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Similarities Amid the Difference:

Caregiving Burden and Adaptation Outcomes of Children and Adolescents with
Cerebral Palsy and their Parents

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Abstract

Objective. This study had two main objectives: first, to examine the direct and indirect effects, via social support, of caregiving burden on the adaptation outcomes of children/adolescents with cerebral palsy and their parents; and second, to assess the invariance of such models in the clinical vs. the healthy subsamples. **Methods.**

Participants were 210 dyads of children/adolescents and one of their parents (Total $N=420$), divided in 93 dyads of children/adolescents with cerebral palsy and 117 dyads of children/adolescents with no medical diagnosis. Data on caregiving burden, social support and adaptation outcomes were obtained through self-report questionnaires.

Results. Caregiving burden was linked to parents and their children's psychological maladjustment and quality of life both directly (except for children's quality of life) and indirectly through social support. Findings were invariant across clinical and healthy subsamples. **Conclusions.** Caregiving burden may influence adaptation outcomes of children/adolescents with CP and their parents both directly and via their social support perceptions. These patterns are similar to those observed in typically developing children/adolescents.

Keywords: family caregiving, cerebral palsy, social support, adaptation.

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Introduction

Cerebral palsy (CP) is a chronic condition of movement and posture due to non-progressive disturbances that occurred in the developing fetal or infant brain (Rosenbaum et al., 2005). Given its clinical variability and elevated prevalence, CP may be regarded as an interesting prototype of developmental disabilities (Raina et al., 2004).

Research conducted so far has shown that children and adolescents with CP and their parents are at increased risk for impaired quality of life (QL) and psychological maladjustment (Brehaut et al., 2004; Brossard-Racine et al., 2012; Varni et al., 2005). However, there is a paucity of data on the psychosocial factors influencing those outcomes (Livingston, Rosenbaum, Russell, & Palisano, 2007; Rentinck, Ketelaar, Jongmans, & Gorter, 2006), as well as on the comparability of adaptation patterns exhibited by these families and those with typically developing children/adolescents (Magill-Evans, Darrah, Pain, Adkins, & Kratochvil, 2001). Furthermore, the recommended assessment of both child and parent adaptation levels (Barlow & Ellard, 2006) has been rarely adopted, even if such contextual factors have been claimed to be important determinants for the QL of individuals with CP (Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007). The identification of potentially modifiable factors within a parent-child perspective is important to effectively promote more positive psychosocial outcomes and thus reduce the costs related to individual and family burden of disability and care. Complementarily, the examination of adaptation patterns in families with and without children with CP will help improving the clinical

understanding on commonalities and specificities underlying the psychosocial interventions to be developed.

Pediatric Family Caregiving as a Developmental Context

The theoretical framework of developmental psychopathology defines social context as the "...set of interpersonal conditions, relevant to a particular behavior or disorder and external to, but shaped and interpreted by, the individual child." (Boyce et al., 1998, p. 143). Family is the primary social context in which human development takes place (Bronfenbrenner, 1986). In pediatric psychology, the role of the family as a context for the understanding and treatment of chronic health conditions is well-established (Fiese & Sameroff, 1989). Specifically, the social-ecological model of adaptation and challenge in families of chronically ill children has argued for research and intervention practices based on the assessment of the child, parents and their social support network (Kazak, 1989). The caregiving context, in particular, is crucial when examining childhood behavioral development (Carter, Briggs-Gowan, & Davis, 2004), since the most influential aspects of social context are those directly related to children's core developmental needs (Boyce et al., 1998). In fact, a considerable amount of research has demonstrated a significant relationship between the quality of caregiving and a child's ability to adapt to adversity (Armstrong, Birnie-Lefcovitch, & Ungar, 2005).

Although caregiving is a normative component of parenting children and adolescents, the nature and amount of care required by a child with chronic limitations and possible long-term dependence, such as several cases of CP, are distinct (Raina et al., 2005). For some parents, the continuous provision of such care may become burdensome and have deleterious effects on their physical and psychological well-being (Raina et al., 2004). Following a parent-child perspective, it has been claimed that

parents' psychological distress significantly contributes to behavioral and emotional disturbance of chronically ill children (Canning, Harris, & Kelleher, 1996); moreover, it has been reported that when parents successfully manage stressors related to their child's condition, their children tend to experience better social functioning and less distress (Moos, 2002). The examination of models aimed at explaining how family processes influence the psychological adjustment of children with chronic health conditions, has been stated as a research priority for pediatric psychology in general (Drotar, 1997), and for CP in particular (McDermott et al., 1996). In addition, those studies also need to be conducted with models accounting for positive dimensions of adaptation (Barlow & Ellard, 2006), such as QL outcomes.

Family Caregiving, Social Support and Parent-Child Adaptation Outcomes

From a theoretical point of view, the influence of family environment, social support and parents' adjustment on the adaptation of children with chronic conditions has long been established in the disability-stress-coping model (Wallander, Varni, Babani, Banis, & Wilcox, 1989). These core premises were further developed in the transactional stress and coping model for chronic childhood illness, to encompass the mutual interplay between parental and child adaptation (Thompson, Gustafson, Hamlett, & Spock, 1992). In both theoretical formulations, caregiving context was operationalized with the inclusion of variables regarding illness stressors, social support and family functioning. More recently, the inclusion of multiple dimensions of family system functioning and broader contextual features, such as social support, has been recommended for the assessment of caregiving context (Carter, Briggs-Gowan, & Davis, 2004).

For the purpose of the present study, caregiving context was firstly operationalized through caregiving burden. This is a multidimensional construct

integrating negative mood alterations, changes in dyadic caregiver-care recipient relationships, and time infringements resulting from caregiving (Montgomery et al., 2006). Caregiving burden has been found to be a foremost predictor of the psychological maladjustment experienced by caregivers of children with chronic medical conditions (Canning, Harris, & Kelleher, 1996), and of the well-being of caregivers of children with CP in particular (Raina et al., 2005). Three pediatric studies, conducted in the context of pediatric CP, observed significant associations between parental stress and their children's behavioral adjustment (Brossard-Racine et al., 2012) and QL (Majnemer et al., 2007; Wiley & Renk, 2007). Interestingly, these studies mostly relied on parents' report on their children's behavior and well-being, so it remains to be ascertained if these associations will be verified when examining more complex models accounting for both parents and child's reports on adaptation.

Social support, defined here as the existence or availability of significant others to provide adequate help, care or company (Sarason, Levine, Basham, & Sarason, 1983), has been studied as a major determinant of adjustment in children with chronic physical conditions and their parents (Wallander & Varni, 1989, 1998). Within the social-ecological model, it has been commented that mother's positive perceptions of social support are related to more positive attitudes towards themselves and their children and to the provision of more adequate caregiving (Bronfenbrenner, 1986). Accordingly, increased social support was found to be associated with better individual well-being, more positive attitudes and more positive influences in parent-child interactions, for parents of children with disabilities (Dunst, Trivette, & Cross, 1986). For parents of children with CP, in particular, social support has been found to be positively related to parents' mental health (Rentinck et al., 2006).

An alternative and specific way of examining social support as a mediator between parenting stressors and outcomes in pediatric populations has been described by Quittner, Glueckauf, and Jackson (1990). The rationale for the mediator hypothesis was that the chronicity of parenting stress in pediatric health conditions could elicit more negative perceptions of support which, in turn, could increase psychological symptoms; in their study of mothers of children with a disability, the authors found evidence for this mediator effect of social support on the links between child/maternal stressors and mothers' psychological distress (Quittner et al., 1990).

When studying adaptation patterns across different populations (e.g. pediatric vs. healthy), it is important to bear in mind that specific family factors may be of differential importance in various conditions (Daniels, Moos, Billings, & Miller III, 1987). In fact, the invariance of adaptation patterns between families of children with and without CP remains an understudied topic (Britner, Morog, Pianta, & Marvin, 2003). In their study on the mediating role of social support between caregiver stressors and psychological distress, Quittner and colleagues (1990) verified that, although between-groups differences existed at the level of means comparison, the mediation model was valid for both clinical and control samples. A similar stability of associations between variables was reported in other pediatric studies: in one study, mother's higher adjustment and social support were related to better child adjustment in families of children with or without handicaps (Barakat & Linney, 1992); in another study, behavior problems and parenting stress significantly covaried across time in both families of typically developing and developmentally delayed children (Neece, Green, & Baker, 2012). Regarding children and adolescents in particular, Moos (2002) suggested that associations between life stressors, social resources and adaptation might be similar among ill, distressed and healthy youths. Nevertheless, despite the evidence

for a general association between risk and resistance factors and childhood adaptation, Daniels and colleagues (1987) noted that certain variables, such as burden of illness in family, were stronger predictors of adaptation for pediatric patients than for healthy individuals.

The Current Study

The present study was conducted to examine how caregiving burden is associated with parents and children's adaptation outcomes in normative and clinical parent-child samples. Five specific objectives were defined: first, to assess the associations between caregiving burden and parents (P) and children's (C) psychological maladjustment and QL; second, to examine the mediating effect of parents and children's social support on the links between caregiving burden and psychological adjustment and QL; third, to test if the mediation model was moderated by condition (CP vs. typically developing children), gender (boys vs. girls), and age group (children vs. adolescents).

Accordingly, four hypotheses were devised for our study:

- Hypothesis 1: Caregiving burden would be positively related to parents and children's psychological maladjustment and negatively related to their QL;
- Hypothesis 2: Caregiving burden would be negatively associated with parents and children's social support;
- Hypothesis 3: Social support would mediate the links between caregiving burden and the adaptation outcomes of both parents and their children;
- Hypothesis 4: Direct and indirect effects between caregiving burden and parent and child adaptation outcomes would be equivalent in clinical and normative subsamples. Finally, we also examined such model invariance for age and gender groups, but no specific predictions were made in that regard.

Method

Participants

Participants were 210 dyads of children/adolescents and one of their parents (Total $N= 420$), divided in 93 dyads with children/adolescents with CP and 117 dyads with healthy, able-bodied children/adolescents. Children /adolescents (53.8% boys) were between 8 and 18 years old ($M = 12.34$; $SD = 2.91$). Parents, mostly mothers (83.8%) and married (81%), were between 23 and 58 years old ($M = 42.34$; $SD = 5.72$). Descriptive results for both samples, group differences in socio-demographic characteristics, and clinical characteristics for CP sample are depicted in Table 1. Participants in CP and healthy samples only differed significantly in their socioeconomic status (SES): there was a higher percentage of dyads from high and medium SES in the healthy sample, and a higher percentage of dyads from low SES in the CP sample. Regarding the clinical sample, it is worth mentioning that more than half of the cases were related to milder forms of CP, including spastic subtypes (88.1%) with no limitations in walking (62.4%).

Measures

Caregiving burden.

The Revised Burden Measure. This self-report questionnaire included three subscales for different types of burden, namely: objective burden (e.g. “Have your caregiving responsibilities changed your routine?”), subjective burden (e.g. “Have your caregiving responsibilities created a feeling of hopelessness?”) and relationship burden (e.g. “Have your caregiving responsibilities caused conflicts with your relative?”) (Montgomery et al., 2006). Participants answered these questions on a 5-point scale (1 =

Not at all; 5 = A great deal). Those subscales were then combined into an overall score of caregiving burden.

Social Support.

Satisfaction with Social Support Scale. This instrument assesses adults' subjective appraisals on their satisfaction with social support obtained from significant others and activities (Pais-Ribeiro, 1999). The questionnaire comprises 15 items, which target four dimensions of satisfaction with SS: satisfaction with friends (e.g. "I am satisfied with the kind of friends I have"), intimacy (e.g. "When I need to let off steam, I can easily find someone to support me"), satisfaction with family (e.g. "I am satisfied about the way I get along with my family") and social activities ("I lack social activities that satisfy me"). A social support general score was computed, based on the responses provided within a 5-point scale (1 = *Totally disagree*; 5 = *Totally agree*).

Satisfaction with Social Support Scale for Children and Adolescents. This scale assesses satisfaction with social support based on children and adolescents' perceptions on their social experiences with parents, friends and social organizations (Gaspar et al., 2009). The instrument comprises two subscales: satisfaction with social support (e.g. "I am satisfied with the activities and things I do with my group of friends"), and activities connected to social support (e.g. "I would like to participate more in organised activities, such as sport clubs, scouts"). An overall score was calculated from the answers provided for each item within a five point Likert scale ranging from 1 (*Totally disagree*) to 5 (*Totally agree*).

Adaptation Outcomes.

Psychological maladjustment.

Mental Health Inventory – short form (MHI-5). The MHI-5 is a screening instrument aimed at the assessment of two general dimensions of mental health:

psychological distress and psychological well-being (Ware, Snow, Kosinski, & Gandek, 1993, *cit in* Pais-Ribeiro, 2001). The 3-item psychological distress subscale was used in this study to assess the frequency of anxiety and depressive symptoms (e.g. “How much of the time, during the past month, have you felt downhearted and blue?”; “How much of the time, during the past month, have you been a very nervous person?”), within a 6 point response scale ranging from 1 (*Never*) to 6 (*Always*).

Strengths and Difficulties Questionnaire (SDQ). The SDQ is a measure of psychological adjustment for children and adolescents (Goodman, 2001). The self-report version of SDQ was used in this study to assess psychological difficulties related to four main factors: emotional symptoms (e.g. “I worry a lot”), peer problems (e.g. “I get on better with adults than with people my own age”), conduct problems (e.g. “I get very angry and often lose my temper”) and hyperactivity-inattention (e.g. “I am constantly fidgeting or squirming”). For each one of the SDQ items, the respondent states his/her perception within a 3-point Likert scale: 0 (*Not true*); 1 (*Somewhat true*) and 2 (*Certainly true*). The computation of an overall score was performed in order to assess children/adolescents’ psychological maladjustment.

Quality of life.

The World Health Organization Quality of Life Assessment (WHOQOL) – 8-item index (EUROHIS-QOL). EUROHIS-QOL is a screening measure derived from the WHOQOL-100 and the WHOQOL-BREF instruments (Schmidt, Mühlan, & Power, 2005). This measure includes two items to assess each of four QL domains: physical (e.g. “Do you have enough energy for everyday life?”), psychological (e.g. “How satisfied are you with yourself?”), social (e.g. “How satisfied are you with your personal relationships?”) and environmental (e.g. “How satisfied are you with the conditions of your living place?”). Participants answered items on a 5-point response format ranging

from 1 (*Very poor/Very dissatisfied/Not at all/Never*) to 5 (*Very good/Very satisfied/Extremely/Completely*). The overall score was then obtained with the summation of those item scores.

KIDSCREEN-10.

The shortest version of Kidscreen questionnaires is a unidimensional measure of 10 items on physical (e.g. “Have you felt full of energy?”), psychological (e.g. “Have you felt sad?”) and social (e.g. “Have you had fun with your friends?”) aspects of children and adolescents’ QL (Gaspar & Matos, 2008; Ravens-Sieberer et al., 2010). The self-report form was used in the present study. Items of KIDSCREEN-10 were completed in a 5-point Likert scale, ranging from 1 (*Not at all/Never*) to 5 (*Extremely/Always*). An overall QL score was then derived from the summation of those item scores.

Procedures

The clinical sample for the present study was recruited in ten Portuguese Cerebral Palsy Associations between July 2010 and July 2011, after approval by the Direction Boards of those associations. Pediatric subjects were assigned to the study if they met the following criteria: (1) diagnosis of CP established by a physician; (2) age between 8 and 18 years old; (3) minimum intelligence quotient (IQ) of 70. For their parents, a single inclusion criterion was considered: being a primary family caregiver of the child/adolescent with CP. The control sample (i.e. typically developing children) was collected in two Portuguese public schools, between January and June 2010. Children/adolescents were included in this sample if they fulfilled two criteria: aged between 8 and 18 years old, and reporting no diagnosed chronic health condition. For their parents, a single inclusion criterion was considered: to be the parent who spent

more daily time with the child/adolescent. Informed consent forms were obtained from all parents and from children older than 13 years; informal assents were obtained from younger children.

Results

Descriptive and Zero-order Correlations

Descriptive statistics and correlations for all of the measures for both samples are presented in Table 2. Hypothesis 1 and 2 were partially supported. Caregiving burden was positively related to parents' psychological maladjustment and negatively related to their QL and social support. For children, parents' caregiving burden was associated with psychological maladjustment in the expected negative direction; however, there were no significant associations with QL and social support, except a marginally significant correlation between caregiving burden and social support for the CP sample.

Path Models: Testing Direct and Indirect Links between Caregiver Burden and Adaptation Outcomes

Two SEM path models were run with the whole sample testing the direct and indirect links between caregiving burden and adaptation outcomes via social support.

For Model 1, the specified outcomes were parents and children's psychological maladjustment, whereas for Model 2, the outcomes were parents and children's QL. Analysis of raw data with the maximum likelihood estimation method was used. After obtaining the results for the predicted models, we trimmed these models by removing non-significant paths, endorsing a model-generation application of SEM (Jöreskog, 1993, described in Kline, 2005).

In Model 1 (Figure 1 and Table 1), results demonstrated direct and indirect links, through social support, between caregiving burden and parents and children's psychological maladjustment. Results for Model 2 (Figure 2 and Table 2) showed that caregiving burden was associated with parents' QL directly and indirectly, also via social support. In this model, caregiving burden was associated with children's QL only indirectly via children's social support.

Finally, we ran several multi-group analyses for both models according for condition, gender and age group. Firstly, with regard to condition, we found that the differences between the unconstrained models and the structural weights models were non-significant for Model 1 ($\Delta\chi^2(6) = 7.97, p > .05$) and for Model 2 ($\Delta\chi^2(5) = 3.76, p > .05$), confirming that both models were valid for the healthy as well as for the CP samples. Secondly, regarding gender, the difference between the unconstrained and the structural weights model was non-significant for Model 1 ($\Delta\chi^2(6) = 5.50, p > .05$) and for Model 2 ($\Delta\chi^2(5) = 2.64, p > .05$). Finally, with regard to age group, the difference between the unconstrained and the structural weights model was non-significant for Model 1 ($\Delta\chi^2(6) = 11.91, p > .05$). A significant difference ($\Delta\chi^2(5) = 11.37, p = .05$) was found between the unconstrained and the structural weights model for Model 2. We then performed separate equality constraints for each of paths in the model and verified that the significant difference was located in the path linking caregiving burden to parents' QL: this specific standardized coefficient was only significant for the parents-adolescents' dyads ($\beta = -.25, p < .001$) and not for the parents-children's ($\beta = .01, p > .05$).

Discussion

Our main findings verified that parents' caregiving burden was associated with parents' and children's adaptation outcomes through their perceptions of social support. Furthermore, a similar pattern of associations was observed for parent-child dyads of both children/adolescents with CP and healthy, able-bodied children/adolescents. Since Drotar (1997) established a research agenda for the study of parent-child relationships in pediatric contexts, few studies addressed those questions for children/adolescents with CP and their parents. In addition, it was only recently that some authors claimed to have conducted the first assessment of health-related QL from the perspective of children with CP (Varni et al., 2005). To the best of our knowledge, in the area of pediatric CP, our study was the first to examine potential mechanisms through which caregiving burden may affect parent/child adaptation outcomes, while considering children's self-reports and a healthy sample to explore the invariance of those adaptation mechanisms.

Partially confirming this study's first two hypotheses, caregiving burden was significantly related to parents' psychological maladjustment, QL and social support and to children's psychological maladjustment only. These results are aligned with previous research reports (Brossard-Racine et al., 2012; Canning, Harris & Kelleher, 1996; Raina et al., 2005). The absence of a significant relationship between burden and children's QL somehow contradicts previous findings (Majnemer et al., 2007; Wiley & Renk, 2007), a result that might be due to the reduced size of the subsamples in our study. Our findings suggest that caregiving burden is an important determinant of adaptation outcomes for parents and their children with CP, though it may affect children/adolescents in a less pervasive way. This implies that burden assessment in future research should be conducted in relation to specific family member's outcomes

and also that interventions targeting caregiver's burden may positively influence parents and children's psychological adjustment and parents' QL.

Our third hypothesis aimed at testing the indirect effects of caregiving burden on parents and children's outcomes, through their perceptions of social support. This hypothesis was fully corroborated by our findings: social support perceived by children/adolescents and their parents mediated the links between caregiving burden and their psychological maladjustment and QL. These results add evidence to the already identified mediating effect of social support on the links between chronic caregiving stressors and parental adjustment (Quittner et al., 1990). Furthermore, the present study's results extend the relevance of such mediation model in that it may be applied, in addition to parents, to children's adaptation outcomes. The main implication of this finding is that interventions targeting caregiving burden in CP may possibly exert its influence on improved outcomes, via enhanced parent and child's perceptions of social support. Thus, in order to capture the effects of such interventions in the more global social context of children/adolescents with CP and their parents, the assessment of social support perceptions should be taken into account. In fact, caregiving burden was only linked to children's QL through their associations with social support. This particular finding suggests that, for children and adolescents, parents' caregiving burden may only influence specific outcomes when they are related to children/adolescents' perceptions of social support.

Finally, our last research hypothesis was confirmed, in that no differences emerged in the mediation model for the clinical and the healthy samples. This result substantiates the existence of a general association between risk and resistance factors and childhood adaptation (Daniels et al., 1987), and further extends the assertion that more similarities than differences may exist between families of children/adolescents

with CP and families with typically developing children/adolescents (Magill-Evans et al., 2001). Although such evidence is important to deconstruct negative expectations hold by society and health professionals towards families of people with disabilities (Green, 2007), in clinical practice, it should be borne in mind that important differences between adaptation variables may exist (Quittner et al., 1990) and that certain associations between them may matter distinctively for different groups (Daniels et al., 1987). Moreover, differences in these patterns of relationships seem most likely to differ during critical developmental transitions (Quittner et al., 1990), which were not considered in our study.

In this study, the analysis of the invariance of effects between groups was also performed based on gender and age subsamples. Since no gender differences emerged, this was indicative of the models' adequacy for both boys and girls. Regarding age groups (children vs. adolescents), the direct effect of burden on parents' QL was only significant for parent-adolescent dyads. It would be tentative to conjecture that such direct effect could only emerge in later stages of child's development, when an extension of burden over time would have a direct impact on the most global adaptation outcomes; alternatively, the demands of family reorganization during the transition to and the period of adolescence might explain why burden affects parents of teenagers in a significant direct way. However, to fully examine such hypotheses, longitudinal study designs would be required.

Limitations, strengths, and future directions

As recommended in a recent agenda for pediatric psychosocial research (Barlow & Ellard, 2006), this study had the merits of "hearing the voices of children" and including a parent-child perspective in the research approach to a pediatric group that has been notably understudied. Nevertheless, its cross-sectional design stands as its

major limitation: even with SEM techniques, which have been underutilized in pediatric psychology research (Nelson, Aylward, & Steele, 2008), a significant path coefficient remains a necessary but not a sufficient criterion to establish causality (King, King, Rosenbaum, & Goffin, 1999). Despite this major limitation, we endorse the importance of such cross-sectional studies in identifying promising relationships, which may be then further examined in longitudinal designs (Quittner et al., 1990). Our sample mainly included mothers (as primary caregivers) and milder forms of CP; hence, additional caution must be taken in generalizing the results here discussed. Finally, this study was conducted in a Portuguese context. The scales used in this study were all Portuguese validated versions of English original measures, except for the scales of social support, which were first developed in Portugal. Although we expect that similar results would be obtained in other Western countries, future research in other contexts is warranted, especially given that the CP sample in our study mainly came from a low-medium socio-economic background.

Future research should longitudinally examine the patterns of relationships that have gained some support from previous cross-sectional studies; it would be important to assess differences in the adaption patterns exhibited by families with children with CP versus families with typically developing children, during periods of critical developmental transitions, such as the child entering school or the transition to adolescence. In addition, although the role of a primary family caregiver is crucial, there are other relevant influences inside and outside the family (Armstrong et al., 2005), and thus the role of fathers, siblings and peers on children/adolescents' outcomes should be studied in greater depth.

Conclusion

These findings call for special consideration of a parent-child perspective when developing psychosocial interventions for children/adolescents with CP and their parents. In fact, they represent additional evidence for the clinical assumption that assessing and targeting core dimensions of an individual's context is an effective strategy for understanding and improving individual's adaptation outcomes. The observed results further highlight the importance of applying a more comprehensive approach to pediatric family caregiving context, thus encompassing child and parents' social support perceptions in the processes of assessment and intervention.

Complementarily, interventions targeting family caregiving burden in pediatric CP may represent promising cost-effective strategies, since they may presumably exert their beneficial effects on both parental and child levels. Finally, and perhaps most importantly, this study's findings add support for the clinical guideline that psychosocial interventions with these families should acknowledge general adaptational processes in the specific context of CP. Therefore, psychosocial interventions with these families should be more a matter of finding "similarities amid the difference", rather than assuming the fact of having a child with CP as an all-determining difference.

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Table 1. Socio-demographic and clinical characteristics of the sample.

	CP Sample		Healthy Controls Sample		Differences between Samples ⁴
	Children/Adolescents (N = 93)	Parents (N = 93)	Children/Adolescents (N = 117)	Parents (N = 117)	
Age (M/SD)	12.39 (2.83)	41.79 (6.32)	12.31 (2.97)	42.7 (5.18)	C/A: $t = -.20; p > .05$ P: $t = 1.21, p > .05$
Age Group (n/%)					
Children (8-12)	46 (49.5)		61 (52.1)		$\chi^2_{(1)} = .15; p > .05$
Adolescents (13-18)	47 (50.5)		56 (48.9)		
Gender (n/%)					C/A: $\chi^2_{(1)} = 1.22; p > .05$ P: $\chi^2_{(1)} = 1.82; p > .05$
Male	54 (58.1)	12 (12.5)	59 (50.4)	22 (18.8)	$\chi^2_{(1)} = 1.88; p > .05$
Female	39 (41.9)	84 (87.5)	58 (49.6)	95 (81.2)	
Marital status: married (n/%)	-	71 (76.3)	-	99 (84.6)	$\chi^2_{(1)} = 1.88; p > .05$
SES¹ (n/%)					
Low	56 (60.2)		31 (26.5)		$\chi^2_{(2)} = 27.12; p < .001$
Medium	23 (24.7)		64 (54.7)		
High	11 (11.8)		22 (18.8)		
Missing	3 (3.2)		-		
CP Type² (n/%)					
Spastic unilateral	47 (50.5)				
Spastic bilateral	35 (37.6)				
Dyskinetic	4 (4.4)				
Ataxic	2 (2.2)				
Missing	5 (5.3)				
GMFCS³ (n/%)					
I	58 (62.4)				
II	13 (14.0)				
III	10 (10.8)				
IV	7 (7.5)				
V	3 (3.2)				
Missing	2 (2.2)				

Notes.

¹ Socioeconomic status (SES) was determined using a classification system based on parents' job and educational level (Simões, 1994).

² Classification of CP subtypes according to the Surveillance of CP in Europe project (SCPE, 2000).

³ Levels of function according to the Gross Motor Function Classification System (GMFCS) – Expanded and Revised (Palisano, Rosenbaum, Bartlett, & Livingston, 2007).

⁴ Results of comparison tests for socio-demographic variables.

Table 2. Descriptive statistics and matrix of inter-correlations among study variables for parents and children/adolescents in CP (figures in bold font) and healthy samples (figures in non-bold font).

	Parents				Children/Adolescents			
	1	2	3	4	5	6	7	8
Parents								
1. Caregiving burden								
2. Social support	-.35** /.45**							
3. QL	-.39** /.25**	.47** /.48**						
4. Psychological maladjustment	.51** /.31**	-.45** /.45**	-.66** /.61**					
Children/Adolescents								
5. Social support	-.20 ~/.13	.26* /.14	.16 /.09	-.45** /.10				
6. QL	-.15 /.11	.17 /.24**	.21* /.06	-.23* /.17~	.54** /.51**			
7. Psychological maladjustment	.24* /.30**	-.22* /.25**	-.19 ~/.18~	.25* /.17~	-.42** /.53**	-.47** /.46**		
8. Age	.04 /.12	-.17 /.03	-.22* /.03	.20 ~/.22*	.09 /.04	-.12 /.35**	.07 /.09	
9. Gender	-.31** /.12	.19 ~/.08	.21* /.03	-.13 /.07	.00 /.15	.01 /.03	-.18 ~/.18~	-.16 /.05
Mean	2.18 /.72	3.61 /.3.67	3.63 /.3.78	2.79 /.2.33	3.56 /.3.89	4.02 /.4.09	.58 /.51	12.39 /.12.31
SD	1.97 /.72	.67 /.67	.52 /.51	1.17 /.94	.67 /.65	.57 /.55	.29 /.25	2.83 /.2.97
Cronbach's alpha	.90 /.94	.86 /.88	.79 /.82	.86 /.89	.76 /.81	.75 /.75	.77 /.75	-

Note. ** $p < .01$; * $p < .05$; ~ $p \leq .08$

Table 3. Unstandardized coefficients and standard errors (SE) for all parameters and bias-corrected (BC) bootstrap confidence intervals (CI) for indirect effects in Model 1.

Parameters	Unstandardized coefficients (SE)	<i>p</i>	BC Bootstrap 90% CI for Indirect effects
Direct effects			
<i>Within-participants</i>			
<i>Parents</i>			
Caregiving burden→ Social support (P)	-.38 (.06)	<.001	
Caregiving burden→ Psych. Maladjustment (P)	.42 (.09)	<.001	
Social support (P) → Psych. Maladjustment (P)	-.51 (.10)	<.001	
<i>Children</i>			
Social support (C)→ Psych. Maladjustment(C)	-.18 (.02)	<.001	
<i>Across-participants</i>			
Caregiving burden→ Social support (C)	-.18 (.06)	.01	
Caregiving burden→ Psych. Maladjustment (C)	.08 (.02)	<.001	
Indirect effects			
<i>Within-participants</i>			
Caregiving burden→ Psych. Maladjustment (P)	.19 (.06)	<.001	[.11, .30]
<i>Across-participants</i>			
Caregiving burden→ Psych. Maladjustment (C)	.03 (.01)	.01	[.02, .05]

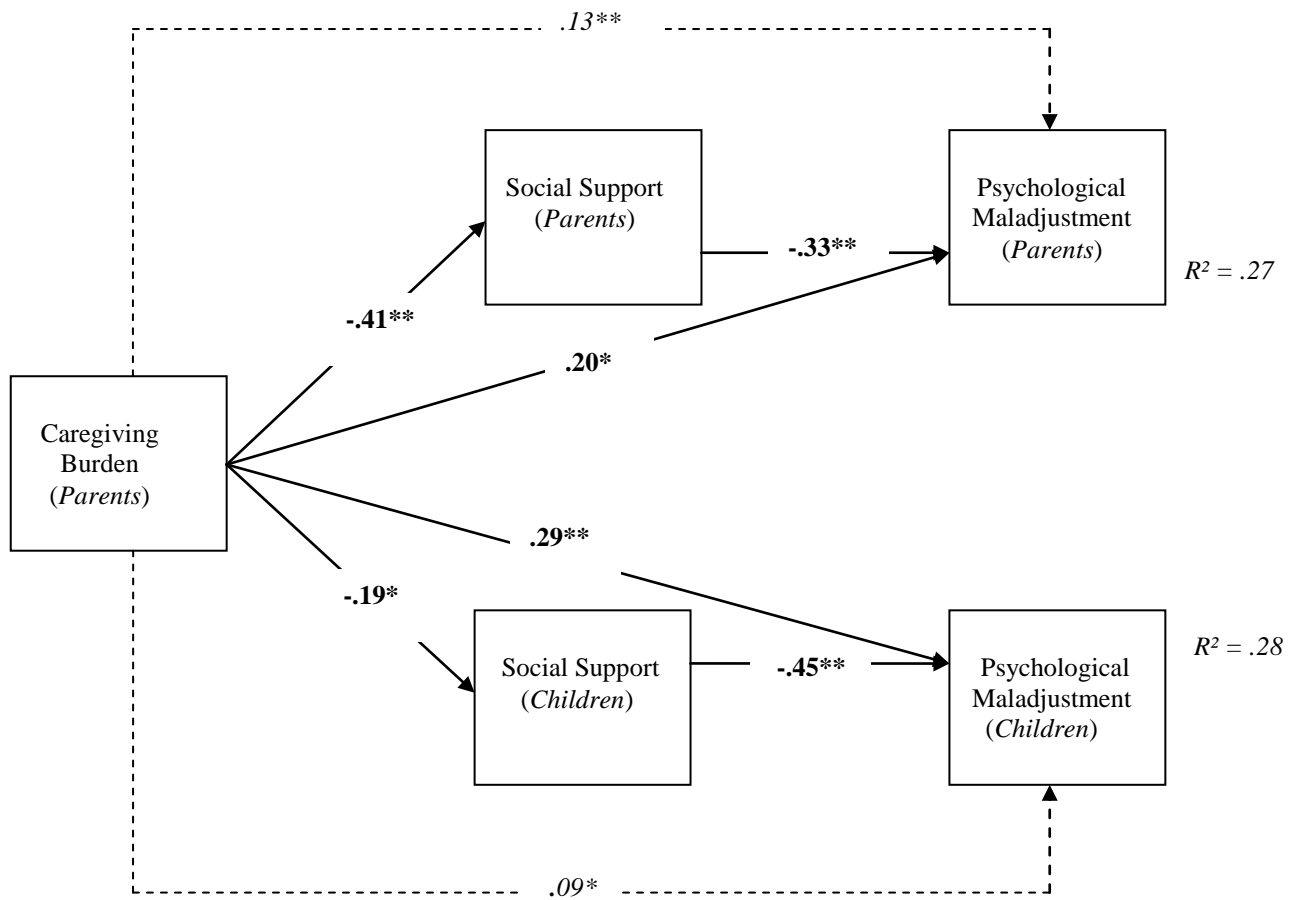


Figure 1. Model 1: Structural equation model testing the direct and indirect effects of caregiver burden on parents and children's psychological maladjustment via social support.

Note. Non-italic bold figures represent standardized coefficients for direct paths; italic figures represent standardized coefficients for indirect paths.. Fit indices for the model were: $\chi^2(2, N = 210) = 3.74$; $p > .05$; CFI = .99; RMSEA = .07. For simplicity, error terms are not shown; $** p \leq .001$; $* p \leq .01$.

Table 4. Unstandardized coefficients and standard errors (SE) for all parameters and bias-corrected (BC) bootstrap confidence intervals (CI) for indirect effects in Model 2.

Parameters	Unstandardized coefficients (SE)	<i>p</i>	BC Bootstrap 90% CI for Indirect effects
Direct effects			
<i>Within-participants</i>			
<i>Parents</i>			
Caregiving burden→ Social support (P)	-.38 (.06)	<.001	
Caregiving burden→ Quality of life (P)	-.12 (.05)	≤.01	
Social support (P) → Quality of life (P)	.32 (.05)	<.001	
<i>Children</i>			
Social support (C)→ Quality of life(C)	.43 (.05)	<.001	
<i>Across-participants</i>			
Caregiving burden→ Social support (C)	-.18 (.06)	≤.01	
Indirect effects			
<i>Within-participants</i>			
Caregiving burden→ Quality of life (P)	-.12 (.06)	.03	[-.24, -.09]
<i>Across-participants</i>			
Caregiving burden→ Quality of life (C)	-.08 (.01)	.03	[-.16, -.04]

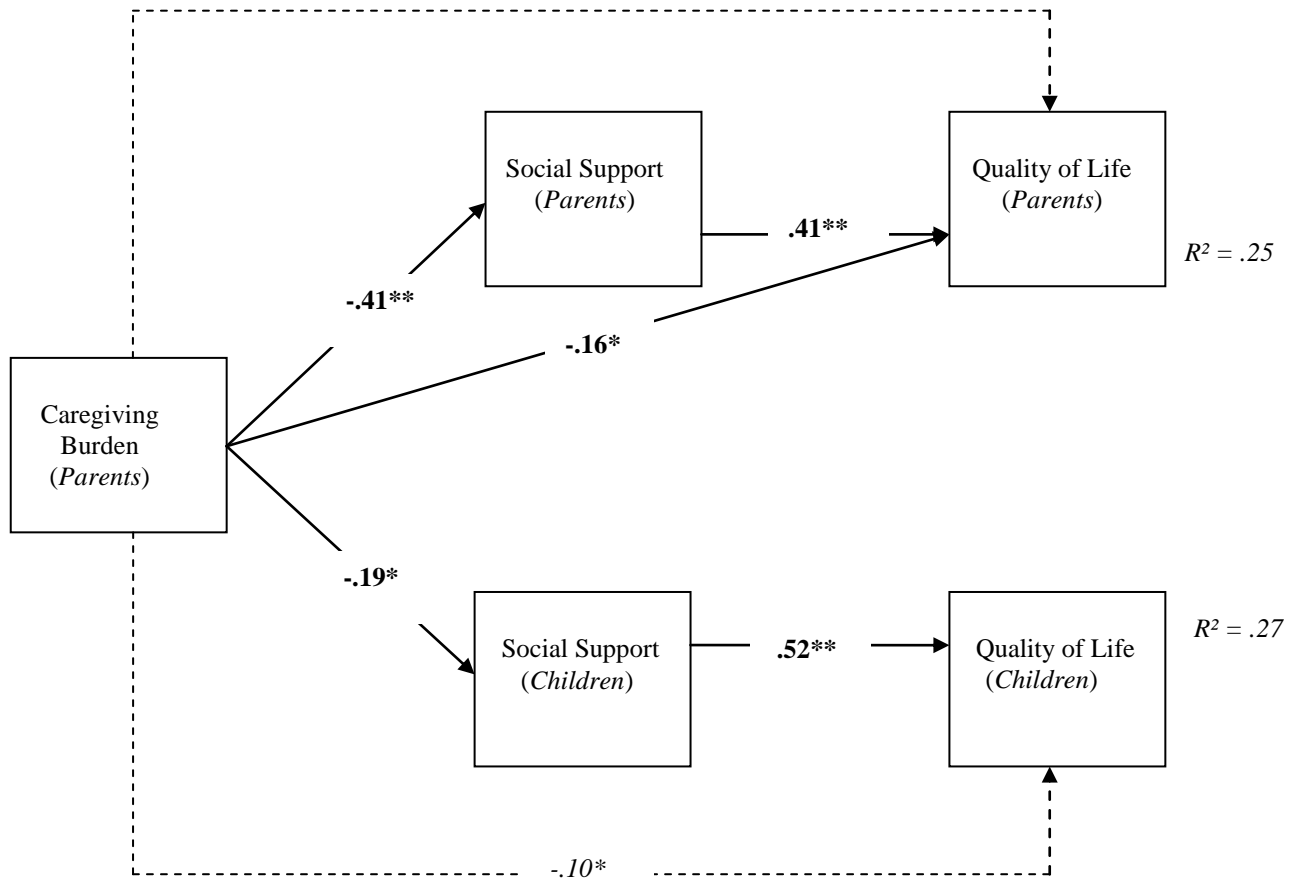


Figure 2. Model 2: Structural equation model testing the direct and indirect effects of caregiving burden and on parents and children's QL, via SS.

Note. Bold non-italic figures represent standardized coefficients for direct paths; figures in italic represent standardized coefficients for indirect paths. Bold figures represent standardized coefficients; non-bold figure represents Pearson correlation coefficient. Fit indices for the model were: $\chi^2(3, N = 210) = 3.97$; $p > .05$; CFI = .99; RMSEA = .04. For simplicity, error terms are not shown; ** $p \leq .001$; * $p \leq .01$.