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The Disability Paradox Revisited:

Quality of Life and Family Caregiving in Pediatric Cerebral Palsy

Carlos Carona · Marco Pereira · Helena Moreira · Neuza Silva · Maria Cristina Canavarro

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C. Carona ✉

Cognitive Psychology Institute, Coimbra University · Coimbra Cerebral Palsy Association · Portuguese

Federation of Cerebral Palsy Associations

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

M. Pereira · H. Moreira · N. Silva · M. C. Canavarro

Cognitive Psychology Institute, Coimbra University, Coimbra, Portugal

Abstract

Parents who have children with cerebral palsy (CP) have been reported to have a more impaired QL and higher levels of burden than parents of typically developing children; however, little is known about the positive dimensions of their caregiving experience. In this study, WHOQOL-Bref and The Revised Burden Measure were administered to a sample of 105 parents of children/adolescents with CP (clinical group) and 117 parents of children/adolescents with no disabilities (control group). Despite the fact that parents of children with CP reported more Subjective Burden and less caregiving Uplifts, there were more similarities than differences in the variables compared between clinical and control groups. For parents of children with CP, the associations between Burden dimensions and QL, and between caregiving Uplifts and QL, were respectively moderate and weak. Caregiving Uplifts were found to moderate the links between Objective Burden and Psychological QL, and between Relationship Burden and Social QL. In addition, differential main effects of Burden dimensions and caregiving Uplifts were verified for Physical, Psychological and Social QL domains. These results highlight the adaptation variability of parents who have children with CP, as well as the importance of acknowledging caregiving uplifts as a resource that may attenuate the impact of burden on their QL.

Keywords: family caregiving; quality of life; cerebral palsy; burden; uplifts.

Introduction

The “disability paradox” was defined as the discrepancy between the objective limitations and suffering posed by certain disabilities, and the reasonable or excellent quality of life (QL) reported by some individuals living with them (Albrecht & Devlieger, 1999). In their attempt to explain why some individuals adapt well despite adverse health conditions, Albrecht and Devlieger suggested that, amidst a variety of factors related to positive outcomes, psychological growth and inner strength could provide a “balanced perspective on life” (p. 983), which in turn could maintain or improve QL for those individuals. Since considerable variability has been reported for adaptation outcomes of parents who have children with chronic health conditions or disabilities (King, King, Rosenbaum, & Goffin, 1999; Raina et al., 2004), the present study reveals a renewed interest in determining the extent of such variability, as well as in moving away from the simplistic cause-effect relationship between caregiving burden and parental maladjustment (Jones & Passey, 2004). A focus on parents as primary family caregivers of children with chronic conditions and disabilities, and the assumption of parental burdens as stressful caregiving circumstances, enables the redefinition of the so-called “disability paradox” as follows: “why do some of these parents report increased levels of caregiving burden, and still perceive a similar or superior QL, in comparison to those parents who care for healthy/able-bodied children?”

For the purpose of illustrating the assessment of this “disability paradox”, cerebral palsy (CP) was specifically elected for this study because of the heterogeneity of forms it may assume, along its significant prevalence and related caregiving burden, thus maintaining the assumption of CP as an interesting prototype of childhood disability (Raina et al., 2004). The core question implied by the redefined “disability paradox” has been put forward by different authors, who were interested in explaining why (or how) some parents adapt better than others to specific demands imposed by the responsibility of caring for a child with a chronic condition or disability. As regards pediatric CP in particular, it has been suggested that the way parents cope with increased caregiving demands, may have implications on their physical and psychological health (Brehaut et al., 2004). In this line of thought, coping is assumed here as a process of cognitive and behavioral efforts to manage demands related to stress (Lazarus, 1993), which may well encompass positive reappraisals as means for reframing a stressful situation in order to acknowledge its positive features (Folkman, 1997).

The reiterated recommendation for placing an emphasis on the understanding the ways that these parents cope, with varying adaptation outcomes, with the care of their child (Beresford, 1994; Eiser, 1990), is particularly important within the pediatric context for two main reasons: first, little is known about the factors

that may lead some parents to exhibit a pattern of resiliency (i.e. positive adaptation following or coexisting with adverse circumstances) (Ha, Hong, Seltzer, & Greenberg, 2008); second, such emphasis could improve the adequacy and specificity of current intervention practices, for which a scarceness of evidence-based literature has been acknowledged (Anderson & Davis, 2011). Additionally, research on this topic is urgently needed because the quality and amount of care provided by these parents to their children represents a significant reduction of public healthcare costs; however, deterioration of their QL may have serious negative consequences such as decreased work productivity, increased healthcare costs for the caregiver, and impairment of their child's adjustment (Davis et al., 2010; Hatzmann, Maurice-Stam, Heymans, & Grootenhuis, 2009).

There were several reasons for our interest in revisiting the notion of “disability paradox”: first, the idea that a pediatric chronic condition not only affects the child/adolescent who has it, but also other family members, particularly their parents (Kazak, 1989); second, the well-established occurrence of considerable heterogeneity in parental adaptation, which challenges the potential of approaching parental stress in those situations from an exclusive deficit model perspective (Yau & Li-Tsang, 1999); third, the possibility of different types of burden and benefit finding coexisting in the subjective experience of raising a child with a chronic condition or disability (Green, 2007); finally, notwithstanding the acknowledged value of a non-categorical approach to illness/disability adaptation processes (Wallander, Pitt, & Mellins, 1990), differences in parental stress and the corresponding professional help are likely to exist across a variety of medical diagnoses, including CP (Wang & Jong, 2004).

In their original article, besides presenting a sharp description of the “disability paradox”, Albrecht and Devlieger (1999) further explained the existence of such paradox in two forms: on the one hand, the discrepancy between serious self-reported limitations and daily adverse experiences, and the good or excellent QL perceived by people with disabilities or chronic health conditions; on the other hand, the divergence between the negativistic views hold by general public and health professionals about those peoples' daily existence, and the fact they report a good or excellent QL. These two forms may be delineated within the present notion of the “disability paradox revisited”: indeed many parents cope and adapt successfully to stressful pediatric caregiving demands (Yau & Li-Tsang, 1999), and health professionals may portray the same prejudices about disability/disease that are prevalent in society, thus labeling some families' positive discourse as unrealistic or confusing, and underscoring their adaptation levels (Green, 2007; Larson, 1998; Yau & Li-Tsang, 1999).

One of the possible mechanisms underlying the “disability paradox” has been termed in literature as “response shift”, describing “a change in the meaning of one’s self-evaluation of QL as result of changes in internal standards, values and the conceptualization of QL” (Sprangers & Schwartz, 1999, p.1509); “response shift” was described as a mediator of an individual adaptation process, while explaining the paradox of a stable self-reported QL in face of life-threatening diseases or disabilities. In order to further conceptually map our study on the “disability paradox revisited”, models deriving from stress-coping theory were preferred because of their central tenet stating that the ways people perceive, input meaning and cope with stress and adversity, differentially influence adaptation (Folkman, 1997). The “disability-stress-coping model” is one of such examples, and was developed to encompass the adjustment continuum experienced by families of chronically ill children (Wallander & Varni, 1998). In this model, risk factors (i.e. disease/disability parameters, functional dependence and psychosocial stressors) and resistance factors (i.e. intrapersonal and socio-ecological factors) are hypothesized to act in complex interplays to determine adaptation outcomes. Within this broad theoretical framework, positive meanings, benefits or uplifts attributed to caregiving process have been pointed out as personal resources linked to successful adaptation (Larson, 2010); complementarily, the emotions elicited by positive meaning finding have been suggested not only to result from certain coping strategies, but also to sustain coping process itself (Folkman, 1997). In fact, even if it seems rather consensual that caring for a child with a chronic condition or disability may become burdensome, high well-being, personal growth and uplifts may coexist and/or derive from challenging caregiving demands (Gupta & Singhal, 2004; Larson, 2010). A similar claim was underlined by Tedeschi and Calhoun (2004), when exploring a model for posttraumatic growth, defined as the occurrence of positive change resulting from struggling with challenging life crises; these authors sustained that such growth could coexist with significant psychological distress, thus suggesting the existence of a ramifying meaning attributed to stressful events.

Such “ramifying meanings” and “outcomes variability” have not been properly addressed, or at least demonstrated, in the research literature on pediatric family caregiving. The adoption of sensitive measurements of the whole range of adaptation (i.e. encompassing physical, mental and social functioning) (Wallander et al., 1990), led to a recent emergence of studies on the QL of parents who have children with chronic conditions or disabilities. These parents have been reported to be at risk for an impaired QL (Hatzmann et al., 2009), and to present a marginally poorer psychological well-being, compared to parents with healthy/non-disabled children (Ha et al., 2008). Furthermore, socioeconomic status (SES) has been observed to influence these parents’ coping and adaptation (Raina et al., 2004; Yau & Li-Tsang, 1999).

Pediatric family caregiving burden or stress has been typically studied as a risk factor within the “disability-stress-coping model”, even if its sources have rarely been described (Wallander & Marullo, 1997). Given the assumption that certain types of burden may differentially affect key outcomes, a multidimensional approach to burden has been argued (Savundranayagam, Montgomery, & Kosloski, 2011). Objective and emotional burdens of care have been commented to be particularly increased in these parents, with greater levels of stress related to child’s older age (Ha et al., 2008) and severity of impairments (Yau & Li-Tsang, 1999). In fact, it has been suggested that increased objective burden may be determined by socio-structural constraints related to caregiving (Green, 2007). Some authors found evidence for a negative association of burden (and not disability objective parameters) with psychological adjustment of mothers who cared for children with chronic physical conditions (Horton & Wallander, 2001); moreover, maternal stress was shown to be uniquely associated with maternal mental health, but not physical or social functioning, even when controlling for demographic and clinical variables (Wallander et al., 1990). Burden and caregiving stress have been hypothesized to influence parental QL via intrapsychic and coping factors (Raina et al., 2004), but research on the role of potential buffers or protective factors that may alleviate their impact is definitely lacking.

Although not abundant, research on burden has been conducted to a much larger extent than the one on positive dimensions of parents’ caregiving experience (such as personal growth, benefit finding and uplifts). Current studies indicate the possibility of growth for families of children with disabilities (Yau & Li-Tsang, 1999), and draw attention to mothers’ common perception of valuable benefits in having a child with a disability, despite of the strain imposed by objective burdens (Green, 2007). Indeed Gupta and Singhal (2004) found that positive perceptions were frequent in parents of children with disabilities, and included a variety of themes such as the child as a source of happiness; the child providing a challenge or opportunity to learn and develop; strengthened intimate relationships; increased personal strength and spirituality, and a changed, balanced perspective in life. Curious enough, most of these positive perceptions were coincident to the five domains of posttraumatic growth proposed by Tedeschi and Calhoun (2004). It has been suggested that finding benefits in the caregiving experience may have a positive impact on the caregiver’s emotional and physical health (Green, 2007), eventually through the promotion of psychological flexibility or the regulation of the deleterious physiological effects of stress (Gupta & Singhal, 2004), but most of these assertions remain untested for pediatric populations. However, although significant subjective burden tends to decrease the perceived benefits of caring (Green, 2007), pediatric family caregivers with high well-being have been reported to

generate positive emotions by using meaning-making reappraisals, such as the experience of personal growth, caregiving uplifts and benefit finding (Larson, 1998; 2010).

In order to improve the study of negative and positive dimensions of pediatric family caregiving, we considered worthwhile the integrated analysis of both variables within a risk-resilience framework (Wallander & Varni, 1998). In the scope of the broader concept of “adaptation”, resilience has been defined as a “dynamic process encompassing positive adaptation within the context of significant adversity” (Luthar, Cicchetti, & Becker, 2000). At this point, it is also noteworthy that despite the frequent interchangeable use of “adaptation” and “adjustment” terms, we endorse the distinction between “adaptation” as an overall process, and “adjustment” as a specific outcome (Thompson et al., 1994). From this standpoint, our literature review suggested that, in addition to burden, caregiving uplifts should be studied as QL predictors (Larson, 2010), and particularly as resources or protective factors (Gupta & Singhal, 2004). According to these perspectives, the role of caregiving uplifts could be examined in two analytical levels: first, as a single determinant of parents’ QL (i.e. a main effect), and second, as a moderator in the association between burden and QL (i.e. an interaction effect). Moderator variables affect the strength and/or direction of the relation between a predictor and an outcome, and their analysis became popular in the study of resilience in pediatric contexts (Rose, Holmbeck, Coakley, & Franks, 2004). If one assumes the experience of caregiving uplifts as a protective or resource factor, one will expect it to modify, ameliorate, or alter the impact of burden on parents’ QL (Armstrong, Birnie-Lefcovitch, & Ungar, 2005). For the present purpose, a further distinction is worthy to note: while a “protective factor” serves its protective role only in the context of adversity, a “resource factor” has a positive impact on the outcome regardless of the presence or absence of adverse conditions (Rose et al., 2004).

Research addressing the QL and caregiving experience of parents who have children with CP is scarce and mostly based on heterogeneous samples, which limits the conclusions that may be drawn about CP specifically (Britner et al., 2003). Moreover, the few studies directly addressing CP are characterized by negative approaches to family adaptation (Magill-Evans, Darrah, Pain, Adkins, & Kratochvil, 2001), unclear conceptual frameworks with no regard for resiliency (Lin, 2000), and an excessive focus on families of young children that largely ignores the adolescence period (Magill-Evans et al., 2001).

Results from studies on the adaptation outcomes of these parents are diverse: some studies found few differences in adaptation patterns (Britner, Morog, Pianta, & Marvin, 2003) and a similar life satisfaction (Magill-Evans et al., 2001), in comparison to parents of typically developing children; other studies observed

poorer mental health (Florian & Findler, 2001), and more psychological and physical health problems (Brehaut et al., 2004), in comparison to parents of children without physical disabilities and other family caregivers, respectively. Complementarily, a qualitative study adopting a grounded theory framework verified an impaired QL in all domains (i.e. physical, psychological and social) for parents caring for a child with CP (Davis et al., 2010).

Regarding the research on burden, it has been argued that higher levels of parental stress in CP do not necessarily equate to lower levels of adaptation (Rentinck, Ketelaar, Jongmans, & Gorter, 2006); nevertheless, caregiving demands were shown to strongly influence physical and psychological health of caregivers of children with CP (Raina et al., 2005). Increased stress and psychological risk have been reported for mothers of children with CP (Florian & Findler, 2001), and issues of relationship burden (i.e. child-related demands and behavior) have been suggested to significantly affect parental stress and well-being (Raina et al., 2005; Wang & Jong, 2004). The need for examining parental adaptation differences between child's age groups has been acknowledged (Florian & Findler, 2001), with the existing literature suggesting better adaptation in families with younger school-aged children, than in families with adolescents (Lin, 2000). For mothers of children with CP, child's older age and family economic conditions were related to increased maternal stress (Mobarak, Khan, Munir, Zaman, & McConachie, 2000). Although disability severity may be an important predictor of parental stress and mental health (Rentinck et al., 2006), it has been suggested that parents of higher functioning children may present higher levels of psychological burden, possibly derived from conflicting expectations (Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003); in another study, the interaction between child's level of impairment and partner support significantly predicted maternal stress (Button, Pianta, & Marvin, 2001). Finally, demonstrating a considerable research gap, we found no references on the study of personal growth, caregiving benefits or uplifts in parents of children with CP.

Our study adopted a balanced and multidimensional approach to the adaptation of parents who have children with CP, through the integration of both positive and negative dimensions of family caregiving, and the selection of multidimensional burden and QL measures. In order to succinctly illustrate the notion of the "disability paradox revisited", the objectives of our study were: (1) to characterize the QL and the caregiving Burden and Uplifts experienced by parents of children with CP, in comparison to parents of healthy/able-bodied children/adolescents; (2) to analyze the associations between caregiving Burden and Uplifts and the QL of those

parents, and (3) to assess the moderating role of caregiving Uplifts in the relationship between Burden dimensions and QL domains.

Accordingly, the following theoretically-driven hypotheses were outlined: first, parents of children with CP would report poorer physical, psychological and social QL, in comparison to parents of children with no chronic physical condition; second, parents of children with CP would present higher levels of Objective, Subjective and Relationship Burdens, and lower levels of caregiving Uplifts, in comparison to parents of children with no chronic physical condition; third, Burden dimensions and caregiving Uplifts would present moderate (negative and positive, respectively) correlations with all QL domains; fourth and last, caregiving Uplifts would moderate the associations between Burden dimensions and Psychological QL (i.e. parents with higher levels of Uplifts would report a better QL across different burden conditions, than those experiencing less caregiving Uplifts).

Method

Participants

The clinical group for this study ($N = 105$ parents of children/adolescents with CP) was collected in ten Portuguese Cerebral Palsy Associations (social institutions of tertiary health care) between July 2010 and July 2011. These parents were assigned to the study if they met the following criteria: (1) having a child aged between 8 and 18 years old, with a diagnosis of CP established by a physician, and a minimum intelligence quotient (IQ) of 70; (2) being the primary family caregiver of the child/adolescent with CP, as suggested by the largest amount of time dedicated to child's health issues and care. In those situations where informal health care was perceived as equally distributed between parents, the one who accompanied the child at the time of assessment protocol administration was included. Cases where results from formal assessments of child's IQ were not available ($n = 13$) were still included in the study, if their child did not present significant cognitive delay, as indicated by gross evaluation of the child's cognitive abilities, and the simultaneous absence of adaptations to school curricula. The inclusion criterion based on child's IQ was considered, because children/adolescents were to simultaneously participate in a parallel study where their self-reports were required. According to the aforementioned criteria, 161 parents of children/adolescents with CP were assigned to participate in the study; subsequently, the further exclusion of 56 parents was based on the following reasons:

seven refused to participate; forty-seven did not visit the institutions during the established period for data collection, and two cases were related to children living in foster care placement.

Parents for a group of controls ($N = 117$) were recruited in two public schools of Coimbra district, between January and June 2010, considering two inclusion criteria: (1) having a child aged between 8 and 18 years old with no chronic health condition or disability; (2) being the parent who spent more daily time with the child/adolescent. In order to achieve the intended sample size, a total of 124 parents were assigned to participate in the study (with no matching procedures), but seven were excluded afterwards: two parents refused to participate; four did not return the questionnaires, and one parent did not report on all the measures.

Measures

The World Health Organization Quality of Life Assessment – Brief Version (WHOQOL-BREF).

WHOQOL-BREF questionnaire comprises 26 items addressing four QL domains: Physical, Psychological, Social Relationships (henceforth: “Social” domain), and Environmental (Vaz-Serra et al., 2006). The Physical domain (e.g. “Do you have enough energy for everyday life?”) integrates the facets of pain and discomfort, energy and fatigue, sleep and rest, dependence on medication, mobility, activities of daily living, and working capacity; the Psychological domain (e.g. “How satisfied are you with yourself?”) assesses the facets of positive and negative feelings, self-esteem, thinking, learning, memory and concentration, body image, and spirituality, religion and personal beliefs; and lastly, the Social domain (e.g. “How satisfied are you with your personal relationships?”) comprises the facets of personal relationships, sex and social support. The subscale assessing the Environmental domain was not used in this work, because it was not aligned with our study’s specific aims; we also did not use the general QL facet, provided by two questions, because of its unacceptable internal consistency in the overall sample ($\alpha=.50$). WHOQOL-BREF items are to be answered within a 5-point scale ranging from 1 (*very poor/very dissatisfied/not at all/never*) to 5 (*very good/very satisfied/extremely/completely*); standardized scores (0-100) for each domain are then computed, with the lowest scores portraying the most impaired QL. Adequate internal consistency values were observed for our general and clinical samples: Physical ($\alpha=.82/.84$); Psychological ($\alpha=.81/.80$), and Social QL domain ($\alpha=.76/.76$).

The Revised Burden Measure. This self-report questionnaire includes distinct, but complementary burden and uplifts measures (Montgomery et al., 2006). Although originally developed for geriatric caregivers,

this measure has been successfully applied to pediatric populations (Crespo, Carona, Silva, Canavarro, & Dattilio, 2011). The instrument includes three burden subscales: Objective Burden (e.g. “Have your caregiving responsibilities left you with almost no time to relax?”); 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?”). Additionally, a measure of caregiving Uplifts is contained within the instrument (e.g. “Have your caregiving responsibilities given your life more meaning?”). Caregiving Uplifts represent a positive psychological state related with caregiving, and include such things as the direct enjoyment from caregiving tasks, an improved relationship with the child, and a generalized positive affect. Responses for all items are to be provided within a 5-point scale (1 = *Not at all*; 5 = *A great deal*), with scores ranging between 6 and 30 for Objective Burden and caregiving Uplifts, and between 5 and 25 for Subjective and Relationships burdens. Adequate internal consistency values were obtained in our general and clinical groups, for all subscales: Objective Burden ($\alpha=.82/.84$); Subjective Burden ($\alpha=.81/.80$), Relationship Burden ($\alpha=.76/76$) and caregiving Uplifts ($\alpha=.76/76$).

Procedure

After getting authorizations from the Direction Boards of participating Portuguese Cerebral Palsy Associations, cases that met the inclusion criteria were identified. Informed consents were then obtained from parents who agreed to participate in the study. During their visit to the institution, parents completed the questionnaires in a room provided for the purpose, with the permanent assistance of a psychologist or social worker acquainted with the research project.

Regarding the collection of control group, authorizations were obtained from the Direction Boards of participating schools. A sufficient number of classes were selected to reasonably achieve the intended sample size (nearly 100 participants). These classes were then visited by a researcher who delivered informed consents and assessment protocols to students, who in turn were expected to return them completed by their parents, nearly one week after.

Statistical Analysis

Statistical analyses were conducted with Statistical Package for the Social Sciences (SPSS, v.20). Missing data, as they were random and low level, were handled by individual mean score substitution, except for socio-demographic and clinical data. The clinical and control groups were characterized with descriptive statistics for socio-demographic and clinical variables, and the homogeneity of characteristics between clinical

and control groups was examined with comparison tests (independent samples *t*-tests and chi-squared tests, for continuous and categorical variables respectively). Reliability of the measures used in this study was assessed through the calculation of their Cronbach's alphas, which were then interpreted as indicators of acceptable ($\geq .70$) or optimal ($\geq .80$) internal consistency (Nunally & Bernstein, 1994).

Differences between conditions (parents of children/adolescents with CP vs. parents of children/adolescents without disabilities) and between age groups (parents of children vs. parents of adolescents) were tested with two multivariate analyses of covariance (two-way MANCOVA), one with the three QL domains and another one with the dimensions of caregiving Burden and Uplifts as dependent variables. These analyses were controlled for SES, by including it as covariate, since there was a significant discrepancy in this variable distribution between clinical and control groups. When multivariate effects were significant, univariate analyses were performed to examine which dimensions of QL and caregiving Burden or Uplifts significantly differed between groups. Effect-size measures (partial Eta squared) were presented for the comparison analyses, considering $\eta_p^2 \geq .01$; $\eta_p^2 \geq .06$; and $\eta_p^2 \geq .14$ as small, medium and large effects, respectively (Cohen, 1988).

In order to assess associations between variables, Pearson's correlation coefficients were computed, and their strength of association interpreted according to the following classification parameters: $\pm .10$ - $\pm .29$ (weak); $\pm .30$ - $\pm .49$ (moderate); $\pm .50$ - ± 1.0 (strong) (Cohen, 1988).

Moderation effects were examined with multiple regression analyses performed in SPSS. Prior to the conduction of moderation analyses, independent and moderator variables were mean centered for products calculation, and afterwards, covariates were entered in the first block, and interaction product terms in the last block of regression analyses. Following the identification of significant interaction effects, the simple slope procedure (i.e. creating three groups based on the mean levels of the moderator variable) was selected for probing possible moderator effects (Aiken & West, 1991). Post-hoc probing of interaction effects between two variables (one independent and one moderator) was necessary for specifying the conditions under which a predictor was significantly related to the outcome (i.e. whether either of the simple slopes was significantly different from zero) (Holmbeck, 2002). This procedure was optimized with the utilization of PROCESS (Hayes, 2012a), a computational tool that provides a SPSS macro for the examination of diverse statistical models that are numbered and analytically described in a command guide supplied for the effect (e.g. simple moderation is represented as "model 1"). These statistical procedures were sequentially used because we were interested in testing both main and interaction effects, and also in obtaining the sophisticated outputs delivered by

PROCESS, which facilitated the graphical depictions of significant interaction effects. For all the examined models, different covariates were introduced to statistically account for shared associations between variables (Hayes, 2012b) and thus explain additional variability in the outcome variables (MacKinnon & Luecken, 2008). These covariates were clinical and socio-demographic variables that were entered because of their significant associations with the outcome variables (Tabachnik & Fidell, 2007): child's age and function level (0 = *no mobility limitations*, 1 = *with mobility limitations*) were entered as covariates for analyses with the outcome variable of Physical QL; SES and child's age for Psychological QL, and child's age for Social QL. Effect sizes of main and interaction (moderating) effects derived from the regression analyses were based on the values of R^2 , which were then classified as small ($R^2 \geq .02$), medium ($R^2 \geq .13$) and large ($R^2 \geq .26$) (Cohen, 1992). A minimum confidence interval of 95% was considered for all the analyses performed in this study.

Results

Sample Characteristics

As presented in Table 1, the collected sample mainly included mothers (more than 80% of the cases), who were married (nearly 80% of the cases). Except for SES, no significant differences were observed for the socio-demographic variables between clinical and control groups. Data on children's variables, such as age group and gender, were homogeneously distributed across both samples. Regarding the clinical group, the majority of CP cases implied, were spastic forms ($\approx 89\%$), with no limitations in walking (63.8%).

Insert Table 1 about here

Differences in QL, Burden Dimensions and Caregiving Uplifts

Regarding QL, the two-way MANCOVA presented no significant multivariate effect of condition, indicating that there were no differences in QL between parents of children/adolescents with CP and the control group, Wilks' Lambda = .98, $F_{(3, 210)} = 1.75$, $p = .16$, $\eta_p^2 = .02$. Children's age had a significant multivariate effect on parents' QL, Wilks' Lambda = .93, $F_{(3, 210)} = 4.92$, $p < .01$, $\eta_p^2 = .07$, specifically on the Psychological domain, where parents of younger children presented better Psychological QL than parents of adolescents (see Table 2). No multivariate interaction effects of condition and age group were found on parents' QL, Wilks' Lambda = .97, $F_{(3, 210)} = 1.87$, $p = .14$, $\eta_p^2 = .03$. The two-way MANCOVA for the dimensions of Burden and caregiving Uplifts, indicated significant multivariate effects of condition, Wilks'

Lambda = .80, $F_{(4, 209)} = 12.96$, $p < .01$, $\eta_p^2 = .20$, and age group, Wilks' Lambda = .93, $F_{(4, 209)} = 3.67$, $p = .01$, $\eta_p^2 = .07$, as well as of the interaction between the two factors, Wilks' Lambda = .94, $F_{(4, 209)} = 3.36$, $p = .01$, $\eta_p^2 = .06$. The univariate analyses, presented in Table 2, showed that parents of children/adolescents with CP reported more Subjective Burden and less caregiving Uplifts than parents of children/adolescents without disabilities, and parents of younger children experienced more caregiving Uplifts than parents of adolescents. Univariate analyses for the interaction effects indicated that parents of adolescents with CP had more Objective Burden than parents of young children with CP, whereas for the control sample, parents of young children reported more Objective Burden than parents of adolescents.

Insert Table 2 about here

Correlations between Burden Dimensions, Caregiving Uplifts and QL Domains

Subjective Burden was observed to be moderately correlated with Physical and Social QL domains, and strongly correlated with Psychological QL. Weak to moderate associations were found between Relationship and Objective Burdens, and QL domains. Caregiving Uplifts were weakly correlated with QL domains, and had no significant associations with Burden dimensions (see Table 3). Given the fact that QL domains targeted different dimensions of the same construct, their inter-correlations were accordingly strong.

Insert Table 3 about here

Main and Interaction Effects of Burden Dimensions and Caregiving Uplifts on Parents' QL

Results from regression analyses examining main and interaction (moderating) effects of caregiving Burden and Uplifts on parents' QL are detailed in Table 4. No main or interaction effects were found for caregiving Uplifts on Physical QL, but Relationship ($b = -1.07$, $p < .01$), Objective ($b = -1.26$, $p < .001$) and Subjective ($b = -1.34$, $p < .001$) Burdens respectively explained 6.4%, 12.5% and 15% of the variance in this QL domain.

As graphically depicted in Figure 1, caregiving Uplifts were found to moderate the negative association between Objective Burden and Psychological QL, $F(5, 96) = 8.15$, $p < .001$, $R^2 = .30$, with those parents who acknowledged medium ($b = -0.82$, $t = -3.17$, $p < .01$) to high ($b = -1.34$, $t = -3.71$, $p < .001$) levels of Uplifts, reporting a less impaired QL than those experiencing low levels of Uplifts ($b = -0.29$, $t = -.90$, $p = .37$). This moderating effect of caregiving Uplifts was far more evident under low to medium Burden conditions, while

tending to decrease in situations of high Objective Burden. Caregiving Uplifts were also found to have a significant main effect on Psychological QL, along with Relationship Burden, $F(5, 96) = 8.36, p < .001, R^2 = .30$], and Subjective Burden, $F(5, 96) = 12.68, p < .001, R^2 = .40$.

As illustrated in Figure 2, a moderating effect of caregiving Uplifts was observed in the negative association between Relationship Burden and Social QL, $F(4, 101) = 5.91, p < .001, R^2 = .19$: parents who experienced medium levels of Uplifts, reported a less impaired QL under conditions of increased Relationship Burden ($b = -1.10, t = -2.74, p < .01$), when compared to those who experienced low levels of caregiving Uplifts ($b = -2.15, t = -3.32, p = .001$). Moreover, parents reporting high levels of caregiving Uplifts seemed to benefit from a relative stability in their Social QL across different levels of Relationship Burden ($b = -.05, t = -.08, p = .93$), when compared to parents reporting low to medium levels of Uplifts. In other words, the association between Relationship Burden and Social QL was significant only for individuals with low to medium levels of caregiving Uplifts. Finally, caregiving Uplifts were positively related to Social QL, along with Objective Burden, $F(4, 101) = 4.78, p < .001, R^2 = .16$, and Subjective Burden, $F(4, 101) = 5.12, p < .001, R^2 = .17$.

Insert Table 4 about here

Insert Figure 1 and Figure 2 about here

Discussion

The notion of the “disability paradox” (Albrecht & Devlieger, 1999) was revisited in this work within the context of pediatric family caregiving. This “disability paradox revisited” was then defined as the discrepancy between the burdensome caregiving experienced by parents who have children with chronic health conditions or disabilities, and the similar or superior QL levels reported by them, when compared with parents of healthy/able-bodied children. For the purpose of illustrating the “disability paradox revisited”, a study on the QL and the positive and negative caregiving dimensions was conducted within a sample of parents who had children with CP. The obtained results confirm the variability of adaptation outcomes in these parents, and highlight the importance of targeting positive and negative dimensions of family caregiving in psychotherapeutic or psychosocial interventions aimed at improving their QL.

Main findings of our study may be summarized as follows: first, QL differences emerged between age groups (i.e. parents of children vs. parents of adolescents), and not between health/function conditions (i.e. children with CP vs. typically developing children); second, parents of children with CP reported more Subjective Burden and less caregiving Uplifts than parents of children without disabilities; third, the QL of parents of children with CP was, in general, moderately associated with Burden dimensions, and weakly related to caregiving Uplifts; fourth, caregiving Uplifts moderated the associations between Objective Burden and Psychological QL, and between Relationship Burden and Social QL of those parents; additionally, there were significant main effects of different Burden dimensions on parents' QL, with main effects also observed for caregiving Uplifts, but only in relation to Psychological and Social QL.

In contrast with the majority studies included in our literature review, and contradicting our initial hypothesis, parents of children with CP in our study reported a similar QL to those parents of children with no disabilities. This contrasting result highlights the importance of challenging professional and societal pessimistic perceptions, which tend to underscore the adaptation potential of these parents and families (Yau & Li-Tsang, 1999). Furthermore, differences with medium magnitude in parental QL emerged between age groups for both parents caring for children with CP or typically developing children, with parents of adolescents reporting lower Psychological QL than parents of children. In fact, adolescence is a developmental period marked by certain tensions for parents and their children, which may increase child-rearing stress and negatively interfere with parents' well-being (Seginer, Vermulst, & Gerris, 2002). The most striking and straightforward insight from these results is the possibility of more similarities than differences existing between parents of children with CP and those of children without a physical disability (Magill-Evans et al., 2001).

In the same line of thought, our second hypothesis was partially confirmed: parents of children with CP reported increased Subjective Burden and decreased caregiving Uplifts. Although levels of Relationship and Objective Burden did not differ between clinical and control groups, apparently disputing previous findings (Raina et al., 2005; Wang & Jong, 2004), considerable prudence is to be taken in generalizing such results. Our clinical group mainly included cases related to high-functioning forms of CP, and excluded those cases with comorbid intellectual disability, though severity of child's impairments and communication competence have been linked to increased parental stress (Yau & Li-Tsang, 1999). Nevertheless, it is worthy to note that parents of higher functioning children with CP may indeed report higher levels of psychological burden than one would expect (Manuel et al., 2003). Those differences observed in our study for Subjective Burden depict a medium

effect and reiterate a need for caution in adopting simplistic “normalizing” attitudes in working with parents of children with CP, because in so doing, important intervention needs may be not properly screened and targeted. In our total sample and somehow consistent with the aforementioned results for Psychological QL, caregiving Uplifts were significantly lower in parents of adolescents than in parents of children, although such difference between age groups was smaller than the one between physical health conditions. Complementarily, while parents of children in control sample reported increased Objective burden than parents of adolescents, the opposite tendency was observed in our clinical sample, where parents of adolescents with CP reported higher Objective burden than parents of children with CP. This is to say that, despite most parents acknowledge childhood parenting as more enjoyable (even if more physically demanding), and adolescence parenting as more stressful (Seginer et al., 2002), such differences may assume distinctive features in the context of CP. During the adolescence period, the performance or achievement of certain developmental tasks related to family relationships, peers and autonomy may be more complicated for youths with CP, and his parents may gravely realize the stability of their child’s impairments, along with the probable occurrence of life-long challenges and the need for respective adjustments and caregiving (Lin, 2000; Magill-Evans et al., 2001). The fact of having a child with a disability may drive some parents to seek alternative meanings for their caregiving daily experiences, through positive reappraisals and benefit finding (Larson, 2010), but those positive appraisals tend to diminish during adolescence and the transition to adulthood (Lin, 2000). Additionally, cultural beliefs and prejudices about disability may be fostered within this context of seemingly increased vulnerability, and withdraw parents of children with CP from experiencing positive perceptions on their lives and parenting.

Despite the fact that moderate associations between caregiving variables and QL were conjectured in our third hypothesis, the obtained results were not that linear and depict a more complex and varied frame of correlations. Most of the associations between Burden types and QL domains were moderate, but Subjective Burden was strongly related to Psychological QL, and weak to moderate correlations were observed between Relationship Burden and QL domains. Complementarily, the strength of the association between caregiving Uplifts and parents’ QL was weak, and no significant association was verified between Burden dimensions and caregiving Uplifts. This latest result is particularly noteworthy since it suggests that relatively opposite, contradictory aspects of family caregiving do not necessarily correlate as negative or as stronger as one would intuitively predict. In fact, it has been commented that distress and psychological dysfunction may occur with positive experiences of personal growth (Joseph & Linley, 2006). An immediate implication of such assertion is that, even if burden dimensions and caregiving Uplifts do not portray different facets of the same construct, they

may indeed be assumed as plausible (and often simultaneous) reactions to the complex experience of caring for a child with a disability. Interestingly enough, the successful effort of these parents on integrating and finding a balance between positive and negative facets of their exceptional caregiving experience has been labeled as “the embrace of paradox” (Larson, 1998). The experience of such “paradox” is further discernible in our results: moderate correlations between Burden and QL constitute additional evidence for the risk of equaling caregiving stress to parents’ adaptation (Beresford, 1994; Rentinck et al., 2006). In addition, although significant and slightly in line with previous statements (Larson, 2010), associations between caregiving Uplifts and QL domains were weak. Thus, despite the influence caregiving Uplifts may have on these parents’ well-being, the experience of such positive perceptions should not be addressed as exclusive factors for the improvement of their QL. Finally, given the fact that the adopted measure for the assessment of Subjective Burden mainly included items on the experience of emotional stress, tension and anxiety, the stronger association observed between this Burden dimension and Psychological QL seems straightforwardly explicable.

Since moderation effects of caregiving Uplifts were found not only for Psychological QL, and not for all Burden dimensions, our fourth and last hypothesis was not confirmed. However, thought-provoking results did emerge: caregiving Uplifts were found to moderate the relationship between Objective Burden and Psychological QL, and between Relationship Burden and Social QL. It has been suggested that it is not caregiving workload (i.e. Objective Burden) per se that causes psychological distress, but rather the interpretation that caregivers attach to the caregiving activities (Savundranayagam et al., 2011). This claim partially explains our first moderation, where parents with medium and high levels of caregiving Uplifts reported a better Psychological QL than those with low caregiving Uplifts; nonetheless, such effect was most visible under low to medium Burden conditions, and notably tended to vanish in the condition of high Objective Burden. This is to say that although positive caregiving perceptions may buffer the impact of Objective Burden on psychological well-being (Gupta & Singhal, 2004), they are not a sufficient mean to prevent Psychological QL deterioration when parents are facing increased Objective Burden; in those situations, parents would benefit more from interventions targeting effective task sharing and time management than, for instance, from cognitive reframing techniques. In those situations where Objective Burden is low to medium, adjunctive interventions seeking to improve the experience of caregiving Uplifts may be valued to promote the best Psychological QL possible. In the second interaction effect observed in our study, caregiving Uplifts were found to moderate the association between Relationship Burden and Social QL, thus adding some evidence for their effects on this particular domain, besides on the physical and psychological ones (Green, 2007). In this moderation effect,

parents of children with CP who experienced high levels of caregiving Uplifts reported a better Social QL than parents experiencing low or medium levels of Uplifts, across all conditions of Burden intensity. Parents who experienced high levels of caregiving Uplifts seemed to benefit from a relative stability in their Social QL across different Burden conditions, in comparison to the other groups of parents, who experienced a stronger association between Burden increase and Social QL impairment. In practical terms, one may say that motivating, teaching and fostering the ability of parents of children with CP, to acknowledge and experience uplifts from their caregiving activity, may prevent them from the deleterious effects of Relationship Burden in their Social QL. In both moderations observed in our study, caregiving Uplifts influenced the strength (and not the direction) of the association between Burden and QL; moreover, caregiving Uplifts positively influenced QL outcomes, regardless of the presence of adversity (i.e. across all Burden conditions). According to Rose et al. (2004), caregiving Uplifts were then to be regarded as “resource factors”, and not as “protective factors”, which would otherwise decrease the likelihood of a negative outcome, but only under adverse conditions (i.e. high Burden condition). A final remark on the observed interaction effects relates to the correlational matrix verified for the associations between Burden dimensions, caregiving Uplifts and QL domains. Although moderation analysis typically requires fewer assumptions on the associations between variables than mediation, it has been suggested that having a moderator variable that is uncorrelated with both the predictor and the criterion, increases the likelihood of obtaining clearly interpretable interaction terms (Baron & Kenny, 1986). The fact that in our study, Uplifts were uncorrelated with Burden dimensions, but still weakly associated with QL domains, might have influenced the consistency of results to some degree.

In addition to the aforementioned moderation effects, we also found evidence for some main effects of caregiving Burden and Uplifts on the QL of parents of children with CP. Relationship Burden had a small effect on Physical QL and Objective and Subjective Burden, medium ones, whilst no significant effect was detected for caregiving Uplifts on that same QL domain. These results confirm the significant impact of Burden (mostly Objective and Subjective types) on these parents’ physical well-being (Raina et al., 2005), but do not support the hypothesis of caregiving Uplifts influencing their Physical QL (Green, 2007). As regards Psychological QL, Relationship and Subjective Burdens, along with caregiving Uplifts, displayed medium and large main effects, respectively. Concordantly, some authors have previously commented the significant impact of issues related to relationship (Raina et al., 2005) and Subjective Burden (Ha et al., 2008) on the well-being of parents of children with disabilities (or specifically with CP). As expected, caregiving Uplifts presented the highest main effects for the Psychological QL domain, since positive caregiving perceptions have been related to increased subjective

well-being (Larson, 2010), and more specifically, to greater psychological flexibility and improved self-esteem (Gupta & Singhal, 2004). At last, small main effects were observed for the links between Objective and Subjective Burdens, together with caregiving Uplifts, and Social QL. This result adds support to previous qualitative findings, where parents of children with CP reported impairments in their social well-being due to caregiving responsibilities, which included poorer social support and difficulty in maintaining social relationships (Davis et al., 2010). In agreement with our findings on mean differences between age groups, this variable (along with SES for Psychological domain) was a significant predictor of QL outcomes variability. This result was rather consistent across different QL domains, but despite its concordance with previous reports (Lin, 2000), it challenges the hypothesis of age-related attenuation of the consequences of having a child with a disability, due to parents 'adaptation to stress over time (Ha et al., 2008). Our results on the significant (although small) effect of SES on Psychological QL also lead us to conjecture that the financial burden that has been observed in parents of children with CP (Florian & Findler, 2001; Mobarak et al., 2000), may play an influential role on their psychological well-being.

The cross-sectional design of the present study represents its major limitation: even with careful selection of statistical procedures tailored to answer our research questions, causal relations between variables cannot be drawn from correlational research. As a matter of fact, we have no way of ascertaining if the observed differences between age groups, for instance, are developmental in nature (Magill-Evans et al., 2001). In addition, despite the fact that WHOQOL-BREF questionnaire discriminated parents' QL between age groups, we only had previous evidence of its discriminant validity between clinical and healthy populations (Vaz-Serra et al., 2006). This research work sought to offer and discuss innovative insights into adaptation variables and mechanisms that may underlie the adaptation of parents who have children with CP; nevertheless, we entirely subscribe the idea that "adaptation is not a single event but a multi-factorial determined process over time" (Rentinck et al., 2006, p. 168). Moreover, despite the fact that the comparison of adaptation patterns (e.g. main and interaction effects) between families of children with and without CP remains an understudied topic (Britner et al., 2003), we do acknowledge that such analyses were beyond the aims of this study, for they should be conducted in future research. Another major limitation of our study regards its sampling frames: despite the fact that our sample included cases from the three main regions of national territory, and that some of those cases were visiting the institution only once or twice a year, tertiary health care institutions have been commented to represent a biased context for sample collection (Brehaut et al., 2004). Furthermore, the obtained sample for our study mainly included mothers caring for children with milder forms of CP, thus lacking a wider range of

functional ability levels, which could portray a more accurate depiction of the variety of CP forms. Since gender differences have been reported for the adaptation of parents of children with disabilities (Ha et al., 2008), these two sample characteristics (i.e. function and gender) call for particular caution in generalizing the results here verified. Another potential limitation of our study relates to the risk of a social desirability bias in the participants' response style, since such bias is likely to occur, to some extent, in situations where people are asked about positive emotions or outcomes derived from stressful events they have experienced (Tomich & Helgeson, 2004). Finally, given the fact that our study was centered on the topic of pediatric family caregiving, our assessment protocol solely relied on a single informant (i.e. the primary family caregiver), as well as on the level of individual members, rather than on the family as a whole (Magill-Evans et al., 2001).

Despite bearing in mind the limitations just discussed, we acknowledge the innovative features and promising insights derived from this study. Very little attention has been given to the study of positive dimensions of family caregiving (Green, 2007), and to the best of our knowledge, our study was the first to quantitatively analyze the experience of caregiving Uplifts in the context of pediatric CP, and its interactions with parents' Burden and QL. With this research, we sought to move from an excessive focus on negative outcomes to the study of resiliency, within a clear conceptual framework, namely the stress-coping models. Besides, we conducted an assessment of parents' adjustment that was not restricted to pathological terms (Wallander et al., 1990) or to psychological functioning (Brehaut et al., 2004), and that further included understudied variables such as burden (Horton & Wallander, 2001), here approached from a multidimensional perspective that has been rarely adopted in past research (Savundranayagam et al., 2011). Other strengths of our study corresponded to the overcoming of two important gaps in previous research: one was the inclusion of an adequate control group, and the other was the comparison of different age points (Florian & Findler, 2001). Also in terms of statistical analyses, we examined interactions effects, because the exclusive analysis of main effects could be insufficient for understanding the different conditions under which a variety of determinants operate (Button et al., 2001).

A straightforward implication of our study reflects the need of changing professional attitudes regarding parents of children with disabilities in general, and with CP in particular. Parents may feel more motivated to acknowledge positive aspects of their caregiving, if they are embedded in a social context that facilitates personal and comprehensive meaning making of their parenting experience (Gupta & Singhal, 2004). In fact, health professionals working closer with these parents benefit from a privileged opportunity to offer a

more realistic and positive regard on their experience, which may then counteract some of the prejudices hold by society (Larson, 1998). Far more different than adopting a “normalizing” attitude, health professionals should acknowledge variability in the adaptation of parents of children with CP and assume themselves as positive sources of social support that may actually make a difference. Within such context, parents could openly develop their search for meaning, thus increasing their ability to experience positive caregiving perceptions (Gupta & Singhal, 2004). In other words, health professionals could help these parents “embracing the paradox” of their caregiving experience (Larson, 1998), by genuinely “embracing the paradox” of their clinical challenges themselves.

Another general clinical implication from the present study is the need to incorporate a multidimensional approach to parents’ QL and pediatric family caregiving. Our study demonstrated that the relationships between caregiving variables are not necessarily linear, and their impact is quite differential. A multidimensional assessment of burden may increase intervention effectiveness, through an appropriate allocation of resources (Savundranayagam et al., 2011). Sharing caregiving responsibilities with other sources of support, learning to manage emotional stress, and implementing child behavior modification techniques, for instance, are distinct intervention strategies that may follow a multidimensional assessment to reduce Objective, Subjective and Relationship Burdens respectively. Nevertheless, any caregiving assessment exclusively focusing on negative dimensions may only provide an incomplete picture. It stands clear from our work that considerable levels of caregiving burden and uplifts may indeed coexist, so that despite a component of the intervention may be designed to decrease burden, other may be implemented to foster caregiving uplifts or utilize them as a therapeutic resource.

Given the clinical group that served the basis for our study, some additional clinical implications may be specifically drawn for parents of children with CP: first, interventions targeting distinct burden dimensions may differentially improve these parents’ QL; second, caregiving Uplifts seem to be particularly relevant for the promotion of parents’ Psychological and Social QL, and third, increased levels of caregiving Uplifts may alleviate the impact of Objective and Relationship Burden on parents’ Psychological and Social QL, respectively. Moreover, our results highlight the need of adopting a developmental perspective in working with these parents: the adolescence period may represent a developmental context of increased risk for the reduction of psychological well-being and positive caregiving perceptions. For this reason, greater attention should be directed to these parents’ emotional needs during the transition period from childhood to adolescence. As it has

been stated for interventions facilitating personal growth following adversity (Joseph & Linley, 2006), the development of caregiving Uplifts is to be encouraged, not imposed. In this sense, parents who engage in a mindful experience of their caregiving, may benefit from a broadened attention to different (and often conflicting) aspects of their parenting, and thus mitigate the effects of a narrowed focus on its burdensome aspects (Larson, 2010). For that same purpose, in the psychotherapeutic work with these parents, one should bear in mind that if we do not ask positive questions, we will hardly get a positive answer (Gupta & Singhal, 2004). Furthermore, if psychological interventions often seek to change rigid meanings attached to the individual's experience, we would also suggest that these parents are to be encouraged to value the ramified meaning of their parenting and, after all, of their "caregiving paradox". This clinical implication makes particular sense if one assumes coping as a process where searching and finding positive meanings may elicit positive emotions, which then sustain adaptive coping processes themselves (Folkman, 1997).

Future directions for the research of adaptation processes of parents who have children with CP were sharply synthesized by Britner and colleagues (2003), who argued for longitudinal, multi-measure and multi-respondent designs. Longitudinal designs are needed to determine causal links between variables and enlighten the dynamic interplay between negative and positive dimensions of adaptation across time. Age differences observed in literature and in our study underline the need of researching adaptation change and/or stability from childhood to adolescence, and from adolescence into adulthood. Moreover, there is a considerable research gap on the nature, extent and impact of personal growth and perceived benefits experienced by parents of children with CP. This research gap calls for the incorporation of qualitative methods in mixed designs that also include quantitative measures, in order to comprehensively capture the complexity of that phenomenon in this group. Finally, for the purpose of exploring mutual interplays between child and parents' adaptation, the applicability of transactional models to pediatric CP remains to be examined, preferably in multi-respondent research designs.

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Table 1. Socio-demographic and clinical characterization of clinical and control samples

| | Parents of Children with CP (<i>n</i> = 105) | Parents of Children without Disabilities (<i>n</i> = 117) | Differences between Samples ¹ |
|----------------------------------|---|--|---|
| <i>Parents' Variables</i> | | | |
| Age (M/SD) | 41.5 (6.5) | 42.8 (5.2) | <i>t</i> = 1.56; <i>p</i> = .12 |
| Gender (n/%) | | | |
| Male | 12 (11.5) | 22 (18.8) | $\chi^2 = 2.23$; <i>p</i> = .14 |
| Female | 93 (88.5) | 95 (81.2) | |
| Marital status: | | | |
| Married (n/%) | 79 (76.0) | 99 (84.6) | $\chi^2 = 2.63$; <i>p</i> = .11 |
| SES² (n/%) | | | |
| Low | 67 (63.8) | 31 (26.5) | $\chi^2 = 34.77$; <i>p</i> < .01 |
| Medium-High | 34 (32.4) | 86 (73.5) | |
| Missing | 4 (3.8) | - | |
| <i>Children's Variables</i> | | | |
| Age (M/SD) | 12.0 (2.9) | 12.3 (3.0) | <i>t</i> = .83; <i>p</i> = .41 |
| Age Group (n/%) | | | |
| Children (8-12) | 59 (56.2) | 61 (52.1) | $\chi^2 = .47$; <i>p</i> = .49 |
| Adolescents (13-18) | 46 (43.8) | 56 (47.9) | |
| Gender (n/%) | | | |
| Male | 63 (60.0) | 59 (50.4) | $\chi^2 = 2.05$; <i>p</i> = .15 |
| Female | 42 (40.0) | 58 (49.6) | |
| CP Type³ (n/%) | | | |
| Spastic unilateral | 53 (50.5) | | |
| Spastic bilateral | 40 (38.1) | | |
| Dyskinetic | 4 (3.8) | | |
| Ataxic | 3 (2.9) | | |
| Missing | 5 (4.8) | | |
| GMFCS⁴ (n/%) | | | |
| I | 67 (63.8) | | |
| II | 15 (14.3) | | |
| III | 12 (11.4) | | |
| IV | 6 (5.7) | | |
| V | 3 (2.9) | | |
| Missing | 2 (1.9) | | |

¹ Results of homogeneity testing between clinical and control samples.

² SES levels were determined using a classification system based on parents' job and educational level (Simões, 1994), followed by variable dichotomization.

³ According to the classification proposed by the Surveillance of CP in Europe project (SCPE, 2000).

⁴ Levels of function according to the Gross Motor Function Classification System (GMFCS) – Expanded and Revised (Palisano, Rosenbaum, Bartlett, & Livingston, 2007).

Table 2. Differences in QL, Burden dimensions and caregiving Uplifts between clinical and control samples

| | Parents of Children with CP | | Parents of Children without Disabilities | | Condition effects (CP vs. control sample) | | | Age group effects (children 8-12 vs. adolescents 13-18) | | | Interaction effects (condition X age group) | | |
|--------------------------------------|------------------------------|---------------------------------|--|---------------------------------|---|-----------------|------------|---|-----------------|------------|---|------------|------------|
| | Children (<i>n</i> = 56) | Adolescents (<i>n</i> = 44) | Children (<i>n</i> = 61) | Adolescents (<i>n</i> = 56) | <i>F</i> _(1,212) | <i>p</i> | η_p^2 | <i>F</i> _(1,212) | <i>p</i> | η_p^2 | <i>F</i> _(1,212) | <i>p</i> | η_p^2 |
| | <i>M</i> (<i>SD</i>) | <i>M</i> (<i>SD</i>) | <i>M</i> (<i>SD</i>) | <i>M</i> (<i>SD</i>) | | | | | | | | | |
| Quality of Life | | | | | | | | | | | | | |
| <i>Physical QL</i> | 77.36 (13.05) | 70.13 (19.13) | 74.53 (13.90) | 76.40 (13.44) | 0.03 | .86 | .00 | 1.73 | .19 | .01 | 4.32 | .04 | .02 |
| <i>Psychological QL</i> | 73.36 (11.64) | 65.15 (16.96) | 76.23 (11.03) | 71.50 (13.92) | 1.94 | .17 | .01 | 12.73 | < .01 | .06 | .61 | .44 | .00 |
| <i>Social QL</i> | 71.88 (14.78) | 65.34 (19.60) | 72.27 (15.12) | 71.73 (15.54) | 2.34 | .13 | .01 | 2.56 | .11 | .01 | 1.89 | .17 | .01 |
| Caregiving Burden and Uplifts | | | | | | | | | | | | | |
| <i>Relationship Burden</i> | 9.05 (3.88) | 7.70 (3.76) | 8.80 (3.47) | 8.43 (3.74) | 0.07 | .79 | .00 | 2.87 | .09 | .01 | .86 | .36 | .00 |
| <i>Objective Burden</i> | 13.16 (4.92) | 13.32 (5.13) | 14.28 (5.09) | 12.05 (4.89) | 1.14 | .29 | .01 | 2.27 | .13 | .01 | 3.78 | .05 | .02 |
| <i>Subjective Burden</i> | 11.66 (4.62) | 12.82 (4.78) | 10.10 (3.66) | 9.13 (4.45) | 17.22 | < .01 | .08 | 0.03 | .88 | .00 | 3.24 | .07 | .02 |
| <i>Caregiving uplifts</i> | 21.07 (4.02) | 20.00 (5.12) | 24.26 (3.84) | 22.30 (4.92) | 20.11 | < .01 | .09 | 6.21 | .01 | .03 | .43 | .51 | .00 |

Table 3. Matrix of inter-correlations among variables for parents of children with CP

| | Physical QL | Psychological QL | Social QL | Relationship Burden | Objective Burden | Subjective Burden |
|---------------------|----------------|---------------------|--------------|------------------------|---------------------|----------------------|
| Psychological QL | .71** | | | | | |
| Social QL | .54** | .61** | | | | |
| Relationship Burden | -.26** | -.35** | -.26** | | | |
| Objective Burden | -.42** | -.31** | -.29** | .49** | | |
| Subjective Burden | -.46** | -.56** | -.35** | .56** | .62** | |
| Caregiving Uplifts | .13** | .29** | .26** | -.09 | -.02 | -.14 |

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

Table 4. Regression analyses (main and interaction/moderating effects) for parents of children with CP

| | <i>Dependent variables</i> | | | | | |
|-----------------------------|--|---------------------|---|---------------------|---------------------------|--------------------|
| | Physical QL | | Psychological QL | | Social QL | |
| | <i>B</i> (SE) | ΔR^2 | <i>B</i> (SE) | ΔR^2 | <i>B</i> (SE) | ΔR^2 |
| <i>Relationship Burden</i> | | | | | | |
| Child's age ^a | -1.27 (.54) [*] / -4.82 (3.21) | .076 [*] | -1.42(.44) ^{**} / 5.53 (2.68) [*] | .117 ^{**} | -1.20 (.54) [*] | .042 [*] |
| Relationship Burden Uplifts | -1.07 (.40) ^{**} | .064 ^{**} | -1.19 (.33) ^{***} | .102 ^{**} | -1.11 (.40) ^{**} | .063 ^{**} |
| Relationship B. x Uplifts | .41 (.34) | .010 | .91 (.28) ^{**} | .066 ^{**} | .95 (.34) ^{**} | .047 [*] |
| | .07 (.11) | .004 | .14 (.09) | .018 | .23 (.11) [*] | .038 [*] |
| Total R^2 | .16 | | .30 | | .19 | |
| Adjusted R^2 | .11 | | .27 | | .16 | |
| <i>F</i> (final model) | 3.59 ^{**} | | 8.36 ^{***} | | 5.91 ^{***} | |
| <i>Objective Burden</i> | | | | | | |
| Child's age ^a | -1.08 (.51) [*] / -2.81 (3.13) | .076 [*] | -1.14 (.44) [*] / 7.72 (2.70) ^{**} | .117 ^{**} | -1.00 (.55) | .042 [*] |
| Objective Burden Uplifts | -1.26 (.30) ^{***} | .125 ^{***} | -.80 (.26) ^{**} | .060 ^{**} | -.85 (.32) ^{**} | .060 [*] |
| Objective B. x Uplifts | .30 (.33) | .013 | .78 (.29) ^{**} | .083 ^{**} | .84 (.36) [*] | .055 [*] |
| | -.08 (.06) | .015 | -.12 (.05) [*] | .038 [*] | -.03 (.06) | .002 |
| Total R^2 | .23 | | .30 | | .16 | |
| Adjusted R^2 | .19 | | .26 | | .13 | |
| <i>F</i> (final model) | 5.85 ^{***} | | 8.15 ^{***} | | 4.78 ^{**} | |
| <i>Subjective Burden</i> | | | | | | |
| Child's age ^a | -.85 (.52) / -5.08 (3.07) | .076 [*] | -.90 (.42) [*] / 6.45 (2.48) [*] | .117 ^{**} | -.87 (.55) | .042 [*] |
| Subjective Burden Uplifts | -1.34 (.31) ^{***} | .15 ^{***} | -1.43 (.25) ^{***} | .218 ^{***} | -.95 (.33) ^{**} | .082 ^{**} |
| Subjective B. x Uplifts | .29 (.32) | .006 | .81 (.26) ^{**} | .060 ^{**} | .77 (.34) [*] | .042 [*] |
| | -.02 (.05) | .001 | .03 (.04) | .002 | .03 (.06) | .002 |
| Total R^2 | .23 | | .40 | | .17 | |
| Adjusted R^2 | .20 | | .37 | | .14 | |
| <i>F</i> (final model) | 5.97 ^{***} | | 12.68 ^{***} | | 5.12 ^{**} | |

Note. The unstandardized regression coefficients (*B*) concern the analyses in which all main and interaction effects were entered (last step).

^a Child's age was entered as covariate in all regression analyses performed, along with function level (for Physical QL) and SES (for Psychological QL).

* $p < .05$; ** $p < .01$; *** $p < .001$

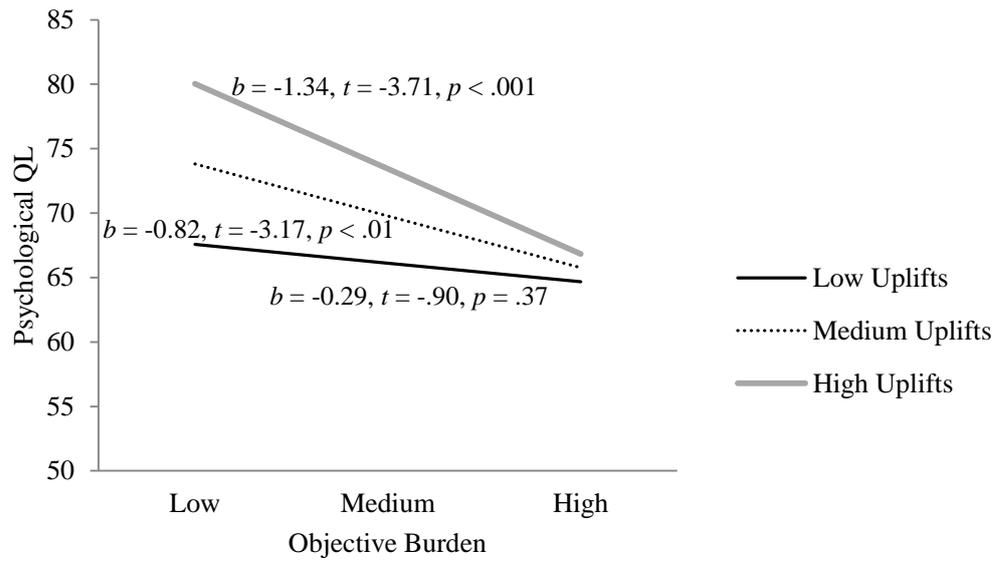


Figure 1. The moderating effect of caregiving Uplifts on the association between Objective Burden and Psychological QL of parents of children with CP

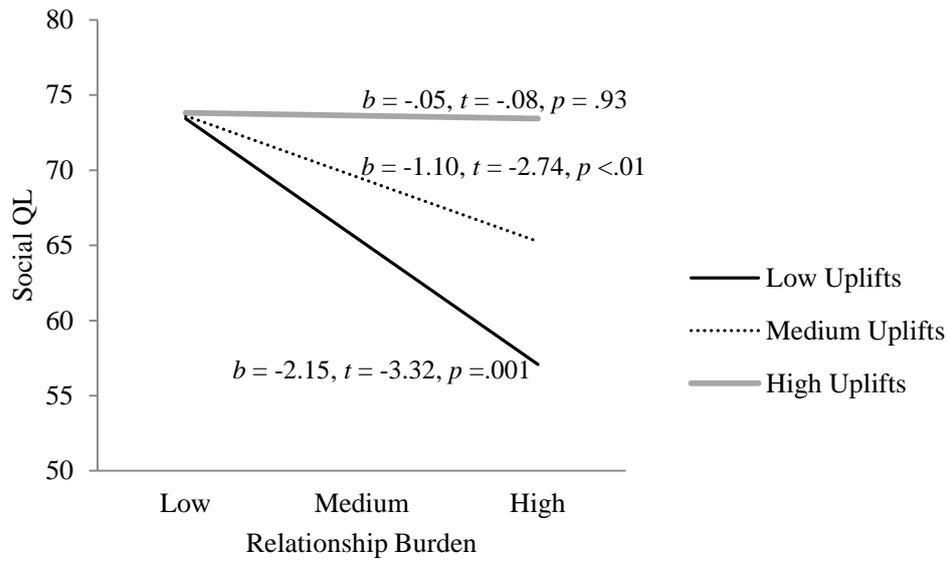


Figure 2. The moderating effect of caregiving Uplifts on the association between Relationship Burden and Social QL of parents who have children with CP