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Caregiving Burden and Parent–Child Quality of Life Outcomes in Neurodevelopmental Conditions: The Mediating Role of Behavioral Disengagement

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Abstract The aim of this study was to analyze the direct and indirect effects, via parents' behavioral disengagement coping, of caregiving burden on the quality of life (QL) of parents and their children with neurodevelopmental conditions. Self-completion questionnaires on the target variables were administered to a sample of 156 parents who had a child with a neurodevelopmental condition, namely epilepsy ($n = 65$) and cerebral palsy ($n = 91$). Structural equation modeling was used to test a mediation model and ascertain direct and indirect effects among study variables. Significant direct effects of caregiving burden on parents' and their children's QL were found. Additionally, caregiving burden had a significant indirect effect on parents' QL, via behavioral disengagement, but not on their children's QL. Finally, this model was found to be invariant across conditions and patients' age groups. Caregiving burden may be elected as a strategic intervention target to improve parent–child QL outcomes in neuropediatric settings. Parents should be encouraged to avoid or reduce behavioral disengagement coping in relation to their caregiving stress, and alternatively adopt active coping strategies that may positively affect their children's QL and impede or attenuate the deleterious effects of caregiving burden on their own QL.

Keywords Caregiving burden · Quality of life · Behavioral disengagement

Introduction

Caring for a child with a neurodevelopmental condition is a particularly challenging parenting situation, because the increased levels of caregiving stress may exert negative effects on parents' and their children's adaptation outcomes (Garner et al., 2011; Peer, 2011). Given the fact that coping strategies can facilitate or hinder positive family adaptation to caregiving stress (Lin, 2000), the examination of parents' coping behaviors, such as behavioral disengagement (e.g., giving up one's life goals and valued directions; refusing advance care planning), may be useful to improve our understanding of modifiable variables linking parent–child stressors and outcomes. In addition, empirical data on this topic will help inform effective interventions aimed at promoting the successful coping and adjustment of parents and their children with neurodevelopmental conditions.

Families and parents of children with chronic conditions are at greater risk for increased stress and decreased quality of life (QL) compared to families of typically developing children (Brehaut et al., 2004; Raina et al., 2005). Moreover, the risk for psychological problems, which, along with caregiving demands, are strong predictors of caregivers' psychological well-being (Raina et al., 2005), is exacerbated in children who have conditions that affect the central nervous system, especially seizure disorders, and in adolescents who have a long-term physical disability, such as cerebral palsy (CCD & CPACFH, 1993).

Within the "disability-stress-coping model", psychosocial stresses (such as caregiving burden) are hypothesized

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to influence adaptation outcomes in both direct and indirect ways, through intrapersonal, social-ecological and coping resources (Wallander et al., 1989). These coping strategies or responses are cognitions and behaviors that a person uses to reduce stress and/or to moderate its impact, and may fulfill two functions: a problem-focused function of directly solving the stressful event, and an emotion-focused function of relieving the tension aroused by the stressful event (Lazarus & Folkman, 1984). Caregiving burden is essentially characterized by an experience of overload that results from an imbalance of perceived demands and resources, which may ultimately lead to feelings of helplessness (Chou, 2000). For this reason, two additional premises of the stress-coping model are particularly noteworthy: first, that exposure to unsolvable problems is a threat, and second, that the selection of a coping strategy is influenced by the way an individual appraises the threatening situation (Lazarus & Folkman, 1984).

In the context of parenting children with disabilities, avoidant emotion-focused coping, involving wishful thinking, denial or avoidance, has been positively related to psychological maladjustment, such as depressive mood (Judge, 1998) and posttraumatic stress symptoms (Guðmundsdóttir, Guðmundsdóttir, & Elklit, 2006). In addition, emotion-focused coping style has been found to mediate the association between social stressors and stress outcomes in family caregivers of children with developmental disabilities (Peer, 2011). Nevertheless, the need for examining the associations between parents' coping tendencies and their global, multidimensional adaptation outcomes, such as QL, remains a substantial research gap. The distinction between problem-focused and emotion-focused coping, though important, does not account for the specificity of very different coping responses, which is overlooked due to the aggregation of coping "strategies" under the broadband notions of coping "styles" (Carver, Scheier, & Weintraub, 1989). The present research work focuses on a single coping strategy, namely behavioral disengagement, in order to further inspect a specific avoidant coping behavior that has been distinctively linked to depression, helplessness and powerlessness in different populations (Burker et al., 2005; Taft et al., 2007).

Behavioral disengagement is a coping tendency characterized by reducing one's efforts to deal with the stressor, or even quitting the attempts to achieve goals with which the stressor is interfering. From a theoretical stance, behavioral disengagement is an avoidant emotion-focused coping strategy (Lazarus & Folkman, 1984) that tends to occur when people anticipate poor coping outcomes and is thus linked to the psychological concept of "helplessness" (Carver et al., 1989). According to "learned helplessness theory" (Abramson, Seligman, & Teasdale, 1978), family caregivers' maladjustment could result from a perceived absence of control over the outcome of caring for a child with a chronic condition. In stressful caregiving situations, in which goal attainment is difficult, it is expected that goal disengagement will not be the first coping response; instead, reflective appraisal of the stressful event will most likely be the first response to unexpected difficulties, which may ultimately lead to the achievement of the desired goal. This is to say that, in these situations, persistence is more adaptive than disengagement.

In order to obtain a broad clinical depiction of neurodevelopmental conditions, epilepsy and cerebral palsy were elected for the present study, because of their large prevalences in neuropediatrics; along with spina bifida, which was not included in this study, they may be considered representative of conditions that are defined primarily by a dysfunction in the central nervous system (Nassau & Drotar, 1997). The current study was theoretically grounded on the "disability stress-coping-model" (Wallander et al., 1989), while incorporating a parent–child perspective to pediatric stress-coping processes (Carona, Crespo, & Canavarro, 2013). Specifically, the study was aimed at analyzing the direct and indirect effects (via parents' behavioral disengagement coping) of caregiving burden on the QL outcomes of parents and their children with neurodevelopmental conditions. Accordingly, the following two hypotheses were devised: first, caregiving burden would be negatively related to parents' and their children's QL, and second, parents' behavioral disengagement would mediate the links between caregiving burden and parent–child QL outcomes. Finally, given our interest in examining a model that would apply to different neurodevelopmental conditions and to parent–child dyads of children with different ages, we further tested the model invariance across conditions (epilepsy vs. cerebral palsy) and age groups (children vs. adolescents); given the exploratory nature of these analyses, we made no specific predictions in that regard.

Methods

Participants and Setting

This study had a cross-sectional design. Using the non-probabilistic sampling method of convenience (i.e., participants are enrolled because of their availability or easy access), parents of children with epilepsy were recruited in the outpatient services of pediatric neurology of three Portuguese public hospitals and parents of children with cerebral palsy were recruited in ten Portuguese Cerebral Palsy Associations, between March 2009 and July 2011. The study was approved by the Ethics Committees and Direction Boards of both hospitals and cerebral palsy Associations. Parents of children with neurodevelopmental conditions were included in the sample if they met the following criteria: (1) having a child aged between 8 and 18 years-old, with a diagnosis of epilepsy or cerebral palsy established by a physician, and with no comorbidities with intellectual disability, other chronic health conditions or severe psychiatric disorders; (2) being the parent who, at the time of assessment, assumed the primary role in providing informal health care to the child/adolescent. The study's aims and procedures were explained in detail and written consent forms were obtained. Parents who agreed to participate completed the assessment protocol in an assigned office at the health institution their child attended, and with assistance from a trained researcher. Despite the fact that response rate was not ascertained for the epilepsy sample, 161 parents of children with cerebral palsy were initially assigned to participate in the study in agreement with the aforementioned inclusion criteria. Subsequently, 70 cases were eliminated for a variety of reasons: 7 refused to participate; 47 cases did not visit the institutions during the established period for assessment protocol administration; 2 cases were related to children living in foster care; and 14 cases did not complete all the intended measures.

Variables and Measures

Caregiving Burden

Caregiving burden was assessed as a latent variable comprising three subscales—Relationship Burden, Objective Burden and Subjective Burden—from the Portuguese version of The Revised Burden Measure (Montgomery & Kosloski, 2006). The Relationship Burden scale (5 items) measures the parents' perceptions of their children's behavior as overly demanding [e.g., "Have your caregiving responsibilities caused conflicts with your relative (child with a disability)?"]; the Objective Burden scale (6 items) measures the impact of caregiving activities on parents' free time (e.g., "Have your caregiving responsibilities decreased time you have for yourself?"); and the Subjective Burden Scale (5 items) assesses the negative affect that results from caregiving (e.g., "Have your caregiving responsibilities created a feeling of hopelessness?"). All items were answered using a 5-point Likert scale, with higher scores representing greater caregiving burden. Although originally developed for geriatric caregivers, the Portuguese version of this measure, for which psychometric studies are currently in progress, has been successfully applied to pediatric populations (Carona et al., 2013; Crespo, Carona, Silva, Canavarro, Dattilio, 2011).

Behavioral Disengagement

The behavioral disengagement coping strategy was assessed using the abbreviated Portuguese version of the COPE Inventory (Carver, 1997). This subscale includes two items measuring the extent to which parents reduce efforts to deal with stressful events as a general coping tendency. The two items (i.e., "I give up the attempt to get what I want"; "I just give up trying to reach my goal") were answered on a 4-point Likert scale, with higher scores indicating greater use of the coping strategy. The instrument has been adapted for the Portuguese population and demonstrated adequate levels of reliability and validity (Pais-Ribeiro & Rodrigues, 2004).

Quality of Life

Parent's QL was a latent variable composed of the Physical (7 items; e.g., "Do you have energy for your everyday life?"), Psychological (6 items; e.g., "How satisfied are you with yourself?") and Social Relationships (3 items; e.g., "How satisfied are you with your personal relationships?") subscales from the Portuguese brief version of the World Health Organization Quality of Life Assessment Questionnaire (WHOQOL-BREF). All items were answered with a 5-point Likert response scale, with higher scores indicating better QL. The Portuguese version of the instrument has been cross-culturally adapted according to the WHOQOL Group guidelines (WHOQOL Group, 1998), and demonstrated very good psychometric properties in terms of reliability and validity (Vaz-Serra et al., 2006).

Children/adolescents' QL was assessed by the parents, using the Portuguese proxy-report version of the KIDSCREEN-10 Index (Ravens-Sieberer et al., 2010; Gaspar & Matos, 2008). This questionnaire comprises 10 items, to be answered within a 5-point Likert scale, and provides a global index of subjective health and well-being. As a one-dimensional measure, it would be impractical to compose a latent variable of this construct with 10 items, because such procedure would greatly increase the number of estimating parameters, for which the sample size would then be markedly insufficient. Therefore, this global, unidimensional index was divided into two parcels, with five items randomly distributed each, in order to allow the respective latent variable to be computed (Little, Cunningham, Shahar, & Widaman, 2002). The Portuguese version of the KIDSCREEN-10 questionnaire exhibited adequate levels of reliability in previous studies with pediatric samples (Carona et al., 2013).

Statistical Methods

Statistical analyses were conducted with SPSS v.20.0 (SPSS Inc., Chicago, IL, USA). Missing data, which were random and less than 5 %, were handled by individual mean score substitution, except for socio-demographic and clinical variables. Descriptive statistics were calculated for socio-demographic and clinical variables and the homogeneity of sample characteristics between epilepsy and cerebral palsy groups was examined by independent-samples *t* tests (continuous variables) or χ^2 tests (categorical variables).

For all subscales, descriptive statistics were calculated and differences between clinical groups (epilepsy vs. cerebral palsy) on burden subscales and parents' QL dimensions were tested with multivariate analyses of variance (MANOVA) and on behavioral disengagement and children/adolescents' QL with univariate analyses of variance (ANOVAs). For these analyses, results were considered statistically significant at a *p* value lower than .05.

Structural equation modeling (SEM) was performed with analysis of moments structures (AMOS, v.20). The models' goodness of fit was assessed based on the maximum-likelihood χ^2 and on the main approximate goodness-of-fit indexes, namely the comparative fit index (CFI) and the root mean square error of approximation (RMSEA). A model was considered to have a good fit when CFI $\geq$.95 and RMSEA $\leq$.06 and an acceptable fit when CFI $\geq$.90 and RMSEA $<$.10 (Browne & Cudeck, 1993; Hu & Bentler, 1999). The reliability of observed and latent variables was respectively examined by using Cronbach's alpha values and composite reliability, as estimated from the squared sum of standardized factor loadings divided by the addition of squared sum of standardized factor loadings and error variance terms (Hair et al., 2010). The assessment of latent variables was preferred within the present research design as a suitable means of summarizing a number of variables in fewer factors, and facilitating the generalization of relationships between them (Bollen, 2002). The statistical significance of indirect effects was evaluated using bootstrap resampling procedures with 2,000 samples [95 % bias-corrected confidence interval (BC 95 % CI); Preacher & Hayes, 2008].

Multi-group analyses were conducted to test the invariance of the structural model between neurodevelopmental conditions (epilepsy vs. cerebral palsy) and age groups (children vs. adolescents). The χ^2 difference method ($\Delta\chi^2$) was used to compare the unconstrained model with a model in which factor loadings and structural weights were fixed to be equal across groups (Byrne, 2010). When using this procedure, the observation of non-significant differences between the unconstrained model and the structural weights model is indicative of the model's overall validity for the different groups under examination.

Results

Table 1 presents the socio-demographic and clinical characterization of participants. No significant differences between the epilepsy and cerebral palsy groups were found for parents' or children/adolescents' socio-demographic characteristics.

In order to test between-group differences among the study's main variables, a series of MANOVA and ANOVA was conducted. The MANOVAs detected no significant differences between epilepsy and cerebral palsy groups on caregiving burden, Wilks' Lambda = .97, $F(3, 152) = 1.76$, $p = .16$, or parents' QL, Wilks' Lambda = .98, $F(3, 152) = 1.30$, $p = .28$. Results from univariate analyses for each subscale are displayed in Table 2. Likewise, no significant differences between conditions were found on behavioral disengagement or children/adolescent's QL (Table 2).

Prior to the examination of the hypothesized mediation model, a measurement model was tested to verify the multidimensionality of theoretical constructs. Thus, a confirmatory factor analysis testing the links between the latent variables (A—caregiving burden; B—behavioral disengagement; C—parents' QL; D—children/adolescents' QL) and their observed indicators was performed. The measurement model had very good fit, with $\chi^2(29) = 45.29, p = .03$; CFI = .97 and RMSEA = .06. All observed indicators loaded significantly on the respective latent variable, with standardized regression weights above the threshold of .50 (Table 3). The composite reliability for the latent variables was adequate and, except for behavioral disengagement, above .70 (Hair et al., 2010). The caregiving burden was positively correlated with behavioral disengagement and both were negatively correlated with parents' and their children's QL (Table 3).

Subsequently, the structural model testing the direct and indirect effects, via behavioral disengagement, of caregiving burden on parents' and their children's QL was inspected (Fig. 1). The model had good fit, with $\chi^2(30) = 58.17$, $p = .002$; CFI = .95 and RMSEA = .08 and explained 68 % and 36 % of variability in parents' and children/adolescents' QL, respectively. Significant direct effects of caregiving burden on parents' and their children's QL were found. Additionally, caregiving burden had a significant indirect effect on parents' QL, via behavioral disengagement ($\beta = -.22$, $p = .01$, BC 95 % CI -1.13 to $-.05$), but not on their children's QL ($\beta = -.10$, $p = .13$, BC 95 % CI $-.53$ to .02).

Finally, to test the invariance of the model between neurodevelopmental conditions (epilepsy vs. cerebral palsy) and age groups (children vs. adolescents), we performed multi-group analyses. There were no differences between the unconstrained model and the model in which the factor loadings and structural weights were fixed to be equal across conditions, with $\Delta\chi^2(5) = 6.38$, $p = .27$, and across age groups, with $\Delta\chi^2(5) = 10.52$, $p = .06$, confirming that the model was valid for both clinical and developmental groups.

Table 1 Descriptive statistics for socio-demographic and clinical variables of the epilepsy and cerebral palsy groups

	Epilepsy ($n = 65$)	Cerebral Palsy ($n = 91$)	Differences between samples
Parents' socio-demographic characteristics			
Age, *M* (SD)	42.42 (7.20)	41.47 (6.26)	$t = .87$; $p = .38$
Gender, *n* (%)			
Male	8 (12.3 %)	8 (8.8 %)	$\chi^2 = .48$; $p = .49$
Female	57 (87.7 %)	82 (90.1 %)	
Missing	–	1 (1.1 %)	
Socioeconomic status[a], *n* (%)			
Low	42 (64.6 %)	56 (61.5 %)	$\chi^2 < .01$; $p = .98$
Medium–high	23 (35.4 %)	31 (34.1 %)	
Missing	–	4 (4.4 %)	
Children/adolescents' socio-demographic characteristics			
Age, *M* (SD)	12.52 (2.88)	12.07 (2.82)	$t = .99$; $p = .33$
Age group, *n* (%)			
Children 8–12	28 (43.1 %)	48 (52.7 %)	$\chi^2 = 1.59$; $p = .21$
Adolescent 13–18	37 (56.9 %)	42 (46.2 %)	
Missing	–	1 (1.1 %)	
Gender, *n* (%)			
Male	34 (52.3 %)	50 (54.9 %)	$\chi^2 = .11$; $p = .75$
Female	31 (47.7 %)	41 (45.1 %)	
Clinical characteristics			
Cerebral palsy type[b], *n* (%)			
Spastic unilateral	–	42 (46.2 %)	
Spastic bilateral		37 (40.7 %)	
Dyskinetic		2 (2.2 %)	
Distonic		2 (2.2 %)	
Ataxic		3 (3.3 %)	
Missing		5 (5.5 %)	
Severity[c]/levels of functioning[d], *n* (%)			
Not at all severe/level I	16 (24.6 %)	56 (61.5 %)	
A little severe/level II	16 (24.6 %)	12 (13.2 %)	
Somewhat severe/level III	17 (26.2 %)	12 (13.2 %)	
Moderately severe/level IV	12 (18.5 %)	7 (7.7 %)	
Quite severe/level V	2 (3.1 %)	2 (2.2 %)	
Very severe/–	1 (1.5 %)	–	
Extremely severe/–	0 (0 %)	–	
Missing	1 (1.5 %)	2 (2.2 %)	

[a] Socioeconomic status was determined using a classification system for the Portuguese context based on the parents' jobs and educational levels (Simões, 1994; unpublished Doctoral Dissertation)

[b] According to the classification proposed by the Surveillance of CP in Europe project (SCPE, 2000)

[c] The severity of epilepsy was classified by physicians into 7 levels, according to the Global Assessment of Severity of Epilepsy (GASE) Scale (Speechley et al., 2008)

[d] Levels of function in cerebral palsy were determined by physical therapists and classified into 5 levels, according to the Gross Motor Function Classification System (GMFCS)—Expanded and Revised (Palisano, Rosenbaum, Bartlett, & Livingston, 2007)

Discussion

The present study gathered promising evidence for the development of a specific stress-coping model that accounts for parent–child QL outcomes and may be applicable to different chronic conditions in the context of neurodevelopmental pediatrics. Caregiving burden was found to be moderately and negatively related to the QL of parents and their children with neurodevelopmental conditions, confirming the study's first hypothesis. This result

Table 2 Descriptive statistics and mean differences in caregiving burden dimensions, coping and QL outcomes between epilepsy and CP groups

	Epilepsy *M* (SD)	Cerebral Palsy *M* (SD)	$F_{(1,\ 154)}$	*p*	η_p^2 [a]
Caregiving burden					
Relationship burden	1.86 (.87)	1.77 (.80)	.47	.50	.003
Objective burden	2.10 (.90)	2.27 (.84)	1.41	.24	.009
Subjective burden	2.67 (1.02)	2.57 (.98)	.38	.54	.002
Behavioral disengagement	.59 (.67)	.40 (.67)	3.29	.07	.021
Parents' QL					
Physical	3.84 (.62)	3.92 (.89)	.58	.45	.004
Psychological	3.81 (.53)	3.75 (.61)	.40	.53	.003
Social	3.85 (.62)	3.78 (.69)	.48	.49	.003
Children/adolescents' QL	3.65 (.58)	3.67 (.62)	.04	.83	.000

[a] Partial Eta square reference values: $\eta_p^2 \geq .01$ = small effect size; $\eta_p^2 \geq .06$ = medium effect size; $\eta_p^2 \geq .14$ = large effect size

adds evidence for the assertion of parenting stress as an important determinant of parents' (Raina et al., 2005) and their children's QL (Carona et al. 2013), and highlights its pertinence in the context of neuropediatrics.

Caregiving burden was also found to be indirectly linked to parents' QL (but not to their children's QL), via behavioral disengagement coping, partially confirming the study's second hypothesis. This finding suggests that, for parents who have children with neurodevelopmental conditions, increased caregiving stress may impair coping processes and outcomes, by eliciting a greater use of behavioral disengagement coping strategies. Specifically, this means that the experience of caregiving burden and overload in this parenting context expectably triggers feelings of hopelessness and helplessness, which may then predispose these parents to disengage from their goals either related to parental caregiving or not. It is therefore expectable that such disengagement contributes to the deterioration of their QL perceptions, which essentially represents the individual's subjective perception of his/her position in life in relation to his/her goals, expectations, standards and concerns (The WHOQOL Group, 1998).

Concurrently, parents' behavioral disengagement coping was independently, though weakly related to their children's QL. There are two immediate implications of this finding: first, it suggests that caregiving burden may affect parents' and their children's QL through distinctive

Table 3 Pearson correlations, factor loadings and reliability for observed and latent variables

Variable	1	2	3	B	4	5	C	6	7	8	D	9	Factor loadings	Reliability
A. Caregiving burden				**.37****			**−.62****				**−.50****			**.77**
1. Relationship burden	–												.65**	.84
2. Objective burden	.54**	–											.72**	.87
3. Subjective burden	.51**	.56**	–										.81**	.87
B. Behavioral disengagement							**−.64****				**−.28****			**.62**
4. Item 1	.08	.19*	.21*		–								.73**	–
5. Item 2	.18*	.26**	.21**		.44**	–							.60**	–
C. Parents' QL											**.60****			**.81**
6. Physical	−.23**	−.40**	−.43**		−.41**	−.37**		–					.82**	.83
7. Psychological	−.29**	−.29**	−.50**		−.38**	−.30**		.68**	–				.84**	.79
8. Social	−.26**	−.22**	−.36**		−.28**	−.23**		.55**	.56**	–			.64**	.75
D. Children/adolescents' QL														**.88**
9. Parcel 1	−.25**	−.30**	−.38**		−.10	−.28**		.37**	.44**	.21**		–	.80**	.65
10. Parcel 2	−.24**	−.33**	−.42**		−.16	−.23**		.46**	.53**	.32**		.76**	.96**	.67

Inter-correlations and reliability for latent variables are shown in boldface

** $p \leq .01$; * $p \leq .05$, two-tailed

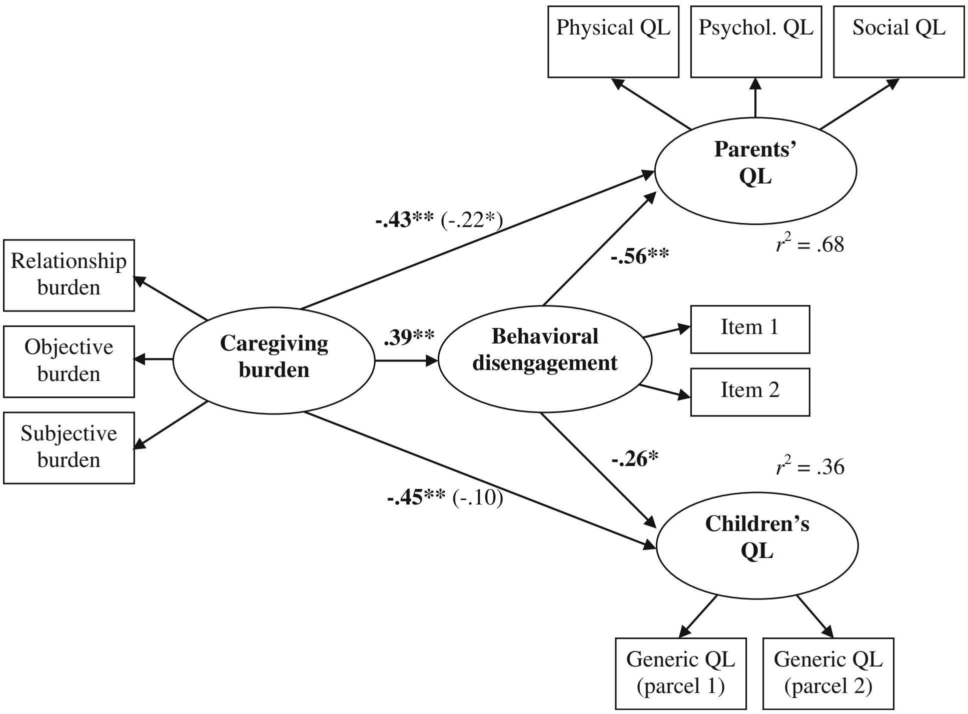

Fig. 1 Structural equation model testing the direct and indirect effects, via behavioral disengagement, of caregiving burden on parents' and their children's QL. Bold figures represent standardized regression weights for direct paths; non-bold figures in brackets represent standardized regression weights for indirect paths. For simplicity, measurement error terms are not shown.*$p \leq .05$; **$p \leq .01$

mediating pathways, which possibly include different variables or coping strategies; and second, given the fact that the QL of children/adolescents with chronic conditions is correlated with their parents' QL (Carona et al., 2013; Silva, Crespo, & Canavarro, 2013), it tentatively suggests that impairment in parents' QL due to parental maladaptive coping may ultimately affect the QL of their children with a neurodevelopmental condition. In fact, this result adds specific evidence for the general and understudied claim that altered coping in the parent may have serious deleterious effects on the child's psychosocial adjustment to living with a chronic condition (Duffy, 2011).

The final model drawn from this study revealed that, for parents, caregiving burden was directly and indirectly linked, through behavioral disengagement coping, to their QL; and that for children, parental burden and behavioral disengagement were independently, though significantly and negatively related to their QL. Within an exploratory level of analysis, preliminary evidence was found for the model applicability to different neurodevelopmental conditions. The observed model invariance across conditions is thus suggestive of its adequacy to portray common stress-coping-adaptation mechanisms, which may ultimately guide and facilitate psychosocial assessment and intervention routines in neuropediatric settings. Although our results further indicated the applicability of the model to pediatric patients of different age groups, namely school-aged children and adolescents, the observed model invariance was not unequivocal, and hence additional caution should be taken in assuming that result, mostly because such age differences tend to exist in the coping-adaptation patterns of these families (Lin, 2000).

The foremost implication of this study's findings is that caregiving burden should be regarded as a strategic intervention target by clinicians working in neuropediatric settings, in order to effectively promote parent–child adaptation outcomes. The inherent multidimensionality of caregiving burden calls for a differential assessment of parents or other family caregivers' needs, in order to tailor interventions accordingly (Chou, 2000). For example, developing effective time management, reframing the meaning of caregiving and arranging for positive parent–child interactions, are all different intervention strategies to distinctively and respectively target the objective, subjective or relationship burdens. This study's results also imply a complementary clinical guideline: the generalized use of behavioral disengagement coping by parents who have children with neurodevelopmental conditions should be avoided or reduced, in order to prevent or diminish the deleterious effects of caregiving burden on parents' QL, and to simultaneously promote positive QL outcomes in their children. Therefore, these parents should be encouraged to develop active coping efforts and to counteract behavioral tendencies that are related to helplessness, hopelessness and powerlessness. This could be best achieved through the implementation of behavioral activation procedures, which are essentially aimed at refocusing individuals on their goals and valued directions in life, by encouraging them to pursue meaningful activities that they have been avoiding or abandoning, while exploring the function of the underlying cognitive-behavioral processes, such as disengagement for instance (Veale, 2008).

Despite its contributions, this study encompasses a number of criticisms: first, its cross-sectional design impedes the positive establishment of directionality between variables, even if directional paths were hypothesized according to literature review; second, its sample size, though adequate, did not achieve the optimal dimension for the conduction of SEM multi-group comparisons; third, epilepsy type was not controlled in the study, even if there is some evidence for the distinctive role of seizure type on patients' QL (Baker, Gagnon, & McNulty, 1998); fourth, though standing as a common limitation in pediatric psychology research (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005), this study's sample of parents mainly included mothers, thus impeding the conduction of further analyses to ascertain model (in)variance for fathers and mothers; fifth, there was no common assessment of condition severity, which did not ultimately allow the adequate control of this variable in the analyses performed; and lastly, it solely relied on parents' reports on their children's QL, thus excluding children/adolescents' self-reports, which are to be equally valued in pediatric QL research. Future research on this topic should examine the proposed mediating pathways longitudinally and ascertain the differential mediating role of other specific coping strategies, such as self-blame or denial, in order to provide the most specific and effective guidelines to psychosocial interventions in family pediatrics.

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Human and Animal Rights and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation of the participating institutions (Portuguese Federation of Cerebral Palsy Associations; Leiria Santo Andre Hospital; Coimbra Pediatric Hospital; Coimbra University Hospitals) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all subjects for being included in the study.

Conflict of Interest Carlos Carona, Neuza Silva, Carla Crespo, and Maria Cristina Canavarro declare that they have no conflict of interest.

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