Self-control and coping responses are mediating factors between child behavior difficulties and parental stress and family impact in caregivers of children with severe epilepsy

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ABSTRACT

Objectives: To gain a better understanding of parental support needs by assessing parental individual psychological factors as mediating factors between child behavior difficulties and parental perceived stress and family impact of severe childhood epilepsy.

Methods: One-hundred and sixty two parents of children with severe epilepsy were enrolled in the survey during the hospitalization of their child at the Danish Epilepsy Center. Questionnaires targeted the impact on the family, coping style responses, sense of control, and the level of parental perceived stress.

Results: Serial mediation models demonstrated a mediating effect of self-control and emotional coping (EMCOP) response between child behavioral difficulties and both parental stress (F(4, 127) = 56.371, p < 0.001, R² = 0.64) and family impact (F(3, 134) = 32.202, p < 0.001, R² = 0.42). Low level of control was associated with a higher level of EMCOP response, and a high EMCOP response was associated with greater perceived stress and family impact. Social support ceased to be a protective factor for parental stress in the presence of decreased self-control and higher levels of EMCOP response.

Conclusion: Individual caregiver psychological factors influence the degree to which sequelae of epilepsy impact family life and perceived stress in parents. Coping interventions should direct awareness toward the life-control aspect, coping response styles, and illness-specific factors to ensure that appropriate support is provided. Maintaining parental resources is essential, and the parents’ capacities to handle the child’s behavioral difficulties should be considered.

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1. Introduction

Caring for a child with a chronic and sometimes life-threatening disease such as severe childhood epilepsy engenders high levels of psychopathology and stress in caregivers [1–5]. The causes of this high impact might seem evident; however, the relationship between illness-related factors and the level of impact on caregivers is not always a direct association. Comorbidity, including behavioral problems, occurs frequently in childhood epilepsy [6–8], and it is suggested that child behavioral difficulties are predominately related to parental stress rather than illness-related factors such as seizure frequency or type of diagnosis [2,9,10].

Parental stress may further challenge the sustenance of a positive parent–child relation [11–13], and more significant behavioral difficulties are seen in children where the caregiver–child relation is challenged [14,15]. Furthermore, the nature of epilepsy elicits unpredictable life situations for many families, and parents may experience a lower sense of control in their own lives. Impairment or loss of control is associated with higher levels of stress in western cultures [16], and it is well established that an impaired sense of control is linked with psychopathology [17,18]. The early construct of control orientation by Rotter [19] comprises a continuum of external and internal locus of control. External locus of control at one end of the continuum is the generalized belief that outside forces determine important life events more than the person herself does. This could be factors such as fate, luck, or the influence of powerful others. The powerful others with the ability to control the lives of parents to children with epilepsy would be such as policy makers who decide the treatment available for childhood epilepsy. It could be anyone responsible for treatment,
or the people who assist the family to get the needed support at home or have impact on which institutional support the child may receive. At the opposite end of the continuum is the internal locus of control, which is the generalized belief of personal control over important life events with the option to act. Additionally, according to the transactional theory by Lazarus et al. [20–22], the relationship between impaired locus of control and stress should be understood in the context of adaptive coping mechanisms.

The transactional theory suggests that situational characteristics determine the adaptability of a strategy and that no specific coping strategies are to be preferred a priori. Locus of control is viewed as subordinate to coping strategies; hence, locus of control should be linked with emotional influence via coping strategies. Lastly, social support appears to be an essential buffer for the influence of stressful situations on mental distress and physical illness [23,24]. We have previously shown an association between self-control, social support, and perceived stress in parents of children with severe epilepsy [2], which is in line with known resilience factors in parents of children with developmental disabilities [25].

The current study investigated the influence of parental psychological resources as mediating factors for the impact of severe childhood epilepsy on parental stress development and broadened this perspective into family life impact.

2. Methods

2.1. Participants

Parents of children diagnosed with epilepsy (aged 0–18 years) were approached for participation in the study when hospitalized with their child at the pediatric department of the only tertiary epilepsy center in Denmark—the Danish Epilepsy Centre, Filadelfia. Participants signed informed consent, and data handling guidelines from the Danish Data Protection Agency were followed. We excluded non-biological caregivers and parents who were not native Danish speakers. During the 12-month period of data collection, parents of 287 children were asked to complete the study survey.

2.2. Measures

2.2.1. Family impact

The impact of epilepsy on the family was measured by the Impact on Family Scale (IFS) [26]. The original 24-item scale was explicitly designed to measure the impact of pediatric chronic illness on the family, measuring four distinct domains: personal strain, familial/social impact, financial impact, and mastery. A revised IFS scale with 15 of the original 24 items was later recommended for measuring a single impact factor, showing good to excellent psychometric properties [27,28]. The scores are measured on a four-point Likert scale, where a low total score defines a high impact. In the current study, the 15-item scale was used as a single factor measure of the general impact on the family, and sub-analyses were performed on two of the original scales—personal strain and familial/social impact—due to the qualitative nature of the questions in these two scales.

2.2.2. Parental stress

The caregiver’s level of perceived stress was measured with the 10-item Perceived Stress Scale (PSS-10) [29]. This is a self-reported questionnaire that evaluates the degree to which individuals believe their lives have been unpredictable, uncontrollable, and overloaded during the previous month. A higher score resembles higher levels of perceived stress. The 10-item scale has proved superior to the original 14-item scale and has shown acceptable psychometric properties across various cultures and countries [30].

2.2.3. Parental resources

The Multi-dimensional Scale of Perceived Social Support (MSPSS) [31] and the Visual Analogue Scale of Self-control (VAS-SC) [19,32,33] were used to evaluate external and internal resources in caregivers, respectively. The MSPSS is a 12-item measure of perceived adequacy of social support from three sources: family, friends, and significant other. It is a seven-point Likert scale where higher scores equals higher levels of support. The subscales and the total scale have good internal reliability with Cronbach's alpha (α) levels between 0.81 and 0.94 [34]. The total scale was used in this present study. The VAS-SC consists of a 10-centimeter line anchored at each end by two opposing statements related to the experience of self-control. At the high end of the scale (to the right) is a statement of not controlling in what direction the responder's life is taking (low level of self-control). Hence, the higher the score, the lower the sense of control. The VAS scale measures have reliable psychometric properties compared to Likert-scale measures [35,36].

2.2.4. Parental coping

The Coping Style Questionnaire (CSQ) [37] is a 37-item, four-point Likert scale measure of parental coping styles. A higher score represents a more pronounced response style. This questionnaire distinguishes between four different coping styles, each with acceptable internal consistency of the scales (Cronbach's alpha (α)): rational coping (RATCOP; α = 0.85), emotional coping (EMCOP; α = 0.74), avoidance coping (AVCOP; α = 0.69), and detached coping (DETCOP; α = 0.90) [38].

2.2.5. Child characteristics

The Strength and Difficulties Questionnaire for Parents (SDQ-P) [39] measured the child's level of difficulties and prosocial behavior. The SDQ is a widely used and reviewed 25-item questionnaire [40–42] and has national norms [43]. It includes five subscales: Emotional Symptoms, Conduct Problems, Hyperactivity, Peer Problems, and Prosocial Behavior. The total scale was used in this study as a proxy measure of the sequelae of childhood epilepsy. A higher total score approximates higher levels of behavior difficulties.

The caregiver provided diagnostic information concerning the child. A child neurologist reviewed the diagnostic information regarding epilepsy diagnosis and type of seizures for the purpose of categorized analyses matching the diagnostic criteria of the International League Against Epilepsy (ILAE) [44]. Epilepsy-related factors included the type of epilepsy, type and frequency of seizures, the child’s age at seizure onset, and years with epilepsy. Demographic information included gender and age (caregiver and child) and caregiver education, job situation, and marital status.

2.3. Statistical analysis

Quantitative statistics were analyzed using IBM SPSS version 24. All questionnaire variables were screened for missing data, and Little's MCAR test was performed. Missing values up to 20% at item or case level were imputed using the expectation–maximization (EM) method. This method was run for each subdomain in composite scale measures (IFS, MSPSS, CSQ, SDQ-P). Summary statistics were calculated for child factors and sociodemographic factors. Possible predictive caregiver- and child-associated variables were first tested for their bivariate correlation with the caregiver's level of perceived stress and family impact. They were entered into the multivariable analyses if they were correlated at p < 0.20 or were identified a priori as being of interest based on
previous research. The level of statistical significance was set at \( p < 0.05 \). Estimation of statistical power was assessed with the G*Power 3.1 [45]. To avert a potential clustering effect of parents included from the same household, we assessed all parental individual psychological factors and outcome measures (IFS, MSPSS, CSQ, VAS-SC) across same-gender co-admitted and single-admitted parents (ANOVA). No significant differences were found for any outcome measure. Grouping co-admitted and single-admitted parents irrespective of gender (two groups) did not reveal any significant differences either.

Hierarchical linear regression analyses were performed to assess a possible mediation effect of parental psychological factors (CSQ-P, VAS-SC) on caregiver-perceived stress (PSS-10) and family impact (IFS), respectively. Assumptions of residual normality, linearity, and homoscedasticity were assessed, and outliers were removed from the further analysis. Multicollinearity among the explanatory variables was assessed using the variance inflation factor (VIF). The PROCESS macro by Hayes [46] was used for mediation analyses.

### 3. Results

The survey was completed by 162 caregivers (of whom 125 were mothers and 37 fathers) aged 27–60 years (mean 39.8 years, SD 6.7) of 140 children with epilepsy, giving a response rate of 49%. Both parents of 22 children participated in the survey. The children had a mean age of 8.9 years (0–18 years; SD 4.6) and a mean duration of epilepsy of 4.03 years (SD 3.72) (Table 1). Children of parents who declined to participate in the survey had a mean age of 9.3 (0–18 years; SD 4.4) and 43% were girls. Parent and child characteristics have been described in full previously [2].

#### 3.1. Mediating factors of perceived stress

We demonstrated in a previous publication that social support, the child’s difficulties, and self-control were significant predictors of the level of the caregiver’s stress when controlling for demographic factors and child epilepsy variables [2]. In the current study, we added coping style into the regression analyses and found that EMCOP added significantly to the model. It appeared to mediate the impact of child difficulties on parental perceived stress, reducing the magnitude of the direct effect on perceived stress by 28% (\( \beta = 0.36 \) vs. 0.25). It further reduced the direct effect of self-control on perceived stress by 43% (\( \beta = 0.48 \) vs. 0.29). None of the other three coping styles (DETCOP, RATCOP, AVCOP) remained significant in further analyses beyond bivariate analyses (Table 2). In a serial mediation model with self-control and EMCOP as mediating factors of perceived stress and controlling for social support as a confounding factor, both factors mediated the relationship between child difficulties and parental stress in serial; indirect = 0.05, SE 0.03, 95% CI [0.01, 0.11] (Fig. 1). With this mediating effect of self-control and EMCOP, social support no longer showed a significant effect on parental stress \( b = −0.07, t(127) = −0.22, p = 0.8227 \) (Table 3). Contrast analyses between indirect effects were non-significant.

#### 3.2. The impact on family

The age at which the child was diagnosed with epilepsy, the nature of the seizures, and child difficulties were significant predictors of the overall impact on family life (Table 4). Generalized tonic-clonic seizures alone or with other types of seizures were significantly associated with family impact compared to seizure-free children or other types of seizures alone. The younger the child at diagnosis and the more difficulties parents considered their child to have at the time of the survey, the higher the impact on the family. The child factors remained significant when entering parental psychological factors into the regression analyses. Self-control and EMCOP style increased the explained variance of the model significantly (\( \Delta R^2 = 0.131 \)) and decreased the direct effect of child difficulties on family impact with a total of 38% (\( \beta = 0.45 \) vs. 0.29). A significant indirect effect was demonstrated in mediation analysis with self-control and EMCOP mediating between child difficulties and impact on the family (Fig. 2) for both mediators separately and in serial; indirect (completely standardized) = −0.05, SE 0.03, 95% CI [−0.12, −0.00] (Table 5).

When we repeated the analyses on the two IFS domains of personal strain and familial/social impact (suppl. Table A1), we found that self-control mediated the relationship between child difficulties and impact on both scales (familial/social; indirect = −0.10, SE 0.04, 95% CI [−0.18, −0.08], personal strain; indirect = −0.07, SE 0.03, 95% CI [−0.15, −0.02]) (suppl. Figure A and B). However, coping style remained significant only in predicting personal strain \( (b = −0.04, t(135) = −4.34, p < 0.001) \) (suppl. Table A2 and B) and mediated the relationship between child difficulties and personal strain together with self-control in serial mediation analyses, indirect = −0.06, SE 0.02, 95% CI [−0.10, −0.02]. All contrast analyses between indirect effects were non-significant.

### 4. Discussion

The study results indicate that parental psychological factors influence the degree to which sequelae of epilepsy impact family life and the level of perceived stress in parents. The degree of child behavior difficulties impacts how parents experience being in

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**Table 1** Characteristics of children with epilepsy and their caregivers.

| Children                                      | Characteristics with epilepsy and their caregivers. |
|-----------------------------------------------|---------------------------------------------------|
| Number of patients (girls %)                  | 140 (46)                                          |
| Age, M (SD)                                   | 8.9 (4.6)                                         |
| Years with epilepsy, M (SD)                   | 4.0 (3.7)                                         |
| Epileptic diagnosis, n (%)                    | 26 (19)                                           |
| ESES                                          | 21 (14)                                           |
| Seizure frequency, n (%)                      | 37 (30)                                           |
| Seizure-free                                  | 42 (34)                                           |
| Caregivers, n (%)                             | 162 (77)                                          |
| Number of parents (mothers %)                 | 117 (72)                                          |
| Employed                                      | 106 (65)                                          |
| Coping Style                                  |                                                   |
| RATCOP                                        | 29.0 (5.0)                                        |
| EMCOP                                         | 26.4 (6.0)                                        |
| DETCOP                                        | 12.0 (2.7)                                        |
| AVCOP                                         | 19.6 (3.8)                                        |
| Self-control                                  | 4.4 (3.1)                                         |

M = mean. SD = standard deviation. n = number. ESES = Electrical status epilepticus during slow-wave sleep. RATCOP = rational coping. EMCOP = emotional coping. DETCOP = detached coping. AVCOP = avoidant coping.
control of their own lives. A lower level of control is associated with a higher level of EM Cop response, and a higher EM Cop response is associated with higher levels of perceived stress and family impact.

These findings diverge from a recent study on emotion-focused coping strategies and family burden in parents of children with epilepsy [47], where emotion-focused strategies were a protective factor for parental psychopathology. However, the authors assessed coping strategies using the widely used COPE questionnaire [48], which is linked to the dispositional perspective of coping mechanisms. The COPE questionnaire encompasses appraisal, humor, positive reinterpretation, and religious beliefs as active coping strategies. In contrast, our study's EM Cop response style (CSQ, EM Cop) encounters the feeling of being overwhelmed, sad, helpless, and isolated [21,37].

The theoretical understanding of coping mechanisms is broadly speaking divided into dispositional and contextual perspectives, or more explicitly, coping dispositions and coping responses [48]. The differences between instruments measuring dispositional or contextual coping mechanisms are essential to note when comparing findings across studies. It is most likely, however, that coping mechanisms operate in a combination of the two perspectives, emphasizing that individuals are active agents who can impact the outcomes of stressful life events and be shaped by them.
Collectively, the two perspectives indicate that parental stress results from the degree to which parents can handle the child’s difficulties and is not merely a direct effect of the severity of the child’s behavioral difficulties.

On a conceptual level, our study results correspond to the general literature about the mutual interaction of self-control and coping strategies when an individual is challenged by a stressful event [20,22] and about parental coping related to childhood illnesses [10,51]. Although not significant after controlling for epilepsy-specific factors and self-control, the three other coping styles were significantly correlated with perceived stress in the bivariate analyses. Rational and detached coping were negatively correlated with stress, while avoidant coping (as with EM COP) was positively correlated with stress. In a contextual perspective, a person adapts their coping response to different situations [22].

Our results indicate that rational and detached coping responses may act as protective factors toward parental stress, while both avoidant and EM COP responses can cause higher levels of stress. Our results further indicate that parents who respond with a higher level of EM COP to high levels of child difficulties and have lower self-control will experience higher stress levels and more impact on family life. Thus, in a preventive perspective, the knowledge of how caregivers respond to stressful events could help clinicians to predict potential higher levels of stress in parents and provide support accordingly to prevent further impact.

### Table 4
Hierarchical regression analysis predicting family impact.

| Model | SE B | \(\beta\) | sr | SE B | \(\beta\) | sr | SE B | \(\beta\) | sr |
|-------|------|---------|---|------|---------|---|------|---------|---|
| Model 1 | 4.9125 | 3.848 | 53.871 | 3.570 | 58.847 | 4.031 |
| Model 2 | -0.228 | 0.242 | -0.091 | -0.087 | -0.254 | 0.217 | -0.101 | -0.108 | -0.241 | 0.213 | -0.096 | -0.105 |
| Model 3 | 0.925 | 0.277 | 0.345 | 0.295 | 0.871 | 0.249 | 0.324 | 0.308 | 0.826 | 0.245 | 0.308 | 0.300 |
| Diagnosis, EE | -2.538 | 3.134 | -0.090 | -0.075 | -3.070 | 2.820 | -0.109 | -0.101 | -4.017 | 2.785 | -0.142 | -0.133 |
| Diagnosis, ESES | 0.279 | 2.978 | 0.009 | 0.009 | 0.472 | 2.678 | 0.016 | 0.016 | 0.603 | 2.621 | 0.020 | 0.021 |
| Seizure type, GTC/GTC+ | -3.831 | 2.442 | -0.316 | -0.300 | -7.738 | 2.202 | -0.281 | -0.297 | -6.508 | 2.184 | -0.248 | -0.268 |
| Child difficulties | -0.246 | 2.053 | -0.011 | -0.011 | -0.639 | 1.847 | -0.029 | -0.032 | -0.542 | 1.808 | -0.025 | -0.028 |
| Employed | 2.681 | 1.916 | 0.110 | 0.128 | -0.121 | 1.800 | -0.005 | -0.006 | -0.038 | 1.762 | -0.002 | -0.002 |
| Self-control | -1.334 | 0.249 | -0.380 | -0.446 | 0.097 | 0.290 | -0.249 | -0.290 | -0.399 | 0.161 | -0.210 | -0.290 |

Fig. 2. Statistical diagram of the serial multiple mediator model for family impact.

### Table 5
Model summary for the serial multiple mediator model for family impact that is depicted in Fig. 2.

| M1 | M2 | Y | B | 95%CI | SE B | \(\beta\) | B | 95%CI | SE B | \(\beta\) | B | 95%CI | SE B | \(\beta\) |
|-----|-----|---|----|------|------|---------|----|------|------|---------|----|------|------|------|---------|
| X (child difficulties) | | | | | | | | | | | | | | |
| \(a_0\) | 0.120 | [0.04, 0.19] | 0.037 | 0.263 | a_2 | 0.182 | [0.08, 0.29] | 0.053 | 0.223 | c_2 | -0.456 | [-0.68, -0.24] | 0.111 | -0.292 |
| M_1 (Self-control) | | | | | | | | | | | | | | |
| \(d_{11}\) | 1.094 | [0.86, 1.33] | 0.119 | 0.595 | b_1 | -1.104 | [-1.71, -0.50] | 0.304 | -0.316 |
| M_2 (Emotional coping) | | | | | | | | | | | | | | |
| \(i_{k2}\) | 2.268 | [0.99, 3.55] | 0.647 | 1.627 | b_2 | -0.413 | [-0.75, -0.07] | 0.172 | -0.217 |
| Constant | | | | | | | | | | | | | | |
| \(i_{k2}\) | 12.607 | [10.75, 14.46] | 0.938 | 57.550 | i | 57.550 | [51.87, 63.23] | 2.873 |

\(R^2 = 0.070\) \(F(1, 135) = 10.137, p < 0.002\)
\(R^2 = 0.473\) \(F(2, 135) = 6.064, p < 0.001\)
\(R^2 = 0.584\) \(F(3, 134) = 32.202, p < 0.001\)

\(M = \text{mediator variable. } CoV = \text{covariate variable. } B = \text{unstandardized coefficient. CI = confidence interval. } SE B = \text{standard error of } B, \beta = \text{standardized coefficient.}\)

**p < 0.05.
*p < 0.01.
**p < 0.001.
It is noteworthy that the protective factor of social support is no longer significant when lower levels of self-control and higher levels of EMCP responses are present. This finding is contrary to most studies on the beneficial effects of social support [23] and emphasizes the importance of being aware of the combination of lower control and higher EMCP response style. External resources do not seem to help lower the stressful impact of child difficulties on parental stress in these circumstances, and caregivers might need personalized support to handle the impact in a preventative way.

Further analyses of the two original domains of the Family Impact Scale (personal strain and familial/social impact) demonstrated that self-control was a mediating factor between child difficulties and both domains. However, EMCP only mediated the relationships related to personal strain, not familial/social impact. The unpredictable nature of epilepsy (particularly severe childhood epilepsy) is characterized by external and, to some extent, uncontrollable events such as daily seizures, frequent hospital visits, and emergency calls from the child’s institutional setting or when out on visits with family or friends. Daily uncertainty influences long-term decisions as well. Planning for future activities and events such as vacations, school activities, social events, or job/educational-related changes is challenged by the daily care and the uncertainties related to illness prognosis.

These external unpredictable forces are actual events and are not merely related to a generalized belief regarding the degree to which one has personal control over important life events with options to act to maintain control. The events prevent families from engaging in social and leisure activities, regardless of which coping styles they use in the situation. The high risk of loss of self-control might be a specific aspect of childhood epilepsy compared to other childhood illnesses, and preventive interventions should include a specific awareness of this issue. However, studies on the effect of intervention approaches aimed at families with childhood epilepsy are still lacking [52–54].

Further research into how families could be helped in managing their experience of control loss would aid the development of intervention methods. Our study results indicate that generalized intervention methods might not be the optimal way to support all families. Individual characteristics of the caregivers should be considered alongside illness-specific factors in determining the support that is needed.

5. Limitations

Our response rate of 49% is somewhat low. Non-responders indicated that the emotional burden of dealing with the questionnaire and to complete the extensive survey were too demanding while hospitalized with their child. This might indicate that part of the more burdened parents did not enter the study. Thus, our results might underestimate the impact of severe childhood epilepsy.

We used parent-completed questionnaires to assess child difficulties as a proxy measure of sequelae to childhood epilepsy. When assessing a child’s maladaptive behavior in a clinical setting, it is recommended to have two respondents in different settings to assess the child’s behavior, as cross-informant consistency has shown to be somewhat low for the SDQ scale [42]. In our study, however, we were interested in how parents are impacted by their child’s behavior difficulties and not whether their behavior was of clinical concern. Furthermore, the parents provided the epilepsy-related data. These proxy-report data are likely to be more sensitive to subjective understandings; however, a pediatric neurologist reviewed the diagnostic information for any adaption needed to the current diagnostic criteria developed by the ILAE [44].

6. Conclusion

Individual caregiver psychological factors influence the degree to which the sequelae of epilepsy impacts family life and perceived stress in parents. Child behavioral difficulties predict how parents experience the level of control they have of their lives, which further affects parental coping responses. Caregiver psychological factors act as mediators between child behavioral difficulties and the impact on both parents and familial. Therefore, coping interventions for families with childhood epilepsy should direct awareness toward the life-control aspect, alongside illness-specific factors, to determine the support that is needed. This support should be aimed at maintaining parental resources and take into account the parents’ capacities to handle the child’s behavioral difficulties.

7. Note

We confirm that we have read the Journal’s position on issues in ethical publication and affirm that this report is consistent with those guidelines.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found at https://doi.org/10.1016/j.yebeh.2021.108224.

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