

Carona, C., Silva, N., Crespo, C., & Canavarro, M. C. (2014). Caregiving burden and parent-child quality of life outcomes in neurodevelopmental conditions: The mediating role of behavioral disengagement. *Journal of Clinical Psychology in Medical Settings, 21*, 320-328. doi: 10.1007/s10880-014-9412-5

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

Carlos Carona

Neuza Silva

Carla Crespo

Maria Cristina Canavarro

Faculty of Psychology and Education Sciences, The University of Coimbra.

Coimbra, Portugal

Correspondence concerning this article should be addressed to:

Carlos Carona

Cognitive Psychology Institute

Faculty of Psychology and Education Sciences of Coimbra University

Rua do Colégio Novo - Apartado 6153

3001-802 COIMBRA

E-mail: ccarona@fpce.uc.pt

Abstract

Aim. 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.

Method. 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 (SEM) was used to test a mediation model and ascertain direct and indirect effects among study variables.

Results. 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.

Conclusions. Caregiving burden may be elected as a strategic intervention target to improve parent-child QL outcomes in neuropsychiatric 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.

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, may be useful to improve our understanding of modifiable variables linking parent-child stressors and outcomes. In addition, empirical data on this topic will contribute to develop 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), if 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 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, emotion-focused coping, involving wishful thinking, denial or avoidance, has been positively related to depressive mood (Judge, 1998). Besides, 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, 2001). 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 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 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 neuropsychiatry (Ronen, Streiner, & Rosenbaum, 2003; Stanley, Blair, & Alberman, 2000). 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, parents of children with epilepsy were recruited in the outpatient services of pediatric neurology of three Portuguese public hospitals and parents of children with CP 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 CP 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 CP established by a physician, and with no comorbidities with 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 the health institution that their children attended, with the assistance of a trained researcher whenever necessary.

Variables and Measures

Caregiving burden

The 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; the Objective Burden scale (6 items)

measures the impact of caregiving activities on parents' free time; and the Subjective Burden Scale (5 items) assesses the negative affect that results from caregiving. All items were answered using a 5-point Likert scale, with higher scores representing greater caregiving burden.

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. The two items were answered in a 4-point Likert scale, with higher scores indicating greater use of the coping strategy.

Quality of Life

Parent's QL was a latent variable composed of the Physical (7 items), Psychological (6 items) and Social Relationships (3 items) subscales from the Portuguese brief version of the World Health Organization Quality of Life Assessment Questionnaire (WHOQOL-Bref). All items were answered within a 5-point Likert response scale, with higher scores indicating better QL.

Children/adolescents' QL was assessed by the parents, using the Portuguese proxy-report version of the KIDSCREEN-10 Index (Ravens-Sieberer et al., 2010). 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. This global index was divided into two parcels, with five items randomly distributed each, and a latent variable was computed.

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 CP groups was examined by independent-samples *t*-tests (continuous variables) or Chi-square tests (categorical variables).

For all subscales, descriptive statistics were calculated and differences between clinical groups (epilepsy vs. CP) 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).

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 statistical significance of indirect effects was evaluated using bootstrap resampling procedures with 2000 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. CP) and age groups (children vs. adolescents). The Chi-square 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).

Results

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

[Table_1_about_here]

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 CP 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).

[Table_2_about_here]

Previously 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 (caregiving burden, behavioral disengagement, parents' QL and

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).

[Table_3_about_here]

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 (Figure 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 ($\beta = -.22, p = .01, BC\ 95\% \text{ CI} = -1.13/-.05$), but not on their children's QL ($\beta = -.10, p = .13, BC\ 95\% \text{ CI} = -.53/.02$).

[Figure_1_about_here]

Finally, to test the invariance of the model between neurodevelopmental conditions (epilepsy vs. CP) 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.

Discussion

The present study is an original contribution 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 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 neuropsychiatry.

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 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 further 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 neuropsychiatric 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 neuropsychiatric 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; and third, 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.

Acknowledgements: Funding for this study was provided by the Portuguese Calouste Gulbenkian Foundation (Ref. 96783-AS), Institute of Cognitive Psychology, Vocational and Social Development of the University of Coimbra (PEst-OE/PSI/UI0192/2011) and Coimbra Cerebral Palsy Association. Neuza Silva and Carla Crespo were also supported by the Portuguese Foundation for Science and Technology [SFRH/BD/69885/2010 and SFRH/BPD/70063/2010].

References

1. Garner RE, Arim RG, Kohen, DE, et al. Parenting children with neurodevelopmental disorders and/or behaviour problems. *Child Care Health Dev* 2011; 39: 412-21.
2. Peer JW. Coping style as a mediator of stress perception for caregivers of children with developmental disabilities [dissertation]. [Detroit]: Wayne State University; 2011. 143 p.
3. Lin SL. Coping and adaptation in families of children with cerebral palsy. *Except Child* 2000; 66: 201-18.

- Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., ..., & Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: How does it compare with that of other Canadian caregivers?. *Pediatrics*, 114, e182 -e191. [doi: 10.1542/peds.114.2.e182](https://doi.org/10.1542/peds.114.2.e182)

4. Raina P, O'Donnell M, Rosenbaum P, et al.. The health and well-being of caregivers of children with cerebral palsy. *Pediatr* 2005; 115: 626-36.
5. Committee on Children with Disabilities, Committee on Psychosocial Aspects of Child and Family Health (CCD & CPACFH). Psychosocial risks of chronic health conditions in childhood and adolescence. *Pediatr* 1993; 92: 876-8.
6. Wallander JL, Varni JW, Babani L, Banis HT, Wilcox, KT. Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. *J Pediatr Psychol* 1989; 14: 157-73.
7. Lazarus RS, Folkman S. Stress, appraisal, and coping. New York: Springer; 1984.
8. Chou KR. Caregiver burden: A concept analysis. *J Pediatr Nurs* 2000; 15: 398-407.

9. Carona C, Crespo C, Canavarro MC. Similarities amid the difference: Caregiving burden and adaptation outcomes in dyads of parents and their children with and without cerebral palsy. *Res Dev Disabil* 2013; 34: 882-93.
10. Judge SL. Parental coping strategies and strengths in families of young children with disabilities. *Fam Relat* 1998; 47: 263-8.
11. Carver CS, Scheier MF, Weintraub JK (1989). Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol* 1989; 56: 267-83.
12. Burker EJ, Evon D, Loisel MM, Finkel J, Mill M. Planning helps, behavioral disengagement does not: coping and depression in the spouses of heart transplant candidates. *Clin Transplant* 2005; 19: 653-8.
13. Taft CT, Resick PA, Panuzio J, Vogt DS, Mechannic MB. Examining the Correlates of Engagement and Disengagement Coping Among Help-Seeking Battered Women. *Violence Vict* 2007; 22: 3-17.
14. Abramson LY, Seligman MEP, Teasdale J. Learned helplessness in humans: critique and reformulation. *J Abnorm Psychol* 1978; 87: 49-74.
15. Montgomery R, Kosloski K. The league of experienced family caregivers: Measure development. Milwaukee, WI: University of Wisconsin-Milwaukee; 2006.
16. Carver CS. You want to measure coping but your protocol's too long: Consider the Brief COPE. *Int J Behav Med* 1997; 4: 92-100.
17. WHOQOL Group. Development of World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med* 1998; 28: 551-558.
18. Ravens-Sieberer U, Erhart M, Rajmil L, et al. Reliability, construct and criterion validity of the KIDSCREEN-10 score: A short measure for children and adolescents' well-being and health-related quality of life. *Qual Life Res* 2010; 19: 1487-1500.

19. Browne M, Cudeck R. Alternative ways of assessing model fit. In: Bollen K, Long J, editors. Testing structural equation models. Newbury Park, CA: Sage; 1993. 136-62.
20. Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. Structural Equation Modeling 1999; 6: 1-55.
21. Hair JF, Black WC, Babin BJ, Anderson RE. Multivariate data analyses. 7th ed. New Jersey: Prentice Hall; 2010.
22. Preacher KJ, Hayes AF. Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. Behav Res Meth 2008; 40: 879-891.
23. Byrne BM. Structural equation modeling with AMOS: Basic concepts, applications, and programming. 2nd ed. New York: Routledge; 2010).
24. Surveillance of Cerebral Palsy in Europe (SCPE). Surveillance of cerebral palsy in Europe (SCPE): A collaboration of cerebral palsy surveys and registers. Dev Med Child Neurol 2000; 42: 816-824.
25. Speechley KN, Sang X, Levin S, et al. Assessing severity of epilepsy in children: Preliminary evidence of validity and reliability of a single-item scale. Epilepsy Behav 2008; 13: 337-342.
26. Palisano R, Rosenbaum P, Bartlett D, Livingston M. Gross motor function classification system – Expanded and revised. <http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf>, 2007. (Accessed in 10th July 2013).
27. Duffy LV. Parental coping and childhood epilepsy: the need for future research. J Neurosci Nurs 2011; 43: 29-35.

28. Veale D. Behavioural activation for depression. *Adv Psychiatr Treat* 2008; 14: 29-36.

Ronen, G. M., Streiner, D. L., & Rosenbaum, P. (2003). Health-related quality of life in childhood epilepsy: Moving beyond seizure control with minimal adverse effects. *Health and Quality of Life Outcomes*, 1, 36-46.

Stanley, F., Blair, E., & Alberman, E. (2000). *Cerebral palsies: Epidemiology and causal pathways*. London: Mac Keith Press.

Silva, Neuza; Crespo, Carla; Canavarro, Maria C. 2013. "Transactional paths between children and parents in pediatric asthma: Associations between family relationships and adaptation", *Journal of Child and Family Studies*, 0: 1 - 13.

Table 1. Descriptive statistics for socio-demographic and clinical variables of the epilepsy and CP groups.

	Epilepsy (n = 65)	Cerebral Palsy (n = 91)	Differences between samples
Parents' socio-demographic characteristics			
Age, <i>M (SD)</i>	42.42 (7.20)	41.47 (6.26)	$t = .87; p = .38$
Gender, <i>n (%)</i>			
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 , <i>n (%)</i>			
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, <i>M (SD)</i>	12.52 (2.88)	12.07 (2.82)	$t = .99; p = .33$
Age group, <i>n (%)</i>			
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, <i>n (%)</i>			
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 , <i>n</i> (%)		
Spastic unilateral		42 (46.2%)
Spastic bilateral		37 (40.7%)
Dyskinetic	-	2 (2.2%)
Distonic		2 (2.2%)
Ataxic		3 (3.3%)
<i>Missing</i>		5 (5.5%)
Severity ^c / Levels of functioning ^d , <i>n</i> (%)		
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%)	-
<i>Missing</i>	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 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 classified into 5 levels, according to the Gross Motor Function Classification System (GMFCS) – Expanded and Revised (Palisano, Rosenbaum, Bartlett, & Livingston, 2007).

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

	Epilepsy	Cerebral Palsy			
	<i>M (SD)</i>	<i>M (SD)</i>	<i>F</i> _(1, 154)	<i>p</i>	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.

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

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

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

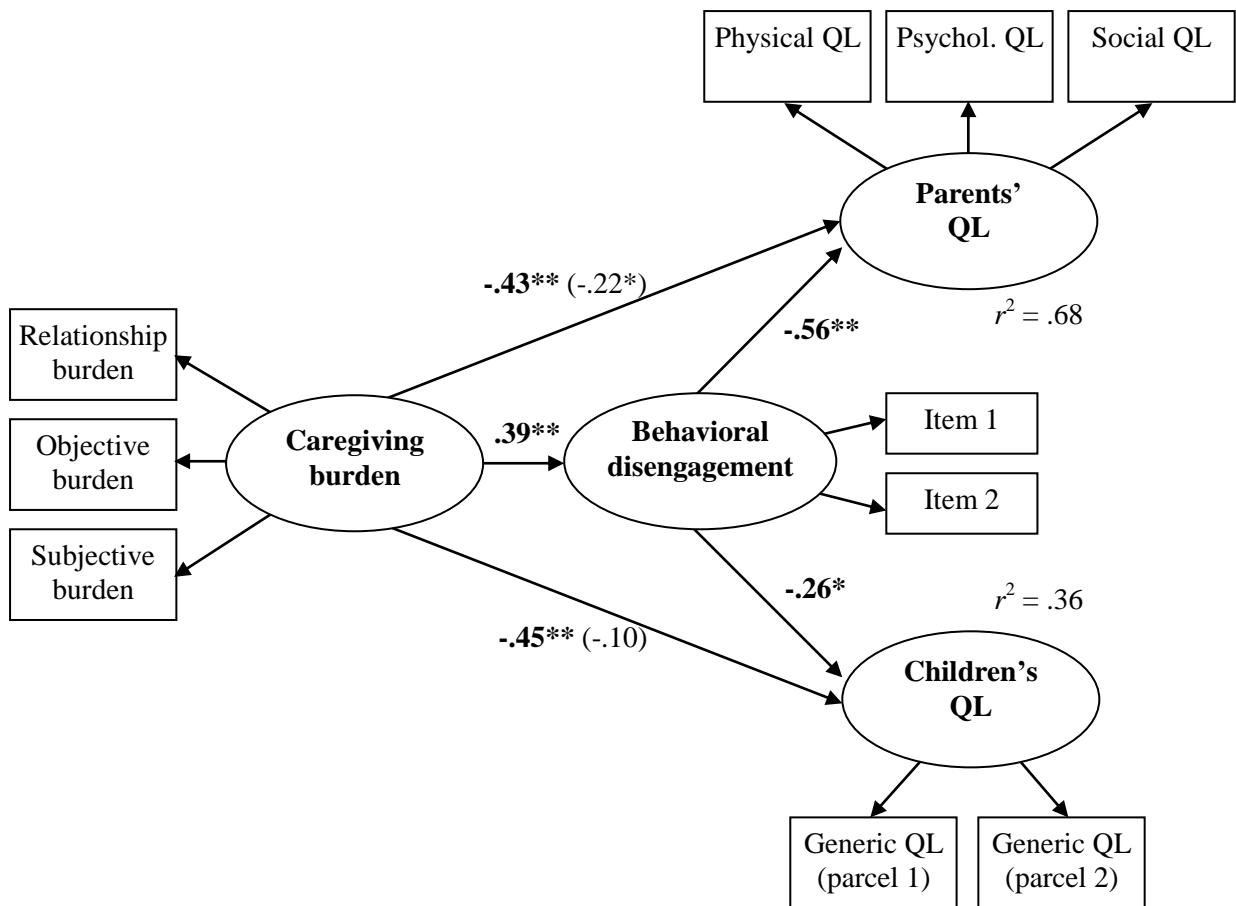


Figure 1. Structural equation model testing the direct and indirect effects, via behavioral disengagement, of caregiving burden on parents' and their children's QL. Bold figures represent standardized regression weights for direct paths; non-bold figures in brackets represent standardized regression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

* $p \leq .05$; ** $p \leq .01$.