



Family burden, child disability, and the adjustment of mothers caring for children with epilepsy: Role of social support and coping



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ABSTRACT

Purpose: This study was designed to contribute to the existing research on the coping behaviors, social support, and mental health outcomes in parents of children with epilepsy in the United States.

Methods: Participants included 152, predominantly Caucasian (89.5%), married (78.9%) women (95.4%). Via a web-based interface, mothers completed questionnaires assessing the impact of their child's disability on their family (i.e., severity of their child's disability, family burden, and personal stress), social resources (i.e., perceived social support), coping (i.e., emotion-focused and social support seeking), and adjustment (i.e., depression and anxiety).

Results: After controlling for demographic variables, mediational analysis revealed that mothers' perceptions of the severity of their child's disability were associated with decreased perceived social support, which was then related to higher reported levels of depression and anxiety. Similarly, low levels of perceived social support partially mediated the relation between family burden and depression, anxiety, and stress. Finally, mothers' perceptions of the severity of their children's disability and family burden were unrelated to their reports of emotion-focused or social support seeking coping. However, their use of emotion-focused and social support seeking behaviors was related to lower levels of depression.

Conclusion: Low levels of perceived social support may help to explain the mechanisms underlying the relation between mothers' perceptions of the severity of their child's disability and family burden on their mental health adjustment, such as depression and anxiety.

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1. Introduction

The consequences of epilepsy extend well beyond the affected children. Primary caregivers of children with epilepsy report high levels of stress (45%) [1], depression (46%) [2], and anxiety (56%) [3]. To date, researchers have found these effects related to the daily demands or burden of parenting a child with epilepsy [4,5], changes in family relationships as a result of the disability [6,7], and the degree of disability or level of functioning in the child [8].

Moreover, past research has indicated that parents' coping strategy choices in this context affect their adjustment. The use of emotion-focused coping strategies (utilized when an individual perceives a stressor as unchangeable) when caring for a child with epilepsy appears related to higher levels of stress [7,9] and depression [10]. Conversely, problem-focused coping strategies (utilized when an individual appraises the situation as modifiable) have been found to contribute to lower levels of parenting stress [7,10,11]. Finally, the degree of social

support that parents receive may reduce their risk for mental health difficulties.

Specifically, among parents caring for a child with epilepsy, higher levels of both received [12] and perceived [13] social support have been associated with lower levels of depression, stress, and anxiety. Moreover, perceived social support is important because it incorporates many facets of assistance that are relevant to caring for a child with epilepsy [14]. That is, social support includes instrumental support for daily hassles or needs, interpersonal support for the emotional stress associated with a chronic illness, and informational support which keeps parents abreast of services and opportunities relevant to caring for their child and themselves [15].

The potential role of social support is emphasized further by research showing that poor maternal adaptation has been found to affect dimensions of parenting [7]. Past research indicates that increased levels of stress, depression, and anxiety are associated with decreases in supportive parenting [7] and higher directive parenting styles [8], which in turn, lowers parent-child relationship quality [16]. These adaptive but less optimal parenting behaviors result in children experiencing less emotional support and autonomy [17] and consequently, increased internalizing behaviors, such as affective or anxiety

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disorders [17]. Correspondingly, internalizing behaviors may cyclically intensify and increase negative interactions between parents and children thereby increasing the burden of parenting a child with epilepsy [16].

This research has provided important information about the direct effects between perceived family burden and perceived degree of child disability on mental health outcomes among parents of children with epilepsy as well as risks to the quality of the parent–child relationship. Nevertheless, it is important to identify potential mechanisms that might serve to mediate these relations and thereby reduce parental stress, depression, and anxiety. Further, given that parents of these children do experience higher levels of mental health stress and adjustment issues, identifying these factors would provide clinicians with specific strategies for intervention.

Accordingly, the aim of this study was to determine whether maternal coping strategies and perceived social support would mediate the relation between their perceptions of the severity of their child's disability and degree of family burden and their self-reported stress, depression, or anxiety. Specifically, it was hypothesized that mothers' perceptions of their children's severity of disability and family burden would be associated with increased use of support seeking and perceived social support and thereby decrease their stress, anxiety, and depression. Conversely, when mothers' perceptions of their children's disability and burden increased their use of emotion-focused coping, it was anticipated that they would report higher levels of adjustment difficulties.

2. Methods

2.1. Participants and procedures

Participants were recruited online through Facebook discussion boards as well as various discussion forum websites related to parenting a child with epilepsy (e.g., epilepsy.com, healthboards.com/epilepsy, epilepsyfoundation.com). Eligible mothers were at least 18 years of age and were the primary caregiver of a child under the age of 18 diagnosed with epilepsy. No other criteria were used to exclude children with epilepsy in order to represent the range of symptomatology and types of families of children with this disorder. The questionnaires were administered through the web interface SurveyMonkey (surveymonkey.com). Respondents were required to electronically sign a consent form to participate in the study. The questionnaires were administered in a randomized order as determined by Survey Monkey. IP addresses were collected and duplicates were discarded to minimize the potential for duplicative responses. Individual names or other identifying information were not collected.

2.2. Instruments

The survey consisted of five previously validated self-report questionnaires. All questionnaires were presented in English.

2.2.1. COPE

Participants completed the COPE [18], which is a well-established questionnaire in the stress and coping research literature. This questionnaire is composed of 15 subscales, each consisting of 4 items measuring a specific type of coping strategy for a total of 60 questions. Participants reported on a four-point Likert scale ranging from 1 to 4 (1 = "I usually don't do this at all", 4 = "I usually do this a lot") to indicate the degree to which they usually engage in the strategy when experiencing stressful events.

In order to compare results with previous studies on parenting children with epilepsy, subscales that were assessed for this study were grouped into two, larger coping scales. The coping scales were as follows: emotion-focused strategies (acceptance, humor, positive reinterpretation, religious coping) [19] and social support seeking

(instrumental, emotional social support) [20]. Both emotion-focused and social support seeking coping subscales displayed acceptable internal reliability in the current study, with Cronbach's α s of .76 and .87, respectively.

2.2.2. Depression Anxiety Stress Scales (DASS)

Participants completed the Depression Anxiety Stress Scales (DASS) [21]. This scale was chosen because it assesses depression and anxiety as well as overall stress, which provided a more comprehensive picture of parental adjustment. The questionnaire features 42 statements, with 14 items for each of the three subscales: depression (e.g. "I felt that I had nothing to look forward to"), anxiety (e.g. "I found myself in situations that made me so anxious I was most relieved when they ended"), and stress (e.g. "I found myself getting upset rather easily"). Participants reported on a four-point Likert scale ranging from 0 to 3 (0 = "Did not apply to me at all", 3 = "Applied to me very much, or most of the time") to indicate the degree to which each statement applied to them over the past week. Scores for items within each subscale were summed to produce a total score. Depression, stress, and anxiety had satisfactory internal consistencies ($\alpha = .94$, $\alpha = .91$, and $\alpha = .93$, respectively).

2.2.3. Questionnaire on Resources and Stress – Fredrich edition (QRS-F)

The mothers' perception of the impact of their children's disability on their stress was measured using the 52-item QRS-F [22]. The measure consists of four subscales: child characteristics (i.e., features of the child that increase the demand on the parent, e.g. "Sometimes I avoid taking ____ out in public"), child incapacitation (i.e., the range of activities a child cannot perform, e.g. "cannot remember what he/she says from one moment to the next"), parent and family problems (i.e. the impact of the child's disability on parents and other family members, e.g., "Other members of the family have to do without things because of ____"), and pessimism (i.e., a pessimistic view of the child's future, e.g. "I often worry about what will happen to ____ when I can no longer care for him/her"). The scale utilizes dichotomous true/false responses (0 = false, 1 = true) to assess each component of maternal perception. Consistent with the recent research using this questionnaire [23], child characteristics and child incapacitation were combined to form a child disability measure (Cronbach $\alpha = .98$).

2.2.4. Interpersonal Support Evaluation List (ISEL)

The Interpersonal Support Evaluation List (ISEL), a 40-item instrument, was used to assess mothers' perceived accessibility of possible social resources (i.e., perceived social support) [24]. Participants reported on a four-point Likert scale ranging from 0 to 3 (0 = "definitely false", 3 = "definitely true"). The ISEL is composed of four social support subscales, ten questions each, measuring; tangible (i.e., perceived availability of palpable aid), appraisal (i.e., perceived availability of emotional support), self-esteem (i.e., perceived availability of someone else to positively compare oneself with), and belonging (perceived availability of people to engage with socially) components. Higher scores indicate greater perceived social support. The subscales were combined to produce a single scale with a high level of internal consistency ($\alpha = .96$).

2.2.5. Impact on Family Scale (IOFS)

Consistent with current research investigating the impact of epilepsy on family functioning [25], the mother's perception of the degree to which their child's epilepsy causes strains on the family (i.e., family burden) was measured with the IOFS [26]. The survey consists of 27 statements subdivided into four dimensions: financial (i.e., the degree to which the child's illness affects the family economically), familial/social (i.e., the degree to which the child's illness affects communication within and outside of the family), personal strain (i.e., parental experienced strain resulting directly from the child's illness), and mastery (i.e., perception of the degree to which they have learned to manage their child's disability). A Likert scale ranging from 1 to 4 (1 = "strongly disagree", 5 = "strongly agree") was used to assess the participant's

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