



Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Adherence to antiepileptic drugs in adolescents with epilepsy

Aimee W. Smith, Constance A. Mara, Avani C. Modi *

Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, 3333 Burnet Ave., Cincinnati, OH 45229-3039, USA

ARTICLE INFO

Article history:

Received 17 October 2017

Revised 12 December 2017

Accepted 15 December 2017

Available online xxxxx

Keywords:

Compliance

Adolescent

Seizure

Health-related quality of life

Barriers

ABSTRACT

Introduction: The aims of the current study were to identify patterns and predictors of adherence in adolescents with epilepsy over one year, as well as its impact on seizures and health-related quality of life (HRQOL).

Methods: Forty-eight adolescents with epilepsy ($M_{age} = 14.8 + 1.5$, 69% female, 73% White: NonHispanic) and their caregivers completed questionnaires assessing demographics, epilepsy knowledge, side effects, adherence barriers, family functioning, and HRQOL at quarterly clinic visits over one year. Adherence was monitored electronically via MEMS TrackCaps. Seizures were determined via chart review.

Results: Baseline adherence was 86.05% and significantly decreased over 12 months ($b = -2.07$, $p < 0.001$). Higher adherence was predicted by higher socioeconomic status (SES) ($b = 0.04$, $p < 0.05$), more side effects ($b = 0.06$, $p < 0.01$), fewer caregiver-reported adherence barriers ($b = 0.18$, $p < 0.05$), and lower family conflict ($b = -0.19$, $p < 0.05$). Change in adherence over 12 months did not significantly predict HRQOL or seizures.

Conclusions: This is the first longitudinal study of objective adherence in adolescents with epilepsy. Given adolescence is a period of vulnerability during development, including declining adherence, caregivers are encouraged to continue collaborating with their adolescents around epilepsy management. Adherence barriers represent an ideal target for intervention and can be implemented in the clinic by frontline providers. Multidisciplinary care can address low SES (social work, financial advocates) and family conflict (psychologists, therapists) in patients with the ultimate goal of optimizing adherence and health outcomes.

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1. Introduction

Adolescents with epilepsy represent a vulnerable population due to increased autonomy and independence in the context of decreased parental supervision [1], as well as neurobiological underpinnings that increase risky behaviors [2,3]. This often results in decreased adherence to their medical regimen, [4] especially when compared with children [5] and adults [6]. Nonadherence to antiepileptic drugs (AEDs) can cause a variety of negative outcomes for individuals with epilepsy, including continued seizures, higher healthcare costs, and poor health-related quality of life (HRQOL) [7–11]. Unfortunately, continued seizures are associated with negative social, emotional, and behavioral outcomes that can persist into adulthood [12–15]. While much work has been done to examine adherence using evidence-based methods in young children [16,17] and adults with epilepsy [18–20], the prevalence of nonadherence in adolescents with epilepsy using objective electronically-monitored data remains unknown. In addition,

the factors that influence nonadherence and its subsequent impact on health and patient-reported outcomes have not been comprehensively and systematically assessed.

Antiepileptic drug adherence in adolescents is likely influenced by individual (age [5,6], family income [10,21,22], disease (time since diagnosis [23], side effects [6], epilepsy knowledge [21,24], individually-identified adherence barriers [8,25,26]), and family factors (e.g., family support [8,16,27]). There is a critical need to identify factors that contribute to nonadherence in adolescents with epilepsy to guide intervention development and prevent poor outcomes in adulthood. Additionally, it is important to examine if longitudinal adherence behaviors impact health outcomes, such as seizures and HRQOL.

The aims of the current study were to identify patterns and predictors of adherence in adolescents with epilepsy over one year, as well as its impact on seizures and HRQOL. Adherence is expected to decline over the course of the year [28]. Younger age [5,6], shorter time since diagnosis [23], higher socioeconomic status (SES) [10,21,22], fewer adherence barriers [8,25,26], fewer side effects [6], greater epilepsy knowledge [21,24], and higher family functioning [8,16,27] are hypothesized predictors of better electronically-monitored AED adherence. Longitudinal adherence will predict better seizure [9,17] and HRQOL [9] outcomes at the end of one year.

* Corresponding author at: Cincinnati Children's Hospital Medical Center, Division of Behavioral Medicine and Clinical Psychology, Center for Adherence and Self-Management, 3333 Burnet Ave., MLC 7039, Cincinnati, OH 45229-3039, USA.

E-mail address: avani.modi@cchmc.org (A.C. Modi).

2. Materials and methods

2.1. Participants and procedure

Participants in this longitudinal study were adolescents (aged 13–17 years old) and their caregivers recruited by trained research assistants during epilepsy clinic visits at a Midwestern children's hospital. They attended four study visits across one year, approximately 3–4 months apart. To meet inclusion criteria, participants had a current prescription of only one antiepileptic drug, could not be diagnosed with a significant developmental disorder (e.g., autism), and had the ability to speak and read English. Caregivers completed a background questionnaire at baseline and the Quality of Life in Childhood Epilepsy Questionnaire at all time points. Adolescents completed the Epilepsy Knowledge Questionnaire (EKQ), Parental Environment Questionnaire (PEQ), and Quality of Life in Epilepsy Inventory for Adolescents. Caregivers and adolescents both completed the Pediatric Epilepsy Medication Self-Management Questionnaire (barriers subscale). The Pediatric Epilepsy Side Effects Questionnaire was completed jointly at all visits, and electronically-monitored adherence was obtained via MEMS TrackCaps and downloaded at all visits. Caregivers and adolescents received reimbursement by gift card for study visits. This research was approved by the hospital's Institutional Review Board, and informed consent/assent was obtained from each caregiver and adolescent prior to study initiation.

Seventy families were approached and 10 declined due to lack of interest or time, resulting in a participation rate of 86%. Four participants never returned questionnaires and were lost to follow-up. Two participants withdrew, and adherence data was unavailable for six participants. Thus, the final sample included 48 adolescents with epilepsy and their caregivers.

2.2. Measures

2.2.1. Background information and medical chart review

Caregivers provided information at the baseline visit regarding the adolescent's age, sex, and race. The Revised Duncan score [29], a measure of SES based on caregiver occupation [30,31] was calculated for each family, with higher scores (range 15–97) indicating higher SES. Caregivers also reported on the presence of six potential comorbid disorders, including attention deficit hyperactivity disorder (ADHD), learning disorders, anxiety, depression, behavioral problems, and social difficulties. Time since diagnosis was obtained from medical chart review.

2.2.2. Epilepsy Knowledge Questionnaire (EKQ [32])

The EKQ is a 47-item questionnaire, assessing knowledge about medical and social aspects of epilepsy using a True or False format. This measure was modified from the original [32] to reflect language and medical practice in the United States. The original instrument was evaluated psychometrically and demonstrates adequate reliability and validity for adolescents with epilepsy.

2.2.3. Parental Environment Questionnaire (PEQ [33])

The PEQ is a 42-item adolescent self-report measure assessing parent–child relationship using a four-point scale with answers ranging from “definitely true” to “definitely false”. PEQ subscales include Conflict, Parent Involvement, Regard for Parent, Regard for Child, and Structure. The current study used only the Conflict (e.g., “My parent often criticizes me.”) and Parent Involvement (e.g., “My parent and I do not do a lot of things together.”) subscales, each containing 12 items. Alpha coefficients were 0.82 for Conflict and 0.74 for Involvement in previous research [33]. Higher scores reflect higher conflict and higher parent involvement.

2.2.4. Pediatric Epilepsy Medication Self-Management Questionnaire (PEMSQ [25]) – Barriers subscale

The PEMSQ is a 27-item questionnaire to assess medication self-management in patients with epilepsy via parent proxy report. The PEMSQ has four scales (epilepsy and treatment knowledge and expectations, adherence to medications and clinic appointments, barriers to medication adherence, and beliefs about medication efficacy). The Adolescent Epilepsy Medication Self-Management Questionnaire was adapted from the parent proxy measure [24]. Only the Barriers to Medication Adherence subscale was used in the present study (parent and adolescent report). Higher scores represent fewer barriers or better self-management around adherence barriers. Examples of barriers include difficulty fitting medication into daily routines, forgetting to give/take the medication, and being embarrassed to take the medication in front of friends or family. Cronbach's alpha for the Barriers to Medication Adherence subscale was 0.76 (parent report) [25] and 0.58 (adolescent-report) [24].

2.2.5. Pediatric Epilepsy Side Effects Questionnaire (PESQ [34])

The PESQ is a 19-item measure assessing side effects of AEDs for youth with epilepsy. Items are rated on a 6-point scale from 0 (not present) to 5 (high severity) and cover a range of neurological, behavioral, gastrointestinal, skin, and motor side effects. Items are summed to obtain a total side effects severity score, with higher scores representing higher severity of side effects. The total score has demonstrated excellent reliability in previous research (Cronbach's alpha = 0.92 [34]).

2.2.6. MEMS 6 TrackCap

The Medication Event Monitoring Systems (MEMS© 6 Trackcap; AARDEX Corporation, Union City, CA), was used to measure daily AED adherence. The MEMS cap attaches to the patient's medication bottle and registers the dates and times that the medication was opened. At each study visit, caregivers and adolescents were asked to report any times that the cap was not used (e.g., vacation). Adherence was defined as the number of doses taken/number of expected doses \times 100%. Daily adherence data were averaged for each month, yielding a total of 12 adherence data points.

2.2.7. HRQOL

Quality of life was measured via both parent report using the Quality of Life in Childhood Epilepsy Questionnaire (QOLICE [35]) and adolescent self-report using the Quality of Life in Epilepsy Inventory for Adolescents (QOLIE-AD [36]). The QOLICE is 79-item caregiver report of the child's quality of life for ages 4 to 18. The measure assesses 15 domains of functioning and an overall quality of life score. Raw scores are converted into standardized scores (0–100), with higher scores indicating better quality of life. Internal consistencies coefficients ranged from 0.76–0.97 for all scales in previous research [35]. The QOLIE-AD is a 48-item self-report measure of health-related quality of life for adolescents with epilepsy (11–18 years old). The measure generates eight subscales (epilepsy impact, memory-concentration, attitudes, physical function, stigma, social support, school behavior, and health perceptions), as well as a total score. Scores can be converted to T-scores. The total score has demonstrated acceptable reliability in previous research (Cronbach's alpha = 0.74 [36]).

2.2.8. Seizures

Seizure frequency was dichotomized to seizure absence or presence for each of the three-month intervals given the heterogeneity of seizure types and frequencies. For analyses, seizure outcome for the final three-month period was used. This variable was determined with medical chart review data, as well as parent and adolescent-report of seizures.

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