



## Research paper

# Similarities amid the difference: Caregiving burden and adaptation outcomes in dyads of parents and their children with and without cerebral palsy

C. Carona\*, C. Crespo, M.C. Canavarro

*The University of Coimbra, Portugal*

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## ABSTRACT

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 clinical vs. healthy subsamples. 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. 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. 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.

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## 1. 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 underlined as 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

\* Corresponding author at: Institute of Cognitive Psychology, Vocational and Social Development, Faculty of Psychology and Education Sciences of Coimbra University, Rua do Colégio Novo-Apartado 6153, 3001-802 Coimbra, Portugal.

E-mail addresses: carona.carlos@gmail.com, ccarona@fpce.uc.pt (C. Carona).

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 improve the clinical understanding on commonalities and specificities underlying the psychosocial interventions to be developed. Therefore, the general aim of the present study was twofold: firstly, to examine the direct and indirect effects, via social support, of caregiving burden on the adaptation outcomes of children/adolescents with CP and their parents, and subsequently, to assess the (in)variance of the hypothesized parent–child adaptation mechanisms in clinical versus healthy subsamples.

### 1.1. Pediatric family caregiving as a developmental context

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 networks (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). Within 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, parents' successful management of illness-related stressors has been linked to better social functioning and less distress in their children (Moos, 2002). The examination of models that describe how family context may 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, more recently, the assessment of models that account for positive dimensions of adaptation, such as QL outcomes, has been equally recommended (Barlow & Ellard, 2006).

### 1.2. Caregiving burden, social support and parent–child adaptation outcomes

The influence of family environment, social support and parents' adjustment on the adaptation of children with chronic conditions has long been theoretically 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 defined by the inclusion of variables regarding illness stressors, social support and family functioning.

For the purpose of the present study, caregiving context was primarily 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 & Kosloski, 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 et al., 1996), and of the well-being of caregivers of children with CP in particular (Raina et al., 2005). Three pediatric studies, which were 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 different adaptation variables.

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 mothers' positive perceptions of social support are related to more positive attitudes toward themselves and their children, as well as to the provision of more adequate caregiving (Bronfenbrenner, 1986). Accordingly, for parents of children with disabilities, increased social support was found to be associated with better individual well-being, more positive attitudes and more positive influences in parent–child interactions (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

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