



# Parental coping and its role in predicting health-related quality of life in pediatric epilepsy

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## ABSTRACT

**Objective:** Psychosocial difficulties are known to greatly impact the health-related quality of life (HRQOL) of a child with epilepsy, and parental coping is a unique aspect that has not been examined in relation to HRQOL in the pediatric population with epilepsy. This study assessed the relationship of parental coping with HRQOL and other clinical and sociodemographic factors.

**Methods:** Data included parental ratings on the Illness Cognition Questionnaire—Parent (ICQ-P) and the Quality of Life in Childhood Epilepsy (QOLCE) questionnaire for 108 children and adolescents with epilepsy (mean 11.34 years of age). The ICQ-P examines parental coping through constructs of illness cognitions while QOLCE determines overall functioning as indicated by parents. Bivariate correlations were conducted to identify significant associations with parental coping, followed by a multiple linear regression to determine the relative contribution of parental coping on HRQOL. Sociodemographic factors on parental coping were explored with an analysis of covariance.

**Results:** Longer duration of epilepsy ( $r = 0.202$ ) and higher HRQOL ( $r = 0.208$ ) were significantly associated with parental acceptance on the ICQ-P. Higher parental helplessness was significantly associated with female gender of the child ( $r = 0.262$ ), diminished HRQOL ( $r = -0.566$ ), greater seizure frequency ( $r = 0.255$ ), and higher number of prescribed antiepileptic drugs (AEDs) ( $r = 0.226$ ). Parent-rated perceived benefits did not have significant association with study variables. Multiple linear regression revealed age of seizure onset ( $\beta = 0.19$ ,  $p = 0.05$ ), seizure frequency ( $\beta = -0.22$ ,  $p = 0.01$ ), and degree of parental helplessness ( $\beta = -0.50$ ,  $p \leq 0.01$ ) as unique predictors of HRQOL. Two separate ANCOVAs revealed no significant associations between maternal education or insurance type on parental helplessness.

**Significance:** Parental coping is significantly related to HRQOL in youth with epilepsy, and elevated feelings of helplessness, along with epilepsy severity, predict lower HRQOL. These findings are the first to demonstrate the unique role of parental coping in HRQOL among youth with epilepsy, and they highlight the importance of providing support to the whole family during pediatric epilepsy treatment.

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## 1. Introduction

The unpredictable nature of seizures and their concerning physical and cognitive consequences can have a significant effect on the health-related quality of life (HRQOL) of youth with epilepsy. Even when epilepsy is well-controlled, children with epilepsy are known to experience poor quality of life and psychosocial difficulties [1,2]. While disease-specific variables play a role in the well-being of children with epilepsy, clinical factors, such as seizure frequency, may not be the most significant contributors to HRQOL [3]. The aspects of psychological,

educational, and social functioning tend to more greatly affect a child's HRQOL compared with other functional domains [4]. Therefore, these children are at increased risk for cognitive deficits, emotional concerns, and restrictions in social activity that make them particularly vulnerable to experiencing low quality of life [5,6].

While the influence of psychological factors on HRQOL have been well-documented, there is less information about the role of family adjustment, specifically parental coping, on patient outcomes in epilepsy. The broader psychology and chronic illness literature indicates that parental stress is an influential factor on child's development and well-being, for both healthy children and children with chronic illness [7,8]. Within pediatric epilepsy, higher stress, anxiety, and restrictions in family life as well as difficulties within parent-child relationships and family functioning and adaptation have been reported [9,10]. These family-

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related factors have been shown to be strongly associated with mental health functioning, which, in turn, can further exacerbate problems with family adjustment by contributing to poorer parent–child interactions, high family stress, parental overcontrol, parental rejection, deficient family mastery, and low parent confidence in managing epilepsy [10–14].

The degree to which parental adjustment influences the child appears to be affected by the parent's perception of the child's illness. Indeed, perceptions of illness, or illness cognitions, have been shown to be an important mediator between illness and psychological adjustment of patients [15–17]. This mediating relationship can be viewed as a measure of how one is coping. Previous literature indicates that how patients react and cope with chronic conditions can account for much of the individual differences in their health status, both physically and psychologically [16]. This is seen by the various forms illness cognitions can take, including more positive thoughts such as acceptance or more negative thoughts such as helplessness, which can have positive or negative effects, respectively. As such, illness cognitions can serve as a useful prognostic factor to predict physical functioning, psychological distress, and potential adaptation to the chronic condition [18].

The negative illness cognitions of parents, and their consequential behavior, have been shown to be related to behavioral issues and emotional symptoms in children with epilepsy [19]. As stress and coping theory suggests, minimal access to resources (i.e., income level to access supportive services) can increase family stress, which in turn can lead to ineffective parenting behavior and coping [10,20]. Moreover, the amount of available resources for families' adaptation to stressors is uniquely associated with the child's HRQOL [21]. For example, Kampra et al. [22] found that parents with a higher educational level and financial status tended to have more open communication styles with their children, which acted as protective factors in their child's adjustment to epilepsy.

Taken together, the available literature thus far highlights the important role of family variables in the adjustment of children with chronic illness. While the epilepsy literature also documents the important contribution of family adjustment to well-being in children, the role of parental coping in the HRQOL of children with epilepsy has not been investigated. Understanding this relationship may provide an important target for intervention that can improve parental adjustment and maximize psychosocial functioning in children with epilepsy [15,23].

In the present study, our purpose was to determine the effect of parental coping within the pediatric population with epilepsy and its level of contribution to HRQOL when considering epilepsy-specific variables. To do this, we first explored parental coping in pediatric epilepsy by considering how illness cognitions reported by the parents relate to clinical and demographic factors. We then determined the extent to which parental coping predicts HRQOL above and beyond demographic and epilepsy-specific characteristics. Lastly, we explored the relationship of sociodemographic factors with parental coping.

## 2. Methods

### 2.1. Participants

Participants in the present study included 108 children and adolescents (47% male) between the ages of 3 years and 17 years (mean age = 11.34; SD = 3.74) who were referred for epilepsy treatment at a tertiary care health center. All epilepsy diagnoses were confirmed by board-certified epileptologists via clinical evaluation and electroencephalographic monitoring. Patients were referred to the pediatric neuropsychology clinic because of the presence of cognitive concerns or as part of a presurgical epilepsy evaluation. Participants were not excluded based on their epilepsy-specific variables as these variables and their impact on paternal coping and HRQOL was of particular interest in this study. However, children with caretakers who could not speak English were excluded from the study because of translational

limitations for the measures that were used. The demographic and clinical characteristics of the sample are shown in Table 1.

### 2.2. Measures

#### 2.2.1. Parental coping

The Illness Cognitions Questionnaire—Parent Version (ICQ-P) is an 18-item parent-rated measure designed to assess parent's illness cognitions about the disease of their child [15]. The ICQ-P measures illness cognitions that reflect different ways of evaluating the aversive character of a chronic condition, namely, helplessness (e.g., “My child's illness controls my life.”), acceptance (e.g., “I can handle the problems related to my child's illness.”), and disease benefits (e.g., “I have learned a great deal from my child's illness.”) [16]. Each scale assesses different coping responses to stressful events. The helplessness scale measures an individual's focus on the negative meaning of a stressor, the acceptance scale measures an individual's ability to diminish the aversive meaning of the stressor, and the perceived benefits scale measures an individual's ability to add a positive meaning to the stressor [16]. Parental ratings are measured on a 4-point Likert scale (1 = not at all, 2 = somewhat, 3 = to a large extent, 4 = completely) and each scale consists of six items. Scores of the ICQ-P scales are calculated by summing the item scores, ranging from 6 to 24. A total score is calculated by summing the ICQ-P scales with scores ranging from 18 to 72. Higher scores for each score of the ICQ-P scale indicate a higher level of the illness cognition. Among the different scales, a higher score can have a different meaning for each scale. While a higher score on Acceptance and Perceived Benefits scale means more positive coping, a higher score on Helplessness indicates more negative coping. The internal consistency of the three-scale scores demonstrated adequate internal consistency (Cronbach's  $\alpha = 0.80\text{--}0.88$ ) [16].

#### 2.2.2. Health-related quality of life

The Quality of Life in Childhood Epilepsy (QOLCE) questionnaire is a 91-item parent-rated measure designed to assess the HRQOL of children, aged 6–18 years, with epilepsy [24]. Parental ratings are measured on a 5-point Likert scale ranging from “very often” or “all of the time” to “never” or “none of the time”. Some questions included ranges of “yes, limited a lot” or “very often” or “excellent” to “no, not limited” or “N/A” or “poor” depending on the item content. The questionnaire incorporates a representative number of functional life domains including physical function,

**Table 1**  
Descriptive values for sociodemographic and epilepsy variables.

Characteristic	Mean (SD) or N (%)
N, (males and females)	108 (47 and 61)
Age (years) (SD)	11.34 (3.74)
Racial background N (% minority)	56 (51.9)
Maternal education N (%)	–
<High school	4 (3.7)
High school	27 (25.0)
Some college	29 (26.9)
College	29 (26.9)
Graduate degree	19 (17.6)
Parental epilepsy history N (% yes)	30 (27.8)
Insurance N (% Medicaid)	34 (31.5)
Age of seizure onset	5.55 (4.20)
Epilepsy duration (years)	5.78 (3.74)
Seizure frequency	
Yearly	30 (27.8)
Quarterly	30 (27.8)
Monthly	25 (23.1)
Weekly	12 (11.1)
Daily	11 (10.2)
Number of current AEDs	1.55 (1.06)
ICQ Acceptance	20.19 (3.45)
ICQ Helplessness	9.38 (3.21)
ICQ Perceived Benefits	20.25 (3.82)
QOLCE Total	61.68 (13.65)

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