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An examination of the Allocation of Treatment Responsibility scale in adolescents with epilepsy

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ABSTRACT

The purpose of the current study was to examine the psychometric properties of the adapted Allocation of Treatment Responsibility (ATR) scale and the distribution of tasks related to oral medication and clinic and laboratory visits in a sample of adolescents with epilepsy. Adolescents with epilepsy ($N = 50$; ages 13–17 years) and their caregivers completed the adapted ATR and a measure of medication management. Internal consistency for the adapted ATR was strong (total and subscale range: 0.75–0.97). Validity was partially supported by significant correlations between adolescent age and ATR oral medication responsibility for both respondent measures. Allocation of Treatment Responsibility total scores were not associated with adherence to medications and clinic appointments. Initial findings are promising and have important implications for assessing the distribution of treatment responsibility among adolescents with epilepsy and their families.

1. Introduction

Adolescence, a developmental period marked by autonomy and independence, is a challenging and vulnerable time for adolescents with epilepsy. Specifically, adolescents are coping with seizure-related restrictions (e.g., no driving if the adolescent has active seizures, swimming with supervision, limited participation in specific sports [1,2]) and continued parental supervision to ensure safety (e.g., keeping the bathroom door open while showering/bathing), all while beginning to manage their treatment regimen (e.g., antiepileptic drugs; AEDs). Moreover, seizures and AED side effects may cause or be related to cognitive/executive functioning difficulties [3–6] and mood and behavior disorders [7], which can lead to poor disease management. Together, disease, safety, and psychosocial factors may pose unique challenges for families of youth with epilepsy entering this developmental period.

Adolescence is often accompanied by decreased parental monitoring and supervision and presumed increases in adolescent disease management [8,9]. Decisions regarding when adolescents should begin to assume more treatment responsibility are largely based on the adolescent's age rather than on their competency with regimen-related tasks [8,10]. This approach is problematic, given that less parental supervision is not always associated with increased adolescent responsibility and can have a profound impact on adherence and health outcomes. Notably, there is a strong body of literature demonstrating the dramatic declines in treatment adherence during adolescence across several populations with chronic illness [11–14]. Pediatric epilepsy is no exception; nonadherence among adolescents ranges from 35 to 79% [3,15]. Several factors may be associated with the decline in disease management during adolescence, including poor disease knowledge, a lack of practice and confidence in performing epilepsy-related tasks, and disease or psychosocial factors affecting the adolescent's ability to successfully manage their epilepsy. Although adolescents can perform some illness-related tasks independently, continued parental involvement has generally been associated with improved medical outcomes [16]. For example, based on the larger pediatric literature [17,18], it is possible that impaired executive functioning (i.e., poor planning/organizational skills) among adolescents with epilepsy contributes to poor adherence, thereby requiring greater parental involvement in order to prevent breakthrough seizures [3].

In addition to shifts in responsibility, adolescence is often marked by changes in the frequency and content of family communication [19,20]. For adolescents with chronic conditions, decreased or ineffective parent–adolescent communication can lead to increased conflict and erroneous assumptions regarding the division of treatment-related responsibilities. For example, adolescents often complain that their parents nag them about taking medications, which leads to increased conflict. Consequently, parent–adolescent discordance has been associated with poor adherence and adverse health outcomes [21–23]. While

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there has been a lack of systematic research on family communication and self-management in adolescents with epilepsy, previous findings underscore the importance of examining discrepancies between adolescent and parent perceptions of each family member's treatment responsibilities, given the likelihood that it can negatively impact treatment adherence and seizure outcomes.

Recently, the Allocation of Treatment Responsibility scale [21] was developed in a transplant population ($N = 39$ patient/caregiver dyads) to assess patient and caregiver perceptions of responsibilities for regimen-related tasks. Results indicated that the ATR is a brief and psychometrically sound measure of the distribution of treatment responsibility across family members, and the distribution of responsibility is associated with medication adherence [21]. To date, the ATR scale has not been adapted or examined in other pediatric chronic conditions, including pediatric epilepsy. However, adapting this reliable and valid measure in adolescents with epilepsy is a first step in examining this important construct.

In addition to identifying how illness-related tasks are allocated among family members, the ATR scale specifically addresses the potential for miscommunication or discrepancies between patients and caregivers as to who is responsible for each task, a factor not included in other measures of treatment responsibility. The construct of treatment responsibility is also important to understand as adolescents with epilepsy transition from pediatric to adult health care; the ATR scale has the potential to identify weaknesses in self-management and targets interventions aimed at facilitating independent care.

The current study had two primary aims: 1) to examine the psychometric properties of the adapted Allocation of Treatment Responsibility (ATR) scale and the distribution of illness-related tasks in a sample of adolescents with epilepsy and their primary caregiver and 2) to examine the relationship between parent and adolescent agreement on treatment responsibility and adherence. Consistent with the original work by Pai and colleagues, it was hypothesized that ATR total and subscale scores would demonstrate good internal consistency. In addition, it was hypothesized that validity for the ATR would be supported by significant associations between ATR total and subscale scores and adolescent age. Specifically, adolescent responsibility would increase and caregiver responsibility would decrease as the adolescent gets older. Finally, greater discordance between caregiver and adolescent treatment responsibilities was hypothesized to be associated with poorer adherence.

2. Methods and materials

This cross-sectional investigation is part of an ongoing longitudinal study examining treatment adherence in adolescents with epilepsy and identifying predictors of adherence over time. Potential participants were recruited during routine new-onset seizure clinic visits at a Midwestern children's hospital. Study inclusion criteria included the following: 1) adolescents between 13 and 17 years of age, 2) diagnosis of epilepsy for any duration of time, 3) epilepsy treatment with only one prescribed antiepileptic drug, 4) absence of significant developmental disorder (e.g., autism), and 5) adolescent and caregiver ability to read and speak English. Each family who met the inclusion criteria was approached separately by a trained research assistant during their regularly scheduled clinic visit. The research assistants explained the study objectives, including understanding how adolescents with epilepsy take their medications and things that make it difficult to take their medication. Once consent was obtained, adolescents and their caregivers were asked to independently complete several paper-based psychosocial questionnaires either in the clinic (if time permitted) or at home (mailed them back). For purposes of the current study, the Background Information Form, Allocation of Treatment Responsibility scale (ATR scale, Patient and Caregiver form), and Pediatric Epilepsy Medication Self-Management Questionnaire (PEMSQ) were examined. Upon completion, adolescents and caregivers each received a $10 gift card. The study was approved by the hospital's Institutional Review Board.

2.1. Measures

2.1.1. Background Information Form

Caregivers completed a Background Information Form during the epilepsy clinic visit that ascertained the child and caregiver's age, gender, and race; caregiver marital status; caregiver occupation; educational history; family composition; socioeconomic status; family seizure history; child history of seizures (e.g., date of first seizure, who witnessed the seizure, number of seizures within the past year); and comorbid illnesses (e.g., learning disorder). A Revised Duncan score [24] was calculated based on caregiver occupation and served as a proxy for socioeconomic status, with higher scores indicating higher socioeconomic status. For households with two caregivers, the higher Revised Duncan score was used.

2.1.2. Allocation of Treatment Responsibility [21]

The adapted ATR is a 16-item self-report measure designed to assess who is responsible for treatment regimen-related tasks for caregivers and patients 7–18 years of age. The ATR includes both patient (ATR-PF) and caregiver (ATR-CF) parallel forms. Adolescent respondents rate their own level of responsibility over the last three months for oral medication (8 items; “I am responsible for checking to see if a refill of antiepileptic drugs is needed”), clinic visits (5 items; “I am responsible for scheduling the clinic appointments”), and laboratory visits (3 items; “I am responsible for remembering to have labs drawn”) on a 4-point Likert scale ($1 =$ none of the time, $2 =$ a little of the time, $3 =$ a lot of the time, and $4 =$ all of the time). Then, they rate their caregiver's responsibility for the same regimen-related task. The same instructions are given to caregiver respondents. Items are summed for a total score (excludes item 2 “Swallowing the pills.”) and three subscale scores (oral medication, clinic visits, and laboratory visits), with higher scores indicating increased perceptions of responsibility (possible range: 16–64). The original ATR [21] was adapted (e.g., substituted AED for immunosuppressive drug, removed items pertaining to holding immunosuppressant medication prior to a clinic visit and bringing medications to every clinic visit) with permission from the author for use in patients with pediatric epilepsy.

2.1.3. Pediatric Epilepsy Medication Self-Management Questionnaire [25]

The PEMSQ is a 27-item measure of medication management in children with epilepsy and consists of four scales (Adherence to Medications and Clinic Appointments, Barriers to Medication Adherence, Epilepsy and Treatment Knowledge and Expectations, and Beliefs about Medication Efficacy). Items are rated on a 5-point Likert scale ($1 =$ strongly disagree, $5 =$ strongly agree) and then summed for a Total Self-Management score, with lower scores indicating poorer self-management. The Adherence to Medications and Clinic Appointments scale (8 items) was used as an external validation measure for total treatment responsibility in the current study and has demonstrated strong internal consistency reliability [25]. Internal consistency for the present sample was 0.88 and 0.92 for child report and parent report, respectively.

2.2. Statistical analyses

First, ATR discrepancy scores were calculated by subtracting adolescent ratings of their own task responsibilities from caregiver ratings of the adolescent's responsibilities for each task. The discrepancy score for the absolute value of each item was then summed to obtain a total discrepancy score for adolescent responsibility (possible range: 0–48). The same process was done for caregiver responsibility. Descriptive analyses, including range of scores, means, and standard deviations, were calculated for the caregiver ATR and the adolescent ATR. Reliability