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Social Support and Adaptation Outcomes in Children and Adolescents
with Cerebral Palsy

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Abstract

Objectives. This study had two main objectives: first, to describe the social support and psychological maladjustment of children and adolescents with cerebral palsy (CP); and second, to test a mediation model where psychological maladjustment was hypothesized to mediate the link between social support and health-related quality of life (HRQL). In addition, the moderating role of gender and age was examined for this mediation model.

Methods. Self and proxy-report questionnaires on the aforementioned variables were administered to a sample of 96 children/adolescents with CP and 118 healthy controls, as well as one of their parents. Univariate and multivariate analyses of covariance were conducted to examine differences in social support and psychological maladjustment, respectively. PROCESS computational tool was used for path analysis-based mediation, moderation and moderated mediation analyses. **Results.** Children/adolescents with CP reported lower levels of social support than their healthy peers, but few differences emerged in terms of their psychological maladjustment. For children/adolescents with CP, internalizing and externalizing problems were found to mediate the link between social support and HRQL, and these indirect effects were not conditional upon age or gender.

Discussion. Children and adolescents with CP are likely have more negative perceptions of social support, but not necessarily more psychological adjustment problems than their healthy, able-bodied peers. Results further suggest that interventions targeting social support perceptions may positively affect HRQL outcomes in children/adolescents with CP, through the improvement of internalizing and externalizing dimensions of their psychological adjustment.

Keywords: Social Support, Adaptation, Health-related Quality of Life, Psychological Adjustment, Cerebral Palsy.

Introduction

Cerebral palsy (CP) was recently described as an “umbrella term” for a group of disorders of movement and posture, attributed to non-progressive disturbances that occurred in the developing fetal or infant brain (Rosenbaum et al., 2005). With a prevalence of 1.5-3.0/1000 live births (SCPE, 2000), CP is the most common physical disability in childhood (Moreno-De-Luca, Ledbetter, & Martin, 2012).

Although there is growing evidence for impaired health-related quality of life (HRQL) (Rosenbaum et al., 2007; Varni et al., 2005) and increased psychological maladjustment in children/adolescents with CP (Brossard-Racine et al., 2012a, 2012b), research on their psychosocial adjustment remains underrepresented in current literature (Vles, Hendriksen, Vles, Kessels, & Hendriksen, 2012), and little is known about the association of specific factors, such as social support, with their HRQL outcomes (Livingston, Rosenbaum, Russell, & Palisano, 2007). Given the fact that such contextual factors are important determinants of HRQL in individuals with disabilities (Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007), more research is needed to examine the circumstances under which social support influences specific outcomes, as well as the potential mechanisms via which it may operate. A deeper understanding on these matters may improve the effectiveness of current psychosocial interventions for children/adolescents with CP, by ascertaining the importance of social support perceptions in their associations with psychological adjustment and HRQL outcomes.

Adaptation Outcomes in Pediatric Cerebral Palsy: Moving From Outcomes

Description to Outcomes Prediction

“Adaptation” is broadly defined as “any process whereby behavior or subjective experience alters to fit in with a changed environment or circumstance” (Colman, 2009, p. 11). In pediatric settings, adaptation outcomes have been operationalized in terms of child/adolescent’s mental health, social functioning and physical health (Wallander, Varni, Babani, Banis, & Wilcox, 1989). Therefore, the multidimensionality of these outcomes is likely to encompass the constructs of psychological (mal)adjustment and HRQL. As regards the adaptation of individuals with CP, research has recently moved from an exclusive focus on impairment and function, to a broader framework where quality of life (QL) and HRQL measures are complementary to traditional functional and medical assessments (Schneider, Gurucharri, Gutierrez, & Spira, 2001).

Although sometimes used interchangeably with the notion of HRQL, QL has been adopted as one of the most important goals of current research in CP (Bjornson & McLaughlin, 2001), and is perhaps “the holy grail of [intervention] outcomes”, as perceived by youths with CP, their parents and medical professionals (Vargus-Adams & Martin, 2009). HRQL may be seen as a component of the holistic concept of quality of life (QL), because it encompasses physical, social and mental dimensions of functioning, along with condition/treatment facets, but excludes a broader range of aspects such as political freedom and economical issues (The European Disabkids Group, 2006). For the purpose of the present review, comments on previous research were based on the theoretical assumption that QL and HRQL are somehow overlapping, but nevertheless, distinct concepts.

Psychological (mal)adjustment in children and adolescents, on the other hand, is generally associated with two broadband dimensions: internalizing and externalizing

problems (Bornstein, Hahn, & Haynes, 2010). Internalizing problems essentially affects the child's internal psychological states, rather than the external world, and include withdrawn, anxious and depressive behavior; externalizing problems, in contrast, relate to children's outward behavior as negatively acting on the external environment, and include disruptive, aggressive and hyperactive behavior (Liu, 2004). Although the predominance of internalizing over externalizing problems has been a consistent finding for children with chronic medical conditions (Thompson, Gustafson, Hamlett, & Spock, 1992), the distinctive importance of examining externalizing problems in pediatric populations has been emphasized (Holmbeck et al., 2008).

On a theoretical level, psychological (mal)adjustment may be regarded as a specific adaptation outcome (Wallander et al., 1989), and as a QL determinant (Bovier, Chamot, & Perneger, 2004; Janssen, Voorman, Becher, Dallmeijer, & Schuengel, 2010). In fact, QL has been described as "the ultimate outcome" in psychosocial rehabilitation practice (Livneh & Antonak, 2005, p. 13). Moreover, the simultaneous assessment of positive and negative dimensions has been recommended as a mean of providing a more complete picture on the individual's adaptation outcomes (Ridder, Geenen, Kuijter, & Middendorp, 2008).

Psychological maladjustment is likely to imply increased burden of disease and deteriorate internal resources (e.g., mastery, self-esteem), and thus impair an individual's QL (Bovier et al., 2004). Therefore, from a conceptual and methodological point of view, psychological (mal)adjustment may be assumed as both a QL determinant and a "first-order outcome" (more specific), and QL and HRQL as "second-order outcomes" (more general).

Children and adolescents with CP have been reported to experience a markedly impaired HRQL, in comparison to children/adolescents with other chronic health conditions (Schmidt et al., 2006) and to their healthy/able-bodied peers (Varni et al., 2005). As a notable

exception in challenging these widespread findings, self-reported QL of children with CP has been found to be mostly similar to the QL perceived by children in the general population (Dickinson et al., 2007). Notwithstanding the contributions of such studies, QL research in pediatric CP has been characterized by a number of criticisms: QL and HRQL have been often used interchangeably or inadequately assessed; children and adolescents have been typically studied as one single group; the adoption of children/adolescents' self-reports has been rare, in contrast to an excessive reliance on parent/proxy-reports; scores have been usually compared to norms and not to homologous peer samples; and determinants of QL and HRQL outcomes have been scarcely studied (Davis et al., 2009; Livingston et al., 2007; Rosenbaum et al., 2007).

On the topic of psychological adaptation outcomes, children/adolescents with chronic conditions are at higher risk for psychological maladjustment (Stawski, Auerbach, Barasch, Lerner, & Zimin, 1997). Moreover, the study of developmental specificities in pediatric populations has suggested that internalizing problems are more common in older children, and that gender differences in externalizing problems tend to emerge earlier than gender differences in internalizing problems (Pinquart & Shen, 2011). As regards pediatric CP in particular, psychological problems seem frequent and include peer difficulties, inattention-hyperactivity, emotional symptoms, increased dependence, withdrawal, obstinacy and antisocial characteristics (Brossard-Racine et al., 2012a; Parkes et al., 2008). In fact, children and adolescents with CP have been reported to achieve less psychosocial adjustment (Vles et al., 2012), besides being five times more likely to present parent-reported behavior problems than their healthy peers (McDermott et al., 1996). Complementarily, some age and gender specificities are noteworthy for CP: a decrease in the frequency of behavior problems has been related to ageing (McCullough, Parkes, Kerr, & McDowell, 2011), and an increased risk

for conduct and hyperactivity problems has been observed for boys (Parkes, White-Koning, McCullough, & Colver, 2009). In addition, even if some evidence has been gathered for the role of psychological maladjustment as a QL predictor in children/adolescents with CP (Majnemer et al., 2007; Wiley & Renk, 2007), the selection of informants on children's outcomes seems influential: while internalizing problems have been related to child and parent-reported HRQL, externalizing problems were related with parents' reports only (Janssen et al., 2010). Regrettably, research on the psychological adjustment of children/adolescents with CP is open to some of the abovementioned criticisms to QL research, namely in terms of the excessive reliance on proxy-reports, the tendency to perform comparisons with norms, and the scarcity of data on psychological adjustment determinants.

Compared to the amount of literature on the adaptation outcomes for other chronic health conditions, studies on pediatric CP are remarkably few (The European Disabkids Group, 2006). A considerable amount of research in this area has been devoted to the description of differences in the adaptation outcomes experienced by clinical and non-clinical populations. Those studies are important because they promote insights on the differentiation of groups, which may be useful for mapping needs and/or allocating resources, but they are still of limited heuristic value to ascertain potentially modifiable associations between determinants, such as social support, and adaptation outcomes (Livingston et al., 2007; Majnemer & Mazer, 2004).

Social Support and Adaptation Outcomes in Children and Adolescents with Cerebral Palsy

Social support was defined here as “social relationships that provide (or can potentially provide) material and interpersonal resources that are of value to the recipient, such as counseling, access to information and services, sharing of tasks and responsibilities, and skill acquisition” (Thompson, 1995, p. 43). This definition was preferred because it implicitly links the individual’s context of social relationships with his/her behavioral development. Social support has been commented as an important factor in developmental psychopathology (Thompson, Flood, & Goodvin, 2006), and stated as a determinant social-ecological factor of adaptation outcomes in the so-called “disability-stress-coping” model of individual and family adaptation to chronic physical conditions (Wallander et al., 1989). In literature, the influence of social support on adaptation outcomes has been hypothesized in two distinct, but complementary models: on the one hand, social support may generally improve adaptation outcomes, whether the person is under increased stress or not (i.e., “main effect model”); on the other hand, social support is likely to impede, reduce or control the detrimental effects of stressful situations (i.e., “buffering model”) (Cohen & Wills, 1985; Thompson et al., 2006). The refinement and examination of a main effect model (i.e. “an indirect effect model”, Bovier et al., 2004) in children and adolescents with CP was selected as a general framework for the present research work.

Social support has been described as a potential causal determinant of psychological symptomatology and other health-related variables (Schwarzer & Leppin, 1991), but the understanding of the mechanisms via which social support is likely to determine such outcomes, still needs to be addressed in research (Helgeson, 2003). In fact, social support may exert indirect effects (i.e. through other variables) on adaptation outcomes, which may even surpass its straightforward direct effects (Schwarzer & Leppin, 1991). Moreover, in research aimed at predicting well-being outcomes, the measurement of subjective aspects of social support, such as perceived support or satisfaction with support, has been recommended

(Vaux & Harrison, 1985). Social support has been reported to increase children and adolescents' QL, with girls perceiving better support than boys, and children better than adolescents (Malkowska, Mazur, & Woynarowska, 2004). As commented earlier for the definition adopted, social support provides a context for the development of social competence in children, which is a good predictor of later externalizing and internalizing problems in preadolescence, and externalizing problems in adolescence (Bornstein et al., 2010). Social support has been also hypothesized to promote QL outcomes through the preservation of feelings of connectedness and a sense of belonging (Helgeson, 2003). On the topic of other age and gender differences, it should be noted that the amount of social support sources tends to increase in adolescence, with multiple resources being related to better adjustment (Levitt et al., 2005), and that girls seem more likely to perceive higher levels of social support than boys (Bokhorst, Sumter, & Westenberg, 2010).

In pediatric populations, increased social support has been related to improved psychological adjustment, and identified as a significant predictor of internalizing and externalizing problems in children/adolescents with chronic physical conditions (Wallander & Varni, 1989). In that study, no interaction effects between social support and age or gender were verified. As regards the determinant role of social support in children and adolescents with chronic conditions, it is important to note that internalizing and/or externalizing problems may be a response to stressful social situations, such as peer rejection (Pinquart & Shen, 2011). Additionally, decreased HRQL due to impaired social functioning has been reported for adolescents with physical disabilities (Stevens et al., 1996). In fact, it has been suggested that children with conditions that involve the central nervous system (such as CP) may face additional social difficulties (LaGreca, Bearman, & Moore, 2002). Nevertheless, for pediatric populations in general, and for pediatric CP in particular, the examination of direct and indirect effects (via the internalizing/externalizing dimensions of psychological

adjustment) of social support on HRQL has not been addressed in research. In the same way, gender and age specificities have not been thoroughly examined in models that hypothesize the links between social support and adaptation outcomes. This rationale calls for the conduction of mediation and moderated mediation analyses, which became popular in developmental and behavioral pediatric research (Rose, Holmbeck, & Franks, 2004). After all, these analyses allow theory development and testing, as well as the identification of potentially modifiable links between variables of interest (Preacher & Hayes, 2004).

The Current Study

The present study adopted a developmental dyadic approach to adaptation outcomes assessment, by examining two complementary models: in the first model, social support, psychological maladjustment and HRQL were exclusively self-reported; in the second model, parent-reported psychological maladjustment and HRQL were combined with child-reported social support. Although more complex, such methodological procedure was thought to improve the clinical validity of our study (cf. Smith, 2007).

The aims for the present study were defined as follows: first, to assess the satisfaction with social support and the psychological maladjustment (i.e. internalizing and externalizing problems) of children/adolescents with CP, in comparison to typically developing children/adolescents; and subsequently, to examine a potential process through which social support may influence HRQL, by testing two dimensions of psychological maladjustment (i.e. internalizing and externalizing problems) as mediators of that relationship. The study further explored age and gender differences in social support and psychological maladjustment, as well as the possibility that the indirect effects of social support on HRQL differed between gender and age groups, and more specifically, whether gender and age

group moderated the path from social support to internalizing/externalizing problems and/or the path from these clusters of psychological symptoms to HRQL. Figure 1 graphically depicts the hypothesized moderated mediation model, as described and adapted from Hayes (2012a).

According to these objectives, three theoretically-driven hypotheses were outlined: (1) children/adolescents with CP would report decreased levels of social support in comparison to their healthy, able-bodied peers; (2) higher levels of self and proxy-reported internalizing and externalizing problems would be observed for children/adolescents with CP, than for healthy, able-bodied children/adolescents; (3) boys would report more externalizing problems than girls, and adolescents would report more internalizing problems than children. Although internalizing and externalizing problems were tested as mediators in the relationship between social support and HRQL, and age and gender moderation effects were examined within that mediation model, we made no specific predictions for those analyses.

Insert Figure 1 about here

Methods

Participants

The sample for this study ($N = 96$ children/adolescents with CP and one of their parents) was recruited in ten Portuguese Cerebral Palsy Associations between July 2010 and July 2011. Pediatric subjects were assigned to the study if they met the following criteria: (1) a clinical diagnosis of CP; (2) age between 8 and 18 years old; (3) minimum intelligence quotient (IQ) of 70. Cases where results from previous formal assessments of IQ were not available ($n=13$) were still included in the study, if they didn't present significant cognitive

delay, as indicated through gross evaluation of their cognitive abilities, and simultaneous absence of any previous adaptation in their school curricula. For parents, a single inclusion criterion was considered: 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. One hundred and sixty one children/adolescents with CP and their parents were assigned to the study, out of which 65 were progressively excluded because of the following reasons: 7 cases refused to participate; 47 did not visit the institutions during the established period for sample collection; 2 cases were only able to provide self-reports, since children were living in foster care placement, and 9 cases did not complete all the questionnaires.

Complementarily, a convenience sample of controls was collected in two public schools of Coimbra district, between January and June 2010. Children and adolescents included in this sample were to fulfill 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: being the parent who spent more daily time with the child/adolescent. A total of 124 children/adolescents were assigned to participate in the study. Since two parents did not allow their children's participation, and four adolescents did not return their parents' questionnaires, a total sample of 118 healthy controls was obtained.

Measures

Satisfaction with Social Support Scale for Children and Adolescents (SSSS). This scale assesses satisfaction with social support, as perceived by children and adolescents (Gaspar et al., 2009). The instrument includes 12 items, for which the individual indicates his degree of agreement along a five point Likert scale from 1 (*totally disagree*) to 5 (*totally*

agree). The items may be grouped in two factors: “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 organized activities, such as sport clubs, scouts”). The overall score resulting from the sum of both factors varies between 12 and 60, with higher values indicating more satisfaction with social support. Adequate internal consistency values were found for our samples of healthy controls ($\alpha = .80$) and pediatric CP ($\alpha = .76$).

. **Strengths and Difficulties Questionnaire (SDQ).** SDQ is a brief measure of psychological adjustment for children and adolescents, allowing both self and proxy-reports (Goodman, 2001). SDQ comprises 20 items assessing psychopathological symptoms, and 5 items targeting prosocial behavior, for which the respondent indicates his perception within a 3 point Likert response scale: 0 (*not true*); 1 (*somewhat true*) and 2 (*certainly true*). Apart from the prosocial factor, an alternative scaling for SDQ has been recently proposed: emotional symptoms (e.g. “I am often unhappy, down-hearted or tearful”) and peer problems (e.g. “Other children or young people pick on me or bully me”) were integrated into a broader scale of internalizing problems; conduct problems (e.g. “I get very angry and often lose my temper”) and hyperactivity-inattention symptoms (e.g. “I am constantly fidgeting or squirming”) were combined into a scale of externalizing problems (Goodman, Lamping, & Ploubidis, 2010). Scores for each one of these broad subscales vary between 0 and 20, with higher values indicating increased psychological maladjustment. Acceptable internal consistency values were observed for internalizing and externalizing subscales within our global sample, for both self and proxy-reports, with Cronbach’s alphas ranging between .67 (CP self-reported internalizing problems) and .82 (controls proxy-reported externalizing problems).

DISABKIDS-37. The generic module (long version) of Disabkids questionnaires is available in self and proxy formats and assesses HRQL of children and adolescents with chronic health conditions (Carona, Bullinger, & Canavarro, 2011; The European Disabkids Group, 2006). Disabkids-37 items are to be answered within a 5 point Likert scale, and may be grouped into six facets: Independence (e.g. “Are you able to do things without your parents?”), Emotion (e.g. “Are you unhappy because of your condition?”), Inclusion (e.g. “Do your friends enjoy being with you?”), Exclusion (e.g. “Do you feel different from other children/adolescents?”), Physical Limitation (e.g. “Is your life ruled by your condition?”) and Treatment (e.g. “Does taking medication bother you?”). Given the fact that most CP cases in our sample were not medicated ($n = 58$), a syntax for a standardized global score (0-100) based on the remaining 31 items was preferred, with lower scores indicating the most impaired HRQL. Good internal consistency values were found in our sample for self ($\alpha = .88$) and proxy reports ($\alpha = .95$).

Procedure

Authorizations were obtained from the Direction Boards of Portuguese Cerebral Palsy Associations participating in this study. Informed consents were obtained from parents regarding their own and their child’s participation (when under 14 years old); these young children were also to assent their own participation, and not to be included even if the parents had previously allowed their participation, but they refused it themselves afterwards. For individuals aged 14 or older, informed consents were obtained from adolescents.

Authorizations for the collection of the control sample were given by the Direction Boards of both public schools involved in this research study. After the selection of a number

of classes to fairly achieve the intended sample size, questionnaires were administered to children/adolescents in the classroom. Parents completed their questionnaires at home and returned them through their children. General procedures for obtaining informed consents/assents were similar to the ones described for the clinical sample.

Data Analysis

Internal consistency of questionnaires integrating the assessment protocol was measured through the calculation of their Cronbach's alphas, which were then classified as minimally acceptable ($\geq .65$), acceptable ($\geq .70$) and optimal ($\geq .80$) (DeVellis, 1991; Nunally & Bernstein, 1994). Descriptive statistics were obtained for clinical and socio-demographic variables, and the homogeneity between clinical and control samples was tested through mean differences tests (Student's *t* tests) or frequency differences for categorical variables (chi-square tests). In order to compare psychological adjustment outcomes between groups, multivariate analysis of covariance (MANCOVA) was performed, examining condition (CP vs. healthy controls), age (children vs. adolescents) and gender (boys vs. girls) group differences in self and proxy-reported internalizing and externalizing problems. When multivariate effects were significant, univariate analyses were used to further explore which dimensions of psychological adjustment significantly differed across groups. Differences in social support between condition, age and gender groups were examined through univariate analysis of covariance (ANCOVA). Given the observed discrepancy in SES frequencies between clinical and control samples ($\chi^2 = 29.38$; $p = .00$), SES was dichotomized (0 = *low*; 1 = *medium/high*) and entered as covariate in univariate and multivariate analyses. Effect-

size measures (partial Eta squared) were presented for the comparison analyses, considering $\eta_p^2 \geq .01$ as a small effect, $\eta_p^2 \geq .06$ as a medium effect, and $\eta_p^2 \geq .14$ as a large effect (Cohen, 1988). No effect sizes were calculated for multiple mediation models because of the inclusion of covariates. Pearson's bivariate correlation coefficients were computed to assess associations between variables, while adopting the following guidelines to classify their strength: $\pm .10 - \pm .29$ (weak); $\pm .30 - \pm .49$ (moderate); $\pm .50 - \pm 1.0$ (strong) (Cohen, 1988).

As conceptually depicted in Figure 1, two moderators (age group and gender) were hypothesized to influence the mediator effects of internalizing and externalizing problems on the links between SS and HRQL. Hence, multiple moderated mediation analyses were elected because they permitted the assessment of both “how” and “when” an indirect effect would occur in models where more than one mediator and one moderator were included. Moderated mediation is said to exist when the mediating effect of a given variable in the relationship between a predictor and outcome depends on a level of a moderator. To test for multiple moderated mediation, PROCESS was used as a computational tool for path analysis-based moderation and mediation analyses, as well as their combination in the so-called “conditional process model” (Hayes, 2012b). Bootstrapping procedures have been reported to be superior to other traditional methods of studying mediation, since they do not require the assumption of a normal distribution to be met, and demonstrate higher power with reasonable control over the Type-I error rate, through appropriate control of confidence intervals (Mackinnon, Lockwood, Hoffman, West, & Sheets, 2002; Preacher & Hayes, 2008). In bootstrapping procedures, cases from the original dataset are randomly re-sampled with replacement to re-estimate the sampling distribution, and from this new sampling distribution, bias-corrected and accelerated confidence intervals (BCa CIs) are then created, with an indirect effect being significant if zero is not contained within the lower and upper CIs (Shrout & Bolger, 2002).

In moderated mediation analyses, indirect effects are thus to be separately computed across the levels of a moderator. PROCESS computational tool provides a command guide where the expansion of the number and complexity of models combining moderation and mediation is clearly portrayed (Hayes, 2012a). In this command guide, for instance, the hypothesized model for the present study (Figure 1) is graphically depicted in conceptual and statistical terms as “model 72”, where “*X*” would stand for SS, “*Y*” for HRQL, “*M_j*” for internalizing and externalizing problems, “*W*” for age group and “*Z*” for gender. This multiple moderated mediation model allows the simultaneous testing of single and combined moderator effects (e.g. X^*W , X^*Z , W^*Z , X^*W^*Z). Other models that were used in the present study, for examining single moderation (model 1), multiple moderation (model 3) and multiple mediation (model 4), are also included in the aforementioned command guide. All PROCESS analyses were run through a SPSS macro, with 5000 bootstrap samples being systematically drawn. In addition, mean centered products computed for moderation analyses, and gross motor function level was entered as covariate (0 = *no mobility limitations*, 1 = *with mobility limitations*), since it was significantly correlated with both self and proxy-reported HRQL (as recommended by Tabachnik & Fidell, 2007). All analyses were conducted for a 95% confidence interval, even though some marginally significant results (i.e. $p \leq .09$) were presented and/or commented for the purpose of clarifying a given sequence of analyses.

Results

Sample characteristics

With the exception of SES, homologous age and gender distributions were observed for children/adolescents in both samples. The majority of proxy respondents were mothers

(>80%), and most cases were classified as pertaining to low/medium socioeconomic backgrounds (possibly due to the fact that school and healthcare contexts elected for sample collection were respectively public and semi-private institutions). As regards the clinical sample, more than half of the cases corresponded to milder forms of CP, including spastic subtypes (88.5%) with no limitations in walking (62.5%).

Insert Table 1 about here

Differences in Social Support and Psychological Maladjustment and Inter-correlations between Variables

Regarding social support, when controlling for SES, significant differences were found between children and adolescents with CP and healthy controls, $F(1, 202) = 6.93, p = .009, \eta_p^2 = .03$ (see Table 2), but not between age, $F(1, 202) = .001, p = .980, \eta_p^2 = .00$, or gender groups, $F(1, 202) = 1.29, p = .258, \eta_p^2 = .01$.

Results on psychological maladjustment indicated the absence of statistically significant multivariate differences between children and adolescents with CP and healthy controls, controlling for SES, $F(4, 199) = 1.55, p = .19$, Wilks' Lambda = .97, $\eta_p^2 = .03$. Univariate effects for each dimension of psychological maladjustment were presented in Table 2. Multivariate effects of age, $F(4, 199) = 2.78, p = .03$, Wilks' Lambda = .95, $\eta_p^2 = .05$, and gender, $F(4, 199) = 3.53, p = .01$, Wilks' Lambda = .93, $\eta_p^2 = .07$, were found. Univariate analyses for age groups showed, however, only a marginally significant difference on parent-reported internalizing problems, $F(1, 202) = 2.90, p = .09, \eta_p^2 = .01$, with parents of adolescents ($M = 5.57, SD = 3.94$) reporting higher levels of internalizing symptoms than parents of children ($M = 4.55, SD = 3.40$). Regarding gender, univariate analyses indicated higher prevalence of externalizing problems, both self, $F(1, 202) = 10.81, p < .01, \eta_p^2 = .05$, and parent-reported, $F(1, 202) = 10.31, p < .01, \eta_p^2 = .05$, for boys ($M = 5.96, SD = 3.29$ for

self-reports; $M = 6.80$, $SD = 3.88$ for proxy-reports), when compared to girls ($M = 4.42$, $SD = 3.07$ for self-reports; $M = 5.02$, $SD = 3.55$ for proxy-reports).

As presented on the right side of Table 2, moderate correlations were generally observed between social support, dimensions of psychological maladjustment, and HRQL.

Insert Table 2 about here

Multiple Moderated Mediation Models

Following the examination of a multiple moderated mediation model (see Figure 1), no significant conditional indirect effects were found for the relationships between social support, dimensions of psychological maladjustment and HRQL; however, when considering parents' reports, an interaction effect between Social Support*Age Group*Gender was found for the link between social support and externalizing problems ($b = .42$, $p < .05$). Given this fact, the moderating role of age group and gender in the relationship between social support and proxy-reported externalizing problems was subsequently explored (testing for model 3 in PROCESS), with the significance of the conditional effect of Social Support*Age Group interaction observed only in girls ($b = .37$, $p = .01$). After restricting analyses for the sample of girls, age group was further examined as a single moderator in the same relationship (testing for model 1 in PROCESS), with a significant conditional effect of social support on externalizing problems observed only in female children ($b = -.31$, $p < .001$). Finally, PROCESS-generated data were used to graphically depict this conditional effect: as shown in Figure 2, the conditional effect of social support on externalizing problems was only significant for children, i.e., the externalizing problems decreased as social support increased only in female children ($b = -0.311$, $t = -3.65$, $p < .001$); for female adolescents, the slope did

not differ significantly from zero, i.e., the conditional effect was not significant ($b = 0.05$, $t = 0.58$, $p = .57$).

Insert Figure 2 about here

Multiple Mediation Models

Since no conditional indirect effects were found, a simplified version of the initial model was tested. This latest version represented a multiple mediation model with no moderating variables (testing for model 4 in PROCESS). As presented in Table 3, both internalizing and externalizing problems were found to mediate the association between social support and HRQL. Moreover, this mediation effect was significant for the model based on self-reports only, as well as for the model combining self and proxy-reports.

Discussion

Main findings of this study may be summarized as follows: first, children/adolescents with CP reported lower levels of social support in comparison to healthy, able-bodied controls; second, there were no differences in self-reported psychological maladjustment between the two groups, and the differences observed in parent-reports were small or marginally significant; third, no conditional indirect effects were observed in the examination of a moderated mediation model; and finally, both dimensions of psychological maladjustment (i.e., internalizing and externalizing problems) mediated the association between social support and HRQL.

When compared to their healthy peers, children and adolescents with CP reported lower levels of social support. This difference was small, yet confirmed our first hypothesis.

This finding is consistent with previous assertions of impaired social relationships in pediatric chronic conditions, and particularly in those affecting the central nervous system, such as CP (LaGreca et al., 2002). Given the fact that social support was assessed in terms of the individual's subjective satisfaction, the observation of lower levels of social support may reflect the existence of adverse social conditions (e.g. isolation) and/or negative subjective appraisals on the received social support. For this reason, interventions aimed at improving satisfaction with social support in children/adolescents with CP, may target their perceptions of adequacy and availability of support sources and/or the objective number of social contacts and activities in their lives.

Contrary to findings reported in previous studies on psychological adjustment of children/adolescents with CP (Brossard-Racine et al., 2012; Vles et al., 2012), our results affirmed the second hypothesis: there were no differences in self-reported psychological adjustment between children/adolescents with CP and their healthy peers, and the observed differences in parent-reports were small or even marginally significant. Interestingly enough, a similar unexpected finding was recently reported for the QL of children with CP, which was observed to be mostly analogous to the QL reported by children in the general population (Dickinson et al., 2007). We believe this unexpected finding may derive from the use of appropriate controls and the inclusion of self-reports (as recommended by Wallander, Schmitt, & Koot, 2001), rather than from the higher frequency of milder forms of CP in our sample, which are not necessarily related to better adjustment (Arnaud et al., 2008). Another plausible explanation is that these results may well depict what has been coined in literature as the "disability paradox" (Albrecht & Devlieger, 1999) or "response shift" (Sprangers & Schwartz, 1999). These notions account for those clinical cases where maladjustment would be greatly expected by external observers, but it is not verified (or is even contradicted)

through patients' self-reports. Response shift, for instance, has been described as an adaptation process to health stressors, and its further examination in the context of pediatric CP could greatly expand our current knowledge on the diversity of trajectories that may emerge during these children and adolescents' development.

Regarding the dimensions of internalizing and externalizing problems, results were in agreement with previous research and confirmed our third hypothesis: boys presented more externalizing problems than girls, and adolescents presented more internalizing symptoms than children (Gortmaker, Walker, Weitzman, & Sobol, 1990; Yang, Li, Zhang, Tein, & Liu, 2008). The fact that differences in externalizing problems were only evident in parent-reports, may be due to the general assumption that parents are more reliable raters of their children's externalizing problems than children themselves (Youngstrom, Loeber, & Stouthamer-Loeber, 2000).

As regards the hypothesized moderated mediation model, the fact that no conditional indirect effects were observed, may well attest the model's adequacy in portraying a potential adaptation mechanism in children and adolescents with CP. Nevertheless, as suggested by our literature review, age and gender differences are likely to occur in the comparison of isolated variables or specific links between them. After all, this plausible claim was to be verified in our study, where age and gender were found to moderate the link between social support and parent-reported externalizing problems. This particular moderation effect may reflect the suggestion that social support is more influential on the level of externalizing problems in girls (Bender & Lösell, 1997), in addition to the observations that such problems are more common in children than in adolescents with CP (McCullough et al., 2011), and that statistical correlations with externalizing problems may only occur in proxy-reports (Janssen

et al., 2010). However, given the small sample size in which these effects were detected, their interpretation should be merely assumed as exploratory.

Finally, we found support for a multiple mediation model in which the link between social support and HRQL was mediated by two dimensions of psychological maladjustment, namely internalizing and externalizing problems. The need to identify variables that may mediate the path from social support to QL outcomes has been stressed in literature (Helgeson, 2003) and, in general terms, the understanding of such mechanisms is potentially enriching for both theory and practice (Shrout & Bolger, 2002). Our results indicate that one of the ways by which social support may be linked to the HRQL of children/adolescents with CP, is through its negative associations with psychological maladjustment. In terms of model reliability and clinical validity, it is noteworthy that such pattern of associations was consistent in both models accounting for self-reports only, and for concomitant child and parent-reports. Nevertheless, these findings do not exclude the existence of other mediating variables in the relationship between social support and HRQL (e.g. coping, health-related behaviors), and even more precisely, in the associations between social support and psychological maladjustment (e.g. social skills, isolation), and between psychological maladjustment and HRQL (e.g. psychosomatic reactions, stigma). Definitely, more research is needed to disentangle these varied patterns of associations between psychosocial determinants and HRQL outcomes.

Limitations and Strengths

The cross-sectional design of this study remains its major limitation. Although the direction of the relationship between variables was hypothesized, the study was based on a clear theoretical rationale and implemented reliable statistical procedures that allowed confidence in results for answering the research questions. Given the scarce literature on the

theme, this cross-sectional study offers promising insights to be further examined in future research. Sampling frames may also stand as a relevant limitation: heterogeneous distribution in a number of clinical variables, including a higher frequency of milder CP forms, argues for additional caution in generalizing the observed findings. Besides, our clinical sample was recruited in tertiary healthcare institutions, which may be prone to some form of selection bias (McDermott et al., 1996).

Albeit these limitations, three distinctive features of our study are to be acknowledged as considerable strengths: first, it “gave voice” to children/adolescents with CP (Varni et al., 2005), while simultaneously including parents’ reports in a dyadic perspective to outcome assessment (White-Koning et al., 2007), which has been more suggested than examined in research; second, it sought to integrate negative (i.e. psychological maladjustment) and positive (i.e. HRQL) dimensions in the assessment of adaptation outcomes; and last, it applied bootstrapping statistical procedures as a mean of model development for a pediatric group where psychosocial research is sparse, in order to clarify some of the mechanisms through which social support is likely to influence HRQL.

Clinical Implications and Future Directions

Findings from this study showed that social support was linked to HRQL both directly and indirectly, via internalizing and externalizing problems. In terms of clinical formulation, these results suggest that negative social support perceptions may impair the HRQL of children/adolescents with CP, through the deterioration of their psychological adjustment. In clinical practice, interventions targeting satisfaction with social support may assume a variety of forms (e.g. increasing participation, training social skills, enhancing positive family relationships), and may positively affect HRQL through the improvement of these child/adolescent’s psychological adjustment (i.e., prevention or reduction of internalizing and

externalizing symptoms). There is some evidence, for instance, on the efficacy of cognitive-behavioral interventions in reducing isolation and increasing social competence for certain pediatric populations (Barlow & Ellard, 2004), but the effectiveness of such interventions remains to be ascertained in children and adolescents with CP.

Longitudinal research is needed to clarify the directionality of the associations observed in this and other cross-sectional studies. Moreover, it would be important to further examine the occurrence of the “disability paradox” in pediatric CP, along with the identification of determinants (such as social support) related to that counterintuitive phenomenon. Finally, the comparison of adaptation patterns between children/adolescents with and without CP would be interesting to differentiate commonalities and specificities that may exist in the adaptation patterns of clinical and normative populations.

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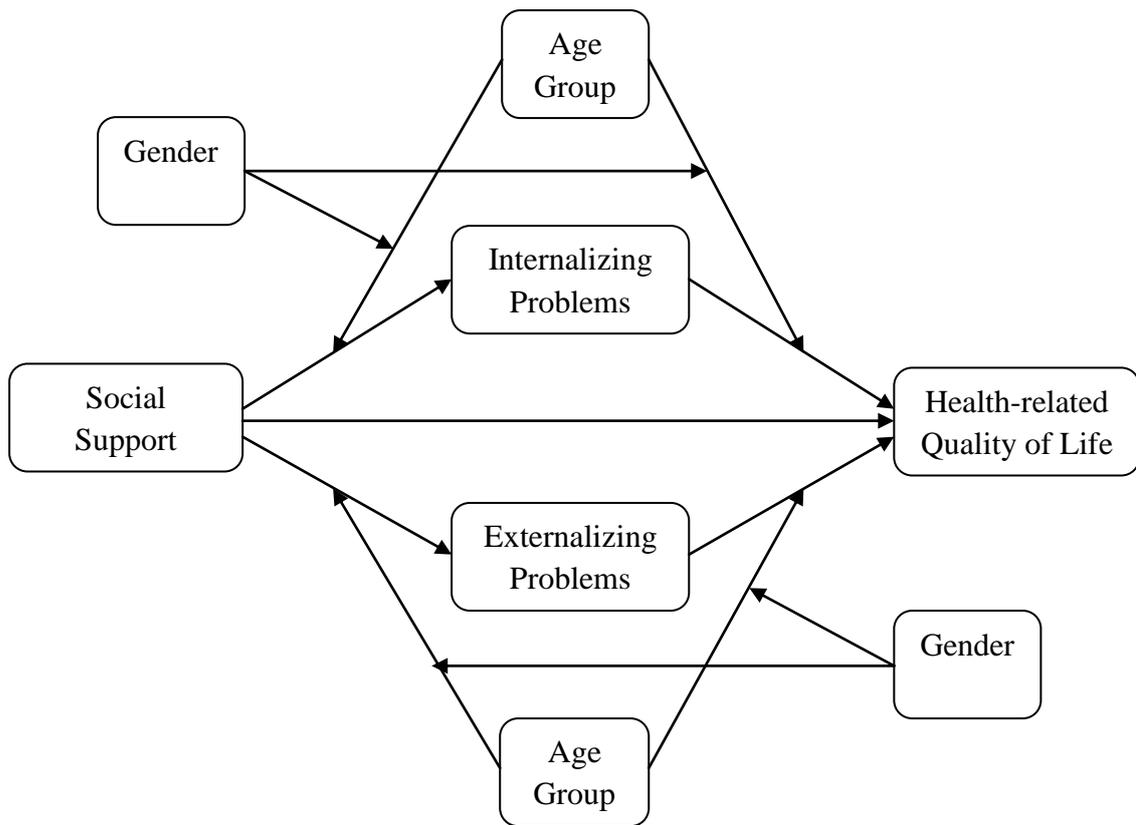


Figure 1. Gender and age group as moderators of multiple mediated pathways from social support to HRQL

Table 1. Socio-demographic and clinical characteristics of CP and control samples

| | CP Clinical Sample | | Healthy Controls Sample | | <i>Differences between Samples⁵</i> |
|--------------------------------------|----------------------------------|---------------------|-----------------------------------|----------------------|--|
| | Children/Adolescents (N = 96) | Parents (N = 96) | Children/Adolescents (N = 118) | Parents (N = 118) | |
| Age (M/SD) | 12.3 (2.8) | 41.8 (6.7) | 12.3 (3.0) | 42.7 (5.3) | $t = -.09$; $p = .93$ |
| Age Group (n/%) | | | | | |
| Children (8-12) | 48 (50.0) | - | 62 (52.5) | - | $\chi^2 = .05$; |
| Adolescents (13-18) | 48 (50.0) | | 56 (47.5) | | $p = .82$ |
| Gender (n/%) | | | | | |
| Male | 56 (58.3) | 12 (12.5) | 59 (50.0) | 22 (18.6) | $\chi^2 = 1.16$; |
| Female | 40 (41.7) | 84 (87.5) | 59 (50.0) | 96 (81.4) | $p = .28$ |
| Marital status: married (n/%) | - | 72 (75.0) | - | 99 (83.9) | - |
| SES¹ (n/%) | | | | | |
| Low | 59 (61.5) | | 31 (26.3) | | $\chi^2 = 29.88$; |
| Medium | 23 (24.0) | | 65 (55.1) | | $p = .00$ |
| High | 11 (11.5) | | 22 (18.6) | | |
| Missing | 3 (3.0) | | - | | |
| CP Type² (n/%) | | | | | |
| Spastic unilateral | 48 (50.0) | | | | |
| Spastic bilateral | 37 (38.5) | | | | |
| Dyskinetic | 4 (4.2) | | | | |
| Ataxic | 2 (2.1) | | | | |
| Missing | 5 (5.2) | | | | |
| GMFCS⁴ (n/%) | | | | | |
| I | 60 (62.5) | | | | |
| II | 13 (13.5) | | | | |
| III | 11 (11.5) | | | | |
| IV | 7 (7.3) | | | | |
| V | 3 (3.1) | | | | |
| Missing | 2 (2.1) | | | | |
| Epilepsy (n/%) | 12 (12.5) | | | | |
| IQ (M/SD) | 92.9 (17.8) | | | | |
| Cognitive level (n/%) | | | | | |
| Borderline ³ (71-84) | 31 (32.3) | | | | |
| Missing | 13 (13.5) | | | | |

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 Borderline Intellectual Functioning [V62.89], as defined in DSM-IV (APA, 1994).

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

⁵ Results of comparison tests for children/adolescents' variables.

Table 2. Differences in internalizing/externalizing problems and social support and matrix of inter-correlations among variables (correlations for CP sample only)

| | CP | Healthy | $F_{(1,202)}$ | p | η_p^2 | 1 | 2 | 3 | 4 | 5 | 6 |
|--|--------------|-----------------|---------------|-----|------------|--------|--------|--------|--------|-------|-------|
| | ($n = 93$) | controls | | | | | | | | | |
| | $M (SD)$ | $M (SD)$ | | | | | | | | | |
| 1. Self-reported internalizing problems | 5.99 (3.50) | 5.13 (3.06) | 1.29 | .26 | .01 | | | | | | |
| 2. Self-reported externalizing problems | 5.47 (3.25) | 5.07 (3.30) | .34 | .56 | .00 | .45** | | | | | |
| 3. Proxy-reported internalizing problems | 6.23 (3.64) | 4.12 (3.49) | 4.79 | .03 | .02 | .48** | .29** | | | | |
| 4. Proxy-reported externalizing problems | 6.81 (3.83) | 5.31 (3.71) | 3.10 | .08 | .02 | .20* | .53** | .30** | | | |
| 5. Self-reported social support | 42.89 (8.08) | 46.63 (7.76) | 4.96 | .03 | .02 | -.39** | -.33** | -.30** | -.34** | | |
| 6. Self-reported HRQL | - | - | - | - | - | -.59** | -.38** | -.35** | -.35** | .50** | |
| 7. Proxy-reported HRQL | - | - | - | - | - | -.37** | -.20* | -.58** | -.29** | .35** | .49** |

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

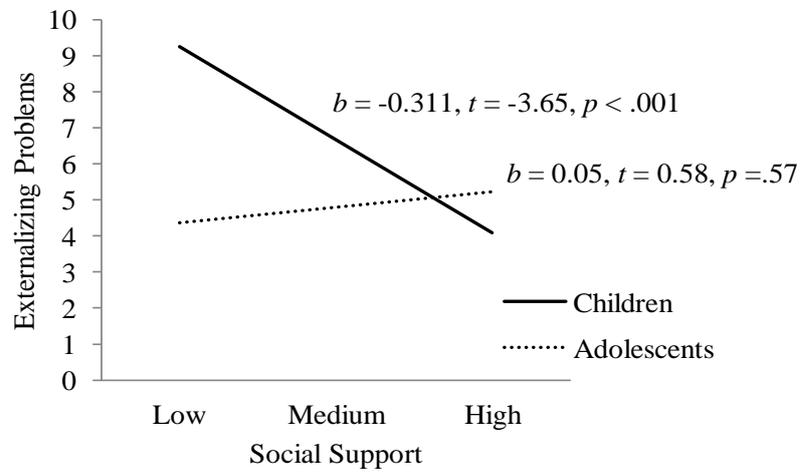


Figure 2. The moderating effect of age group in the association between social support and proxy-reported externalizing problems of child and adolescent girls with CP

Table 3. Summary of multiple mediation analyses for models including self and proxy-reported psychological maladjustment and HRQL (5000 bootstraps).

| | Independent variable | Mediating variable | Dependent variable | Effect of IV on M <i>b</i> (SE) | Effect of M on DV <i>b</i> (SE) | Direct effect <i>b</i> (SE) | Indirect effect <i>b</i> (boot SE) | 95% CI | Total effect <i>b</i> (SE) |
|---|----------------------|------------------------|--------------------|------------------------------------|------------------------------------|--------------------------------|---------------------------------------|-----------|-------------------------------|
| | (IV) | (M) | (DV) | (a) | (b) | (c') | (a*b) | | (c) |
| Self-reported psychological maladjustment and HRQL | Social Support | Internalizing problems | HRQL | -.15 (.04)** | -1.43 (.34)** | .46 (.14)** | .22 (.08) | (.09-.41) | .76 (.15)** |
| | | Externalizing problems | | -.12 (.04)** | -.63 (.36) ^a | | .08 (.05) | (.01-.23) | |
| Proxy-reported psychological maladjustment and HRQL | Social Support | Internalizing problems | HRQL | -.11 (.04)* | -2.57 (.40)** | .31 (.18) ^a | .28 (.12) | (.05-.55) | .71 (.20)** |
| | | Externalizing problems | | -.16 (.05)** | -.76 (.37)* | | .12 (.08) | (.01-.33) | |

Note. * $p \leq .05$, ** $p \leq .01$. ^a marginally significant ($p = .09$)