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Treatment adherence among adolescents with epilepsy: what really matters?

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Abstract

Treatment adherence is often suboptimal among adolescents with epilepsy. Yet 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 (< 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 insuring that teens and parents are in agreement with regards to epilepsy treatment, might contribute to better adherence.

Keywords

Adolescent; Adherence; Epilepsy; Survey; Questionnaire

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 [4, 5, 20, 21]. One important aspect of moving toward self-management is adherence with treatment recommendations.

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Adherence with prescribed medications among adolescents with epilepsy has been consistently poor, with reports of non-adherence ranging from 35% to 79% [1, 3, 10, 15]. Adolescents with epilepsy are not unique -- those with other chronic illnesses, such as cystic fibrosis, diabetes, and asthma, have similarly low rates of adherence [9, 10, 15, 19, 22, 25]. 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, increased clinic and emergency room visits and hospital stays), and bias in clinical trials of promising therapies [6, 17, 20, 22].

Interventions aimed at helping adults to manage their chronic illnesses are based upon promoting an internal locus of control and enhancing self-efficacy [2]. 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 [11, 28]. For example, among mothers of survivors of childhood cancer [29], 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 [14]. 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 adolescent epilepsy patients' adherence and 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 epilepsy, and their parents, were recruited to participate in the study. Inclusion criteria were: 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

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 [14]. 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 subscales 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).

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 with both adults and adolescents [27]. 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); Chance Health LOC Scale (measures whether a person feels health is due to luck, fate, or chance).

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 and parent self-efficacy. The GSE is a widely-used measure, with evidence of reliability and validity in adolescent samples [23].

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 co-morbid 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 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 profile

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 adolescent and parent pairs who completed surveys independently. Demographic and clinical characteristics are summarized in Table 1.

4.2 Assessment of the AEMSQ

Consistency and reliability of the new AEMSQ were examined using CA as the coefficient of reliability. Reliability was very good for the Epilepsy Treatment Knowledge and Expectations (ETKE; CA 0.79) and the Adherence to Medications and Clinic Appointments subscales (AMCA; CA 0.71). However, the Barriers to Medication Adherence and Beliefs about Medication Efficacy scales had relatively low CA values (0.58 and 0.54, respectively). Therefore, only the ETKE and AMCA subscales were used for further analysis.

4.3 Adolescent and Parent Reports of Treatment Adherence, LOC and Self-efficacy

Mean responses to the questionnaire's subscales are presented in Table 2. For self-reported treatment adherence, parent mean scores were significantly greater than adolescent scores, indicating that in the aggregate parents were more likely to report adherence among their adolescent children than were their children about their own adherence. Parents consistently scored higher in epilepsy knowledge and treatment expectations than their cognitively normal adolescent children. For self-efficacy, parent scores were significantly greater than those for adolescents. There were statistically significant correlations between the parent and adolescent scores on the MHLC Internal (Pearson's $r=0.34$, $p=0.002$), Chance ($r=0.23$, $p=0.047$), and Powerful Others ($r=0.28$, $p=0.009$) scales.

4.4 Discordance between adolescent and parent responses

Parents scored, on average, 5.7 points higher on the 40 point ETKE scale than did adolescents. For every parent-adolescent pair, there was discordance in scale scores (e.g. parents and their children never answered exactly the same). Results from all scales showed discordance between parents' and adolescents' responses, as displayed in Table 3.

4.5 Sociodemographic and clinical variables and self-reported adherence

Using t-tests or ANOVAs, as appropriate, none of the sociodemographic variables tested was significantly associated with mean adherence scores (including gender, race, parent education, or household income). Neither age at the time of epilepsy diagnosis, nor duration of epilepsy was related to adolescent- or parent-reported treatment adherence ($p>0.1$ for all correlation coefficients). Therefore, these factors were not included in the multivariate analyses.

4.6 Regression Models

The best multivariate linear regression model for adolescents' self-reported treatment adherence, based on iterative step-wise regression techniques, included two variables (Table 4). Increasing scores on the ETKE subscale was associated with improved adherence. However, higher numbers of siblings was associated with decreased adherence.

Better adolescent ETKE scores were associated with high “powerful others” LOC scores for both adolescents and parents (indicating a sense that powerful individuals, such as physicians or other clinicians, control patients’ health), higher adolescent-reported adherence, and more discordance between the adolescent and parent ETKE scores (Table 5).

The best model for parent-reported treatment adherence included similar, but not identical predictors (Table 6). Measures of LOC and self-efficacy were not related to parents’ or adolescents’ reported adherence. For parents, increased ETKE score and higher numbers of prescribed AEDs were associated with improved adherence, while discordance between parents and their adolescents’ responses on self-reported adherence predicted decreased adherence.

5. Discussion

Ours is the first study to systematically and simultaneously query adolescents with epilepsy and a parent independently regarding factors related to self-reported treatment adherence. Self-reported adherence was better among adolescents who were knowledgeable about epilepsy and its treatment. Adolescents with fewer siblings also had better self-reported adherence, perhaps because they were less challenged to compete for parental monitoring of medication administration.

Just as higher ETKE scores were associated with better parental perceptions of their children’s adherence, an increased number of prescribed anticonvulsant medications was also related to improved adherence. It is possible that an increased number of medications is a marker of more difficult-to-control or complex epilepsy, leading to greater parental vigilance regarding medication administration. Notably, the adolescents’ self-reported adherence was not predicted by the number of medications prescribed.

Our results also suggest that families who perceive their healthcare team as controlling their children’s epilepsy care have improved epilepsy treatment knowledge scores and that these higher scores predict improved self-reported adherence. This finding suggests that working to foster a respected physician-patient relationship, and to enhance adolescents’ understanding of their epilepsy and treatment options might result in improved adherence.

Studies examining self-care among chronically ill adults demonstrate that self-efficacy and a sense of control over one’s life are related to positive health behaviors [7, 18, 26]. This might be related to combating learned helplessness that arises when illnesses (or seizures) are difficult to control. Neither internal LOC nor self-efficacy was related to treatment-adherence among our study subjects, however. This highlights the need to focus specifically on adolescents with epilepsy, as predictors for their treatment adherence might not be the same as adults’.

Additionally, our data suggest that family context is important in understanding adolescents’ epilepsy treatment-related behavior. Our finding that parent/child discordance affects adherence fits into a growing body of literature. Among adolescent transplant recipients, family factors such as cohesion and conflict are reported to be barriers to adherence [24]. Compliance among pediatric cancer patients increased when parents and adolescents agreed on who was responsible for administering medication, medication instructions and treatment effectiveness. Family dysfunction, which includes characteristics such as poor family structure, cohesion and cultural beliefs about medications, has been associated with poorer adherence in several studies of children with chronic diseases, including inflammatory bowel disease, asthma, and transplants [12, 13, 24].

Prior work has shown that certain seizure-related and demographic characteristics of adolescents with epilepsy are likely to affect adherence, such as duration of disease, diagnosis prior to adolescence, number of seizures, socioeconomic status and number of siblings [8, 10, 16, 22]. Among our subjects, neither age upon epilepsy diagnosis, epilepsy type, nor duration of epilepsy were related to EKTE or self-reported adherence. The only sociodemographic factor which contributed significantly to our models was the number of siblings. This may reflect a difference in approach, as we queried adolescents directly, while others have relied on their parents' report of adherence. Also, we only included adolescents who would be capable of answering questionnaires independently. Although this allowed for analysis of the adolescents' responses separately from their parents', a unique aspect of the present work, it also may limit generalizability to patients with intellectual disabilities. Many children with epilepsy and comorbid developmental disabilities have multiple medical problems and may be taking medications for seizures as well as other conditions. They also have many more appointments to see specialty clinicians. These factors are likely to affect adherence.

5.1 Limitations

There were some limitations to our study. We had excellent patient recruitment (95% consented to participate and completed the questionnaires). Therefore we are confident that our sample is representative of our tertiary epilepsy clinic population. However, our respondents came from mostly well-educated Caucasian families with relatively high household incomes, and might not be representative of the general population of adolescents with epilepsy. Because of this, we were not able to stratify our analyses based on socioeconomic status. Our homogeneous demographic profile may be reflected in our respondents' much higher reported treatment adherence, compared with other published reports [1, 3, 10, 15]. For example, adolescents and their parents in our sample reported 94% and 96% adherence to medications, respectively (medication adherence was only one measure in our adherence scale).

Our work resulted in lower reliability scores on the PEMSQ than previously reported [14]. The PEMSQ was originally designed for parents and caregivers of 2-to-14-year-old children with new-onset epilepsy (diagnosed within 6 months). There were no exclusions based upon the child's level of cognitive functioning in that original study. Our research was focused on transition, and targeted families whose 12-to-17-year-old adolescents had been diagnosed with epilepsy at any point in the past. Modifying the scale to reliably measure adherence in a wider population may be necessary.

The AEMSQ resulted in relatively low reliability for the barriers to medication adherence beliefs about medication efficacy subscales. This suggests that these questions may not have been readily comprehensible to adolescents. However, the remaining two scales had good reliability. External validation studies are required in order to determine how well these subscales perform among other groups of adolescents with epilepsy.

5.2 Future Directions

Our results suggest that treatment adherence might be improved by directly addressing the adolescent's knowledge of epilepsy and their treatment plan. Most patients and families receive a great deal of education about epilepsy at the time of initial diagnosis, with a shifted emphasis on assessing treatment efficacy at follow-up appointments. Twenty-eight percent of our subjects were diagnosed with epilepsy before age 5-years. It is likely that these children, now adolescents who have lived with epilepsy for most of their lives, would not have retained any information given at the time of diagnosis, when physicians' communication would have appropriately focused on their parents.

Fifty-one percent of our subjects were diagnosed between the ages of 6 and 11 years. While school-age children are capable of learning about epilepsy and related treatments, care must be taken to speak in simple terms and to provide developmentally appropriate materials. Since our adolescents' knowledge of epilepsy was worse than their parents', and was directly related to self-reported treatment adherence, we suggest that clinicians deliberately provide developmentally appropriate materials and opportunity for on-going education and discussion at each visit. Systematic study of such educational efforts is warranted.

Modifying clinicians' behavior to focus on improving adolescents' knowledge about epilepsy and treatments may lead to improved adherence to treatment recommendations. Minimizing disagreement between teens and their parents regarding epilepsy and medication efficacy might also result in improved treatment adherence. Deliberate focus on each of these elements could assist the neurology treatment team in optimizing the care for adolescents with epilepsy. Optimizing treatment adherence among adolescents with epilepsy may have long-term benefits, empowering these adolescent patients as they transition from parent-focused pediatric neurology care to patient-focused, independent communication with the adult neurologist.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Highlights

- Treatment adherence is often suboptimal among adolescents with epilepsy.
- We assessed predictors of self-reported treatment adherence and epilepsy knowledge.
- Better epilepsy knowledge predicted improved self-reported adolescent adherence.
- Discordance between parent and adolescent responses predicted poorer adherence.
- Enhancing families' knowledge of epilepsy and its treatment may improve adherence.

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 \$25K	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 * 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 * 1)		

* IQR = interquartile range

Table 2
Mean Responses for the Self-Management Questionnaires, Self-Efficacy, and LOC

	N* (Adolescent)	Mean (SD) (Adolescent)	N* (Parents)	Mean (SD) (Parents)	p- value***
Epilepsy Self-Management Questionnaires					
ETKE	88	32.9 (5.0)	86	35.7 (5.2)	<0.001
AMCA	86	36.1 (3.3)	88	37.8 (5.2)	0.013
Locus of Control					
MHLC Internal scale	85	22.8 (4.0)	83	24.5 (3.9)	0.002
MHLC Chance scale	85	19.7 (5.7)	83	17.7 (6.5)	0.021
MHLC Powerful Others scale	87	25.1 (4.9)	86	25.5 (4.6)	0.4
Self-Efficacy					
General Self-Efficacy Scale	86	31.3 (5.1)	87	33.6 (4.2)	<0.001

* Total N was less than 88 for some subscales if either the adolescent or parent did not complete the entire subscale.

** SD = standard deviation

*** paired two-tailed t-test results

Note: LOC = Locus of Control; ETKE = Epilepsy treatment knowledge and expectations Scale; AMCA = Adherence to Medications and Clinic Appointments Scale; MHLC = Multi-dimensional Health Locus of Control

Table 3

Scale and Total Item Discordance Measures

Scale	Possible Range	N	Mean Discordance*
ETKE	0–32	86	5.7 (4.9)
AMCA	0–32	86	3.8 (5.1)
MHLC Internal scale	0–30	80	3.7 (3.1)
MHLC Chance scale	0–30	80	6.5 (4.6)
MHLC Powerful Others	0–30	85	4.6 (3.5)
General Self-Efficacy Scale	0–30	85	5.2 (4.1)
Total Item Discordance	0–184	58	50.3 (17.8)

* Absolute difference in scale values between adolescent and parent responses.

Note: ETKE = Epilepsy treatment knowledge and expectations Scale; AMCA = Adherence to Medications and Clinic Appointments Scale; MHLC = Multi-dimensional Health Locus of Control

Table 4

Predictors of self-reported adolescent treatment adherence

Variable	Coefficient	Standard Error	p-value
Number of siblings	−0.59	0.19	0.003
ETKE score	0.407	0.054	<0.001

Model statistics: $R^2=0.46$; Standard Error 2.5; $p < 0.001$

Note: ETKE = Epilepsy treatment knowledge and expectations Scale

Table 5

Predictors of adolescent epilepsy knowledge & expectations

Variable	Coefficient	Standard Error	p-value
Adherence score	0.73	0.1	<0.001
Adolescent	-0.36	0.07	<0.001
Parent			
Powerful others LOC score	0.19	0.07	0.008
Adolescent	0.21	0.07	0.006
Parent			
Discordance between parent & adolescent ETKE scores	-0.54	0.08	<0.001

Model statistics: $R^2=0.71$; Standard Error 2.8; $p < 0.001$

Note: LOC=Locus of Control; ETKE = Epilepsy treatment knowledge and expectations Scale

Table 6

Predictors of Parent-Reported Adherence

Variable	Coefficient	Standard Error	p-value
Number of current medications	0.79	0.38	.042
ETKE score	0.59	.08	<0.001
Discordance between parent and adolescent adherence	−0.36	.08	<0.001

Model statistics: $R^2=0.752$; Standard Error 2.7; $p < 0.001$

Note: ETKE = Epilepsy treatment knowledge and expectations Scale