Treatment adherence among adolescents with epilepsy: What really matters?

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ABSTRACT

Treatment adherence is often suboptimal among adolescents with epilepsy. However, knowledge is lacking regarding factors that affect adherence. Empirical studies and theories of human development suggest that self-management skills, self-efficacy, and sense of control are related to adherence. Eighty-eight adolescents with epilepsy, and their parents, completed standardized measures assessing epilepsy knowledge and expectations, treatment self-management, sense of control, and self-efficacy. Better self-reported parent adherence was correlated with greater epilepsy knowledge/expectations ($p<0.001$) and more medications ($p=0.042$). Better self-reported adolescent adherence was correlated with fewer siblings ($p=0.003$) and higher adolescent epilepsy knowledge/expectations ($p<0.001$). Greater adolescent epilepsy knowledge/expectations correlated with parent self-reported adherence ($p<0.001$), Powerful others locus of control ($p=0.008$), and adolescent/parent discordance regarding epilepsy knowledge/expectations ($p<0.001$). Interventions that enhance adolescent's knowledge of epilepsy and their treatment plan, while ensuring that teens and parents are in agreement with regard to epilepsy treatment, might contribute to better adherence.

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1. Introduction

Although some children with epilepsy outgrow their seizures, a large proportion will live with epilepsy well into their adult years. There is a growing interest in preparing adolescents with epilepsy to transition from pediatric care to independent care in adult clinics [1–4]. One important aspect of moving toward self-management is adherence with treatment recommendations.

Adherence to prescribed medications among adolescents with epilepsy has been consistently poor, with reports of non-adherence ranging from 35% to 79% [5–8]. Adolescents with epilepsy are not unique — those with other chronic illnesses, such as cystic fibrosis, diabetes, and asthma, have similarly low rates of adherence [7–12]. The effects of non-adherence among chronically ill children can be serious, including health consequences (increased morbidity and mortality), reduced cost-effectiveness of medical care (from unused medications and increased clinic and emergency room visits and hospital stays), and bias in clinical trials of promising therapies [3,11,13,14].

Interventions aimed at helping adults to manage their chronic illnesses are based upon promoting an internal locus of control and enhancing self-efficacy [15]. Research aimed at helping chronically ill adolescents in this area is lacking.

Also missing from the extant literature is an understanding of how adolescent health behavior choices are modulated by their parents. Studies reporting child–parent agreement on issues related to chronic illness demonstrate disagreement in perception of quality of life, disability, pain, and well-being between parents and child [16,17]. For example, among mothers of survivors of childhood cancer [18], maternal beliefs about their child's concerns and problems predict their own worries and concerns but not necessarily those of their child.

It was only recently that a questionnaire was designed specifically to measure medication adherence among children with epilepsy [19]. This questionnaire was designed for parents to complete. We aimed to expand the published work, to query adolescents with epilepsy directly about adherence and disease management, and to assess whether parents and adolescents are in agreement about adherence.

The purpose of this study was to examine the extent to which locus of control, self-efficacy, and parent–child discordance in reporting adolescent adherence were associated with adolescents' self-reported epilepsy treatment adherence. Identifying modifiable factors associated with treatment adherence could inform patient education and psychosocial support interventions that promote adherence of adolescent patients with epilepsy and their eventual transition to adulthood and self-management.

2. Methods

The University of Michigan Institutional Review Board approved this study. In a cross-sectional clinic-based protocol, adolescents with

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epilepsy, and their parents, were recruited to participate in the study. Inclusion criteria were as follows: age 12 to 17 years, a diagnosis of epilepsy or seizure disorder documented by a neurologist in the medical record, a current prescription for an antiepileptic drug (AED), and ability to complete the questionnaire independently. Exclusion criteria were a diagnosis of mental retardation by a neurologist or psychologist noted in the medical record and/or full-time enrollment in special education classes. Both adolescent assent and parent consent were required, and both individuals needed to return completed questionnaires for inclusion in the analyses. Adolescents and parents were not permitted to discuss their answers as they completed the surveys. Respondents were recruited consecutively from patients presenting to the outpatient Pediatric Neurology Clinic at the University of Michigan Health System.

2.1. The questionnaire

2.1.1. Treatment adherence

The Pediatric Epilepsy Medication Self-Management Questionnaire (PEMSQ) was used to assess adolescent treatment adherence from the perspectives of both adolescent patients and their parents [19]. The parents' answers pertained to their own knowledge and beliefs, not their children's. This 27-item measure consists of four subscales: Epilepsy and Treatment Knowledge and Expectations (8 items), Adherence to Medications and Clinic Appointments (8 items), Barriers to Medication Adherence (8 items), and Beliefs about Medication Efficacy (3 items). Mean subscale scores, as well as a total self-management score, were calculated, with higher scores indicating greater adherence. This instrument was originally designed for administration to parents, with excellent reliability (Cronbach's alpha 0.68 to 0.85 reported for individual subscales). For purposes of our study, we collaborated with the authors of the PEMSQ to create a parallel set of items for children to match the parent items, the Adolescent Epilepsy Medication Self-Management Questionnaire (AEMSQ; Appendix 1).

2.1.2. Locus of control

Locus of control (LOC) refers to the extent to which individuals believe that they can control events that affect them. Locus of control was measured with the Multidimensional Health LOC (MHLC), Form B, a well-validated measure used extensively in health outcomes research that has been used for both adults and adolescents [20]. The scale has 18 items and contains 3 domains: Internal Health LOC scale (measures whether a person feels that he/she has control over his/her own health), Powerful Others Health LOC scale (measures whether a person feels that powerful individuals, such as physicians or other health professionals, control health), and Chance Health LOC scale (measures whether a person feels that health is due to luck, fate, or chance).

2.1.3. Self-efficacy

Self-efficacy is the measure of one's own competence to complete tasks and reach goals. The General Self-Efficacy scale [GSE] was used to measure both adolescent self-efficacy and parent self-efficacy. The GSE is a widely-used measure, with evidence of reliability and validity in adolescent samples [21].

2.1.4. Sociodemographic and clinical data

The parents' questionnaire included questions about gender, relationship to the patient, marital status, number of siblings, educational status, and income. Data obtained from the electronic medical record included age, age at epilepsy diagnosis, number of epilepsy-related medications, type(s) of seizure(s), epilepsy syndrome, and comorbid medical conditions.

3. Statistical analysis

As the Adolescent Epilepsy Medication Self-Management Questionnaire (AEMSQ) for adolescents was created and used for the first time in this study, consistency and reliability of these scales were examined using Cronbach's alpha (CA). The relationship between scales was primarily reviewed through bivariate Pearson's correlations. Correlations were calculated between adolescent scales and between parent scales. Finally, correlations between the parents' and adolescents' scores were computed.

Parent–child discordance measures were computed by taking the absolute difference of the scores for each item and also for each scale. The absolute difference of the scale values between parent and child and a total discordance score were also computed by summing together the discordance values for each item that was included in scales.

Iterative step-wise regression methods were employed to develop multivariate models explaining adolescent and parent adherence measures, as well as adolescent epilepsy treatment knowledge and expectations. The variables considered for these models were identified both via specific research aims and the bivariate analyses that identified potential predictors for adherence.

4. Results

4.1. Demographic and clinical profiles

Ninety-three consecutive adolescents, who met study criteria and their parents, were approached for participation in the study. Three eligible participants were not included in the study. One parent declined participation due to lack of interest, another parent declined due to timing of request, and one adolescent was disqualified after completing the questionnaire because the parent did not complete the questionnaire. Thus, the final sample included 88 parent–adolescent pairs who completed surveys independently. Demographic and clinical characteristics are summarized in Table 1.

Table 1
Demographic characteristics of the study sample (N = 88).

		n	%
Patient gender	Female	47	53.4
	Male	41	46.6
Patient race	Caucasian	75	85.2
	Other	13	14.8
Parent gender	Female	73	83.0
	Male	15	17.0
Parent education	Less than high school	1	1.1
	High school graduate	19	21.6
	Some college	33	37.5
	Bachelor's degree or higher	34	38.6
	No response	1	1.1
Total household income	Less than $25 K	16	18.2
	$25,000–49,000	11	12.5
	$50,000 or more	59	67.0
	No response	2	2.3
Number of siblings	Median 1 (IQR[a] 1)		
Epilepsy type	Idiopathic	38	43.2
	Cryptogenic	18	20.5
	Symptomatic	31	35.2
Seizure type	Focal	42	47.7
	Generalized (convulsions)	25	28.4
	Absence	19	21.6
	Unknown	2	2.3
Number of seizures	Seizure free	28	31.8
	<1 per month	36	40.9
	1–2 per month	10	11.4
	3–4 per month	5	5.7
	1 per week	5	5.7
	Daily seizures	4	4.5
Number of anticonvulsant medications	Median 1 (IQR[a] 1)		

[a] IQR = interquartile range.