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Adherence barriers in pediatric epilepsy: From toddlers to young adults

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ABSTRACT

Objective: The objectives of this study were to examine the continuity of adherence barriers across stages of development in pediatric epilepsy and to assess the differential influence of barriers on several important clinical outcomes from early childhood to young adulthood, including adherence, seizures, and health-related quality of life (HRQOL).

Method: A developmentally representative sample of youth 2–25 years with epilepsy was obtained by combining data from five different studies. A total of 269 caregivers and 77 adolescents and young adults were included in this investigation. Participants completed measures of adherence barriers and HRQOL. An electronic monitoring system was used to assess adherence to the primary antiepileptic drug over 30 days. The prevalence of individual barriers across development and their relative importance as predictors of clinical outcomes were examined.

Results: Adherence barriers are characterized by both continuity and discontinuity from early childhood to early adulthood. Barriers such as disliking the taste of medication, parent forgetfulness, and refusal to take medications were significantly more salient during certain developmental periods. No significant differences across age groups were found for other barriers, including difficulty getting to the pharmacy and embarrassment. Certain adherence barriers, such as running out of medications, were more important to particular clinical outcomes despite being low prevalence. Adherence barriers differentially predicted adherence, seizure control, and HRQOL based on developmental stage.

Conclusion: Routine assessment of adherence barriers is imperative from toddlerhood to young adulthood given that the prevalence of barriers and their relative influence on important health outcomes vary by developmental stage. Adherence intervention efforts should be targeted, developmentally tailored, and focused on those barriers that are most predictive of poor outcomes for a given developmental period.

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1. Introduction

Epilepsy is a brain disorder characterized by recurrent unprovoked seizures that affects 470,000 children in the United States [1]. Antiepileptic drugs (AEDs) are the first-line treatment for most children to achieve seizure freedom, symptom management, and increased function. Nonadherence to AEDs has been associated with a variety of undesirable outcomes including limited treatment efficacy (e.g., continued seizures [1–3]), increased mortality [4], higher healthcare utilization [5,6] and costs [6], and lower health-related quality of life (HRQOL) [7]. In youth with epilepsy, approximately 60% of patients exhibit AED nonadherence, as measured by electronic monitoring [3,8]. Adherence has been described as a dynamic behavior, with both stable (e.g., socioeconomic status [8]) and modifiable (e.g., barriers to adherence, psychological functioning) factors that contribute to nonadherence. Given the serious and costly consequences of nonadherence, a better

understanding of malleable contributing factors is critical to guide the development of evidence-based interventions.

Barriers to adherence are modifiable variables that demonstrate consistent associations with nonadherence and suboptimal clinical outcomes in pediatric populations [9,10]. Among children with epilepsy, barriers such as difficulties in swallowing medications, forgetfulness, and refusing to take medications as prescribed have been longitudinally associated with electronically monitored nonadherence [11]. The stability of barriers to adherence has also been documented in children with newly diagnosed epilepsy, suggesting that once a barrier is endorsed, it is likely to persist for a 2-year period without targeted intervention. These findings provide clinically meaningful information about barrier stability, but are limited in their ability to contextualize barriers across the lifespan. No empirical work, to date, has examined barriers from a developmental perspective, and further research is needed to fill a critical gap in the literature regarding the continuity or discontinuity of barriers across stages of development.

Child development is a complex process characterized by qualitative and quantitative changes in many domains of functioning, including biological, socioemotional, behavioral, and cognitive. As a result of these developmental changes that naturally unfold as children mature, the

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types of adherence barriers that children face may also change as they grow. The degree to which different barriers may be more salient at different stages of development, or the extent to which certain barriers become no longer developmentally salient, however, is unknown. For example, pill swallowing difficulties are typically more common among preschoolers compared with adolescents. Further, the relative importance of individual barriers as predictors of adherence across different stages of development has not been empirically studied, despite its critical implications for the creation of developmentally sound interventions.

The first aim of this study was to identify the most highly endorsed adherence barriers at different stages of development (e.g., preschool, school-aged, adolescence, and young adulthood). Guided by developmental principles and prior literature [8,11,12], it was hypothesized that disliking taste, child refusal, and swallowing difficulties would be the most highly endorsed barriers among preschool children; embarrassment would emerge as a highly endorsed barrier among school-aged children; and forgetfulness and competing activities would be the most highly endorsed barriers among adolescents and young adults. A second aim of this study was to compare the frequency of individual barriers by developmental period. It was hypothesized that disliking taste, refusal, and swallowing difficulties would be most prevalent in younger children compared with the other development periods, and that forgetting and competing activities would be most prevalent in adolescents compared with the other developmental periods. The final aim was to evaluate the relative importance of individual barriers as predictors of clinical outcomes (e.g., adherence, seizure control, and HRQOL) at different stages of development. Based on prior studies, we hypothesized that forgetfulness and child refusal would be the most important predictors of adherence, seizure control, and HRQOL among preschool children, and that forgetfulness and competing activities would be the most salient predictors of adherence, seizure control, and HRQOL among adolescents.

2. Material and methods

2.1. Participants and procedures

A developmentally representative sample of 274 youth with epilepsy was obtained by combining data from five different studies examining adherence barriers in children, adolescents, and young adults with epilepsy. Detailed participant and methodology information for each of these studies has been published elsewhere [11,13–16]. A total of 269 caregivers of youth with epilepsy between the ages of 2 and 25 years and 77 adolescents and young adults between the ages of 13 to 25 years participated in this investigation. Exclusion criteria for all studies included developmental delay, non-English speaking, and having a comorbid medical condition requiring daily medication. Recruitment rates for the studies included in this investigation ranged from 66% to 96% [8,13,15,17,18]. Detailed sociodemographic and medical information for the combined sample is presented in Table 1.

For all studies, eligible participants were identified by trained research staff and approached for participation during routine epilepsy clinic visits in a major Midwestern tertiary pediatric hospital. Procedures for providing an overview of study goals and objectives were standardized across studies. Families were given the opportunity to ask questions, which were thoroughly answered prior to obtaining consent, assent, and Health Insurance Portability and Accountability Act (HIPAA) release. Participants completed all measures during the study visit or sent questionnaires back to study coordinators. Only baseline questionnaires were used in this investigation, with the exception of one longitudinal study examining psychosocial functioning and adherence over a two-year study period for children newly diagnosed with epilepsy (e.g., recruited on day of diagnosis [8]). For this study, both the barriers and corresponding adherence data (e.g., 30-day adherence) for each participant were randomly selected out of a total of 10 possible time points spread over a 25-month period. This approach was used to

Table 1
Child demographic and medical information.

Variable	N = 274	
	M	SD
Child age (years)	9.69	4.73
Medication adherence	82.81	22.88
	Frequency	%
Sex		
Male	148	54.0
Female	126	46.0
Age group		
2–5 years	60	21.9
6–12 years	134	48.9
13–17 years	69	25.2
18–25 years	11	4.0
Race		
White	215	78.5
Black	42	15.3
Asian	2	0.7
Biracial	11	4.0
Other	4	1.5
Family income		
<\$10,000	27	9.9
\$10,000–50,000	104	38.0
\$50,001–75,000	48	17.5
>\$75,000	80	29.2
Prefer not to disclose	15	5.5
Seizure type		
Partial	136	49.6
Generalized	91	33.2
Unclassified	47	17.2
Seizures in the last 3 months		
Yes	174	63.5
No	99	36.1
Antiepileptic medication		
Depakote	83	30.3
Tegretol	109	39.8
Keppra	44	16.1
Trileptal	10	3.6
Zarontin	17	6.2
Topamax	4	1.5
Lamictal	5	1.8

better reflect average adherence rather than initial adherence immediately after diagnosis. Thirty-day adherence data were collected following the baseline visit for the remaining studies. Compensation for all participants was provided in the form of a gift card. The Institutional Review Board approved all studies included in this investigation.

2.2. Measures

2.2.1. Demographic and medical information

Across all studies, participants were asked to complete a brief background questionnaire that assessed child age, sex, race, family income, and caregiver marital status. Research staff completed a retrospective medical chart review to extract relevant medical variables, including date of epilepsy diagnosis, epilepsy type, prescribed AEDs, and presence of seizures over the previous 3 months.

2.2.2. Barriers to adherence

The Barriers subscale of the Pediatric Epilepsy Medication Self-Management Questionnaire (PEMSQ [19]) was used to assess treatment barriers that interfere with AED adherence. Caregivers, adolescents, and young adults used a 5-point Likert scale, ranging from “strongly agree – 5” to “strongly disagree – 1” to indicate the extent to which eight different barriers interfere with the AED regimen. Higher subscale scores are indicative of more barriers to adherence. Internal reliability for the self-report Barriers subscale for the current study was $\alpha = 0.79$, consistent with prior studies [19].

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