significant above and beyond important medical variables, such as seizure trajectories and AED side effects. Our data highlights the critical role of parent and family functioning in adherence behaviors in pediatric epilepsy.

We examined predictors of adherence at two key time points in the disease course: early in the diagnosis and one-year following diagnosis. Family SES emerged as an early and late predictor of two-year adherence trajectories. Since SES is typically stable over time, it appears to have ongoing negative consequences, such that lower SES is associated with worse adherence trajectories. It is well-established in the literature that lower SES is associated with poorer adherence among youth with epilepsy[1, 12] and other chronic illnesses[32]. Although SES is non-modifiable, clinicians should be aware that it is an important risk factor for non-adherence to AED therapy.

Parent and family factors played a differential role in predicting two-year adherence trajectories depending on the timing of assessment. Early in the disease course, parent epilepsy knowledge and family-based problem solving and communication were identified as significant predictors of adherence, after controlling for seizure trajectories and AED side effects. Greater parent knowledge of epilepsy was associated with better adherence trajectories soon after diagnosis but not later in the course of the disease. Knowledge has been shown to be a necessary, but not sufficient, factor[33, 34] to improve adherence outcomes in the general adherence literature[35, 36]. However, knowledge plays a minor role[8, 9] in adherence behaviors relative to other parent and family factors.

The ability for families to communicate and problem solve is critical for good adherence soon after diagnosis. Specifically, better family communication and problem-solving skills were associated with more favorable two-year adherence trajectories, above and beyond seizures and side effects. This is a novel finding within pediatric epilepsy, but has been demonstrated in other pediatric diseases[37] and highlights the specific aspects of family functioning that warrant clinical attention. Evidence-based adherence interventions that target problem-solving and communication, such as Behavioral Family Systems Therapy[38], have demonstrated efficacy for improving adherence in adolescents with diabetes and cystic fibrosis[39–42]. In addition, a pilot adherence intervention focused on education and problem-solving has demonstrated initial efficacy in young children with newly diagnosed epilepsy[43]. Future intervention efforts are needed to further enhance communication and problem-solving skills in families of children with epilepsy.

One year following diagnosis, new predictors of adherence trajectories emerged, including parent fears and concerns and parent life stress (e.g., death of family members, significant income reduction, relocation, marital separation). Fewer parent fears/concerns and less life stress were associated with better adherence trajectories. The initial diagnosis and frequent medical monitoring in the form of clinic visits and correspondence with the health care team condition may override any parent concerns or anxiety, resulting in adequate adherence. However, as time increases from the child's diagnosis, the parent's functioning may become more salient with regard to adherence. It is also possible that once the shock of diagnosis wanes, parents start to worry about the long-term effects of epilepsy (e.g., re-emergence of seizures, future health complications secondary to AED treatment), which emerges as they learn more about the condition. This phenomenon has also been documented in the pediatric cancer literature[44–46]. It is likely that parent fears and stress may be handicapping them from engaging in epilepsy management behaviors. All families need time to adjust to the epilepsy diagnosis, new treatment regimen, ongoing seizures, and AED side effects[13, 47]. However, a subgroup of parents who experience fears, concerns, and life stress one year following the child's epilepsy diagnosis appear to have more difficulty with AED adherence. All of these factors, in conjunction with low SES, may mean that some parents lack the resources to administer medication above and beyond the daily demands of their lives. Interestingly, these same variables seem to play a critical role in the child's health-related quality of life[48]. Thus, parent-focused interventions to address fears, concerns, and life stress may be more critical later in the course of the child's epilepsy and could have a positive impact on adherence to epilepsy treatment and ultimately HRQOL.

Overall, inter-disciplinary care, which includes social workers, pharmacists, and psychologists, may be beneficial throughout the treatment process to address these key parent and family behavioral predictors of adherence. A model of care has been established to proactively screen children with epilepsy throughout their disease course, which allows for early identification of both child and family needs[49]. Additionally, members of the psychosocial service are able to provide brief, evidence-based interventions to address these needs. Based on the results of the current study, targeted interventions at critical time points (e.g., one-month after diagnosis, one-year after diagnosis) may need to be incorporated into clinical care. Knowledge of the modifiable factors that are the strongest predictors of adherence over the course of epilepsy treatment could result in more efficient delivery of care. Future treatment studies should examine whether behavioral interventions targeted to the predictors identified in this study would result in improved adherence over time.

4.1. Limitations and future directions

There are limitations of the current study that should be considered, as well as considerations for future research. First, these data are representative of a cohort of young and school-aged children with newly diagnosed epilepsy. Findings from the current study may not generalize to adolescents and young adults with epilepsy or children with developmental disabilities. Future research should incorporate patients spanning a broader developmental level to determine if the modifiable factors identified in this study are relevant. Second, we only examined parent-reported factors as predictors of adherence trajectories due to the developmental level of our sample. There may be psychosocial factors

from the child's perspective that are also critical predictors of adherence and future research should incorporate self-reported measures. Third, this study only evaluated individual and family level influences on AED adherence. Other modifiable and nonmodifiable factors, including aspects of the health care system (e.g., access to resources, patient-provider communication) and community (e.g., peer support), should be examined in the context of pediatric epilepsy adherence. Fourth, the measures designed to assess medication barriers and perceived social stigma had low internal consistency, which may have yielded non-significant results. Finally, there was attrition across the course of the two-year study period, and these participants were more likely from lower SES backgrounds. This may limit generalizability of results.

4.2. Conclusions

Overall, the current study highlights the importance of parent and family factors in predicting two-year adherence trajectories in young children with newly diagnosed epilepsy. Parent and family functioning were associated with adherence above and beyond known medical correlates (i.e., seizure trajectories, side effects), further pointing to their salience and importance with regard to adherence. Behavioral interventions to improve some of these factors exist, and should be continued to be modified and used with pediatric epilepsy.

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Abbreviations

AED	antiepileptic drug
SES	socioeconomic status

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Highlights

- AED nonadherence leads to poor seizure control and uninformed clinical decision making
- There are modifiable predictors of poor adherence after diagnosis
- Psychological interventions can be used to improve adherence in youth with epilepsy

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Table 1

Participant Characteristics (n = 91)

Factor	<i>M</i>	<i>SD</i>
Child age (years)	7.3	2.8
Family Duncan score ^a	53.5	20.6
	<i>n</i>	%
Child sex		
Male	55	60.4
Child race		
White	71	78.0
Black	12	13.2
Biracial	6	6.6
Other	2	2.2
Child epilepsy diagnosis		
Localization-related/Focal	51	56.0
Idiopathic	39	42.9
Cryptogenic	6	6.6
Symptomatic	6	6.6
Generalized	23	25.3
Idiopathic	18	19.8
Cryptogenic	4	4.4
Symptomatic	1	1.1
Unclassified	17	18.7
Idiopathic	17	18.7
Child epilepsy syndrome diagnosis	18	19.8
Childhood/juvenile absence epilepsy	12	13.2
Benign rolandic epilepsy	6	6.6
Child initial antiepileptic drug therapy		
Carbamazepine	51	56.0
Valproic acid	40	44.0
Parent relationship to child		
Mother	74	81.3
Parent marital status		
Married	57	62.6

^a Associated with occupations such as property managers, physician's assistants, mail carriers, sheriffs/law enforcement, and fire prevention

Table 2

Multinomial Logistic Regression: Initial Predictors of Adherence Trajectory Group Status

Variable	χ^2	<i>p</i> value
<i>Individual Factors</i>		
Family socioeconomic status	12.16	< .001***
Seizure trajectories (High/Low)	2.43	.12
Antiepileptic drug side effects	2.02	.16
<i>Parent Factors</i>		
Epilepsy knowledge	4.04	.04*
Parent fears and concerns	1.12	.29
Perceived stigma	0.71	.40
Parent life stress	3.01	.08
Parenting-related stress	3.80	.05
Epilepsy-specific parenting stress	0.02	.88
<i>Family Factors</i>		
Barriers to medication adherence	0.30	.58
Family problem-solving	10.57	.001**
Family communication	9.83	.002**
Behavior control	1.01	.31
Overall family functioning	0.56	.45

*Note.** = $p < .05$;** = $p < .01$;*** = $p < .001$;

Odds Ratios (95% Confidence Intervals) for significant predictors are: SES [OR = 1.058 (1.025,1.092)]; Epilepsy knowledge [OR = 1.095 (1.002,1.196)]; Family problem-solving [OR = 0.621 (0.466,0.828)]; Family communication [OR = 1.611 (1.196,2.171)].

Table 3

Multinomial Logistic Regression: Predictors of Adherence Trajectory Group Status at 1-year Following Diagnosis

Variable	χ^2	<i>p</i> value
<i>Individual Factors</i>		
Family socioeconomic status (SES)	10.07	.002**
Seizure likelihood (high, low)	0.38	.54
Antiepileptic drug side effects	0.15	.70
<i>Parent Factors</i>		
Epilepsy knowledge	3.26	.07
Parent fears and concerns	6.31	.01*
Perceived stigma	0.73	.39
Parent life stress	4.42	.04*
Parenting-related stress	2.72	.10
Epilepsy-specific parenting stress	1.26	.26
<i>Family Factors</i>		
Barriers to medication adherence	0.40	.53
Family problem-solving	0.62	.43
Family communication	0.38	.54
Behavior control	0.03	.87
Overall family functioning	1.94	.16

Note.

* = $p < .05$;

** = $p < .01$;

Odds Ratios (95% Confidence Intervals) for significant predictors are: SES [OR = 1.065 (1.024,1.107)]; Parent fears and concerns [OR = 0.762 (0.616,0.942)]; Parent life stress [OR = 0.980 (0.961,0.999)].