



## Development of a web-based executive functioning intervention for adolescents with epilepsy: The Epilepsy Journey



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### ABSTRACT

**Introduction:** Youth with epilepsy exhibit significant deficits in executive functioning (EF), yet there are few interventions to improve EF for adolescents. The aims of the current study were to develop an individually-tailored intervention, called Epilepsy Journey, to improve aspects of EF through an iterative, patient-centered process including focus groups and usability testing.

**Methods:** Five adolescents and caregivers participated in focus groups. This input was used to develop ten learning modules based on subscales of the Behavioral Rating Inventory of Executive Functions and key issues that may impact EF in adolescents. Six adolescents participated in usability testing and a usability expert conducted a heuristic evaluation. Demographic information, chart reviews and measures of EF were also completed.

**Results:** Focus group participants and their parents reported difficulties with memory, attention, organization, monitoring, initiation, impulsivity, emotional control, sleep, awareness in schools and managing stress. They also identified successful strategies to address memory and organizational difficulties. Usability testing of the resultant Epilepsy Journey modules revealed problems with navigation and identified features that promoted usability, including progress bars and interactive modules. Program modifications were made after each usability trial resulting in a relatively brief, interactive and readily navigable program. Perceived utility was high with all but one participant. Participants rated the content as helpful and indicated they would recommend Epilepsy Journey to others.

**Conclusions:** Feedback from the focus group and usability testing yielded a feasible, acceptable, relevant and user-friendly web-based intervention for adolescents with epilepsy. The Epilepsy Journey program will be further tested in an open pilot with adolescents with epilepsy and associated EF deficits.

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### 1. Introduction

Executive functioning (EF) includes skills necessary for goal-directed and complex activities such as problem-solving, initiating, monitoring, organizing, planning, self-regulating and using working memory [1]. Youth with epilepsy exhibit significant deficits in EF [2–5], with at least 30% having deficits in the clinical range [6]. A recent study indicated that youth with newly diagnosed epilepsy and no significant medical or developmental comorbidities exhibited substantial cognitive and EF deficits compared to healthy controls [7]. For an adolescent with epilepsy, this translates to forgetting to write down or complete assignments, misplacing papers, having a messy backpack, difficulty remembering to take antiepileptic drugs (AEDs) and poor

social decision-making, all of which can have a significant negative impact on quality of life (QOL). Importantly, many EF deficits persist or worsen over time for youth with epilepsy [8–11], with the demands of adolescence constituting a period of increased vulnerability.

Despite the critical need to develop and implement interventions to improve EF in adolescents with epilepsy [12], few interventions exist. For example, a computerized working memory program (Cogmed) was found to be beneficial in improving visual attention span and auditory and visual-verbal working memory in children with symptomatic epilepsy [13,14]. Unfortunately, this program only targeted working memory and attention in a targeted sample of children with symptomatic epilepsy. Over the past decade, Wade and colleagues have conducted a series of studies assessing the efficacy of web-based family and teen-only problem-solving therapy in improving EF and behavior problems following pediatric traumatic brain injury (TBI) [15–21]. Results from these clinical trials suggest that problem-solving approaches may be particularly effective in improving EF in adolescents [15–21]. These benefits seem to derive from improvements

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in metacognitive strategies and self-regulation skills, which have relevance for youth with epilepsy. A web-based format also capitalizes on adolescents' increasing use of technology [22].

While the web-based problem-solving therapy has clear appeal as a starting point, some specific adaptations are needed for youth with epilepsy in contrast to youth with TBI. First, epilepsy is a chronic condition in which both continued seizures and AED side effects can result in worsening of executive dysfunction and neurobehavioral comorbidities (e.g., memory, attention, behavior problems) over time, compared to TBI where improvements in neurobehavioral comorbidities are common during the initial year post-injury. Second, the treatment regimens differ substantially, with epilepsy placing much higher demands on the adolescent and family members, as it requires long-term medical management. Third, while the design of the epilepsy-specific EF intervention draws from the existing teen online problem-solving (TOPS) intervention for TBI, many of the modules from TOPS (e.g., cognitive problems following TBI, behavioral problems, improving communication, recovery) are less applicable to adolescents with epilepsy.

Thus, the aim of the current study was to significantly modify and adapt the TOPS intervention [15–21] to address the unique EF needs of adolescents with epilepsy. The goal was to develop an individually-tailored intervention to improve aspects of EF (e.g., working memory, emotional control, inhibition, monitoring, initiation, problem-solving and organization) through an iterative, patient-centered process that included two phases. In the first phase, the unique needs of adolescents with epilepsy and their families were assessed based on focus groups. In the second phase, the web-based Epilepsy Journey problem-solving intervention was designed, developed and evaluated. Evaluation took the form of multi-modal usability testing which elicited feedback on applicability, content and the individualized approach of the intervention, as well as ease-of-use, acceptance, error rates and time to completion of modules. It was hypothesized that our iterative, patient-centered approach would yield an acceptable, feasible, individualized and highly usable web-based intervention for adolescents with epilepsy suitable for testing in an open trial to assess efficacy in the future.

## 2. Materials and methods

### 2.1. Participants

Study participants were adolescents diagnosed with epilepsy and their primary caregiver.

Participants were recruited during routine medical visits through the Comprehensive Epilepsy Center at Cincinnati Children's Hospital Medical Center. Participants met the following inclusion/exclusion criteria: 1) adolescents aged 13–17 years, 2) diagnosis of epilepsy, 3) primary caregiver consent and adolescent assent to participate in study, 4) ability to read and speak English due to the questionnaires only being validated in English, 5) no other non-epilepsy medical disorders requiring daily medications with the exception of asthma and/or allergies and 6) no diagnosis of significant developmental disorders (e.g., Autism).

### 2.2. Procedure

Potential participants meeting initial eligibility criteria were identified by a trained research assistant, in collaboration with the medical team, and approached during routine epilepsy follow-up clinic visits. A thorough overview of the study was provided to both the adolescent and caregiver, including study procedures, benefits and risks. All questions were addressed and informed consent/assent was obtained. All study procedures were approved by the hospital's Institutional Review Board.

#### 2.2.1. Construction of the initial executive functioning intervention for epilepsy (*Epilepsy Journey*; phase 1)

This cross-sectional study of adolescents with epilepsy and their caregivers employed an iterative process in line with the multi-

method approach (i.e., qualitative and quantitative) previously used in the development of the original TOPS intervention for teens with TBI [23]. All caregivers completed a demographics form and a measure of EF prior to the focus groups/usability testing. Adolescents also completed a self-report measure of EF behaviors (i.e., Behavior Rating Inventory of Executive Function). A medical chart review was conducted by trained research assistants to obtain information about patient medical characteristics (e.g., seizure type, treatment).

Licensed psychologists and psychology trainees (e.g., postdoctoral fellow, graduate student) conducted focus groups. The focus groups had two broad foci: 1) to identify challenges with EF that adolescents with epilepsy experience and strategies for addressing executive dysfunction; and 2) to review the existing TOPS intervention and provide input regarding potential adaptations/modifications to make the new intervention relevant and engaging to adolescents with epilepsy. Adolescents and their parents were asked semi-structured, open-ended questions about how epilepsy affects different areas of the adolescent's EF, based on subscales on the Behavior Rating Inventory of Executive Function (e.g. memory, organization, planning, impulsivity, emotional control, problem-solving, initiation and monitoring). We also asked families about strategies to manage EF deficits that were beneficial for their adolescents. Finally, input regarding the logistics, execution and layout of the TOPS intervention were elicited from adolescents and caregivers. Parents and adolescents participated in separate simultaneous focus groups or individual interviews if they were unable to attend the focus group. Three researchers (AS, LT, & AM) examined the thematic content, and emerging themes were made by consensus. The themes generated from these focus group data were used to develop content areas and logistics of the EF intervention for adolescents with epilepsy, titled *Epilepsy Journey*.

#### 2.2.2. Usability testing (phase 2)

A semi-structured protocol that focused on ease-of-use, acceptance, error rates and time to completion guided usability testing. Trained researchers systematically observed participants under controlled conditions to detect issues that could lead to lack of program adoption or use. In each 1-hour session, participants were asked to 'Think Aloud' as they used the *Epilepsy Journey* intervention. Think Aloud enables evaluation of the thought processes and decision making of participants performing specific tasks using the web-based intervention. Given concerns that participants might have difficulty thinking aloud due to increased cognitive load, epilepsy effects and EF deficits, we coupled the Think Aloud methodology with an approach for conducting usability evaluations with individuals with cognitive impairments, All-Views Empirical Analysis [24,25]. This approach utilizes simultaneous analysis of screen capture, webcam and audio recordings, eye-tracking and trace data (usage analytics) to establish a holistic snapshot of human-computer interaction, allowing researchers to infer usability and accessibility issues in the absence of think-aloud narrative. Each adolescent worked through two randomly-assigned modules.

Morae® usability software captured video of participants thinking aloud while using the system and corresponding screen recordings. Trained researchers recorded field notes, and usability videos were coded by two experts using thematic analysis methods (M.S. and N.G.). An eye-tracking device captured participants' eye fixations and movements, which allows for analysis of errors, observation of gaze behavior while interacting with the web-based intervention and making inferences about user needs (i.e., increasing the size of a button after observing users scanning pages to find the button). Google Analytics, a platform that allows for tracking of participants' behaviors as they interact with a website, captured information such as which pages a visitor views, how long he/she remains on a page and the path through the website. Participants also completed satisfaction, usability and evaluation measures at the end of the study. Modifications were made, as needed, after each participant completed usability testing.

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