



## Self-efficacy for seizure management and youth depressive symptoms: Caregiver and youth perspectives

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### ABSTRACT

The aims of this study were to (1) compare caregiver and youth measures of self-efficacy for seizure management (SESM), as well as report of depressive symptoms and suicidal ideation in youth with epilepsy (YWE) and (2) examine the potential relationship between caregiver SESM and caregiver report of depressive symptoms in YWE. Seventy-seven YWE ages 9–17 completed the Children's Depression Inventory (CDI) and the Seizure Self-Efficacy Scale for Children with Epilepsy (SSES-C). Sixty-five caregivers completed the Behavior Assessment System for Children (BASC-II) and the Epilepsy Self-Efficacy Scale (ESES). Results showed no agreement between youth and caregiver self-efficacy scores. However, there was low to modest agreement in published classifications of depressive symptoms between youth and caregiver ratings of depressive symptoms in youth, with caregivers reporting higher levels of symptoms than the youth reported. Twenty-seven percent of YWE endorsed suicidal ideation. When caregiver report of their own self-efficacy towards their child's seizures and their assessment of their child's depressive symptoms were compared, there was a significant inverse relationship. These findings suggest a multi-informant approach to assessment of depressive symptoms in YWE, the importance of including self-efficacy for seizure management in assessment and treatment of YWE, and provide support for transactional patterns of psychosocial adjustment.

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### 1. Introduction

It is becoming well-known that, in addition to seizures, youth with epilepsy (YWE) are at increased risk for mental health comorbidities, which likely originate from both psychosocial adjustment and neurobiological etiologies.<sup>1,2</sup> Documenting evidence supports prevalence rates of 12–26% for significant depressive symptomatology<sup>3–5</sup> and higher rates of suicidal ideation in YWE.<sup>4</sup> Seizure management can be very difficult for families, and 30–40% of YWE experience breakthrough seizures.<sup>6</sup>

An emerging theory, “self-management,” places emphasis not on illness parameters but on the personal skills or resources needed to manage a chronic illness in the context of everyday life<sup>7,8</sup> and recognizes the necessity of family management given the burden placed on caregivers of youth with a chronic illness.<sup>8</sup>

Indeed, studies suggest that YWE and their caregivers are at increased risk for difficulties with daily epilepsy self-management.<sup>1,9</sup> One particular cognitive self-management skill, self-efficacy for seizure management (SESM), appears particularly salient to YWE. SESM is “the personal conviction of one's capabilities to initiate and successfully complete tasks associated with the daily management of epilepsy”.<sup>10</sup> Lower self-efficacy for seizure management in YWE has shown a significant relationship with more negative attitudes about epilepsy, greater seizure worry, lower family mastery, and greater depressive symptoms.<sup>11–13</sup> In addition, self-efficacy has been shown to contribute to actual self-management outcome behaviors in adults with epilepsy<sup>10,14–16</sup> and individuals with other chronic illness conditions.<sup>17</sup>

Research has shown a significant association between SESM and depressive symptoms in YWE<sup>11–13</sup>; however, no known study has examined caregiver perceptions of self-efficacy to manage their child's seizures and the association of caregiver SESM with youth depressive symptoms, consistent with a family emphasis on self-management<sup>8</sup> and ecological models of family adjustment to chronic illness.<sup>18</sup> Further, no study has compared youth and caregiver report of SESM and depressive symptoms in YWE. Generally, caregiver and self-report of psychological constructs

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and adjustment in youth have low agreement, particularly for internalizing symptoms.<sup>19</sup> This “disagreement” has also been demonstrated in ratings of behavior in youth with epilepsy,<sup>20</sup> suggesting that multiple respondents may be necessary to capture an accurate representation of functioning. This practice is particularly salient for YWE who, due to neuropsychological deficits, may be at increased risk for poor insight into their own behaviors and how their behaviors are perceived by others.<sup>21,22</sup>

To date, researchers have chosen the Child Behavior Checklist (CBCL<sup>23</sup>) to measure behavioral functioning in YWE via caregiver report.<sup>24,25</sup> Limitations of the CBCL include diagnostic weaknesses, such as a discrepancy between item content and conceptualization of child psychopathology, inclusion of particular items on several scales, and a single negative affect subscale representing a combined index of anxiety and depressive symptoms.<sup>22</sup> Few pediatric epilepsy studies have captured depressive symptoms using the Behavioral Assessment System for Children (BASC-II<sup>26</sup>), despite its classification as a “well-established” assessment tool for measuring emotional functioning in youth with a chronic illness.<sup>27</sup> The BASC-II is a conceptually derived instrument and separates internalizing symptoms into depression and anxiety subscales, which is particularly salient to the differentiation of internalizing symptoms in YWE. Bender et al.<sup>22</sup> evaluated the convergent validity of the BASC-II and CBCL in YWE and found concordance across internalizing scales of the two rating systems per caregiver report of behavioral and emotional functioning in YWE.

To address the above-mentioned gaps in the extant literature, the current study was designed with two aims: (1) to measure and compare caregiver and youth self-efficacy for seizure management (SESM) and caregiver and youth report of depressive symptoms and suicidal ideation in YWE, and (2) to examine the potential relationship between caregiver SESM and caregiver report of depressive symptoms in YWE (the youth SESM and depressive symptom association was previously explored<sup>13</sup>). Thus, we hypothesized, in accordance with previously published data demonstrating higher youth psychosocial distress per caregiver report compared to youth report<sup>20</sup> that (1) youth report would be lower than caregiver report of youth depressive symptoms and suicidal ideation, and (2) caregiver SESM would be significant but inversely related to caregiver report of youth depressive symptoms, similar to our findings with youth report.<sup>13</sup>

## 2. Methods and materials

This paper is part of a larger study of psychosocial outcomes in YWE, and the methods (participants, procedures) presented here have been previously published.<sup>28,29</sup> In addition, results on youth self-efficacy for seizure management and depressive symptoms have been published<sup>28</sup> but not in relation to caregiver report of self-efficacy and caregiver report of youth depressive symptoms.

### 2.1. Participants

Children and adolescents ages 9–17 who were diagnosed with epilepsy for at least one year (ICD-9 345 codes) and had at least low average intelligence (IQ > 85; IQ estimates were based on electronic medical record review by an epilepsy nurse specialist or clinical psychologist in consultation with the health care provider) were eligible. Exclusionary criteria were also evaluated via electronic medical record review and were defined as: severe mental health diagnoses (e.g., bipolar disorder, schizophrenia, major depression) and/or developmental disability (e.g., autism spectrum disorder, intellectual disability). Participants were approached during a pediatric epilepsy clinic visit or via telephone if they did not have an upcoming visit scheduled. Of the 113 families who were contacted, 73% ( $N = 82$ ) agreed to participate.

“Not interested” was the most common reason cited for participation refusal. The institutional review board granted approval, and verbal informed consent and assent were obtained from each participant and his/her legal guardian. Families were informed that youth and caregivers would receive modest compensation for their time. Emotional, personal, or logistical reasons precluded five of the 82 enrolled youth participants from completing the telephone interview. Sixty-five caregivers returned caregiver-report questionnaires via mail. Participating caregivers were mostly mothers (89%).

### 2.2. Instruments

#### 2.2.1. Youth report

The Seizure Self Efficacy Scale for Children and Adolescents with Epilepsy (SSES-C; (11)) is a 15-item scale designed to measure self-efficacy in children and adolescents related to the management of their seizures. Children respond on a scale ranging from 1 (“I’m very unsure I can do that”) to 5 (“I’m very sure I can do that”), and a total score is created by summing responses, with higher scores indicating higher self-efficacy. Reliability and validity estimates are strong.<sup>11</sup> Cronbach’s alpha for our study was .85.<sup>13</sup>

The Children’s Depression Inventory (CDI<sup>30</sup>) is a 27-item scale designed for use with children ages 7–17 that measures depressive symptoms over the previous two weeks. Higher score indicate increased depressive symptoms. Raw scores can be converted to T-scores, and a T-score of 66 or greater is considered clinically elevated. Further, a raw cut off score of 16 maximizes the specificity and sensitivity.<sup>31</sup> The CDI has demonstrated adequate reliability and validity in pediatric epilepsy populations,<sup>32,33</sup> and has been deemed a “well-established” assessment tool for depression in pediatric populations.<sup>27</sup> Cronbach’s alpha for our study was 0.87.<sup>13</sup>

#### 2.2.2. Caregiver report

The Epilepsy Self-Efficacy Scale (ESES<sup>14,34</sup>) is a 33-item scale that measures different aspects of efficacy in the self-management of epilepsy. Content and construct validity have been demonstrated to be adequate, and reliability estimates were reported as high.<sup>14,34</sup> With permission from the author, this measure was adapted for the present study so that questions assessed parents’ report of efficacy in managing their child’s seizures (e.g., “I can always manage my epilepsy in new situations” was adapted to “I can always manage my child’s epilepsy in new situations.” Responses ranged from zero to ten. Items were totaled, and higher scores indicated higher levels of confidence in ability to manage epilepsy. For this study, the total score was used as a continuous variable, with higher scores indicating higher self-efficacy. Cronbach’s alpha was 0.92 for the current study.

The Behavior Assessment System for Children-II (BASC-II) (26) is a 160-item questionnaire designed for use by parents that measures youth emotional and behavioral functioning. Caregivers complete the four-choice response format on either the child (ages 6–11 years) or teen (ages 12–18 years) version. As with the CDI, the BASC has also been deemed a “well-established” assessment tool for depression in pediatric populations,<sup>27</sup> and has demonstrated reliability and validity in pediatric epilepsy populations.<sup>22</sup> For the purposes of the current study, only the Depression Clinical Subscale (DEP) was used as a measure of caregiver reported depressive symptoms in youth. This subscale measures excessive feelings of unhappiness, sadness, or stress.<sup>26</sup> Higher scores indicate increased depressive symptoms. Raw scores can be converted to T-scores, with T-scores of 60 or greater considered clinically elevated. In the present study Cronbach’s alpha was 0.91 and 0.87 for the BASC-II (DEP) (raw, 12–18 years), and BASC-II (DEP) (raw, 6–11 years), respectively.

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