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**Quality of Life and its Correlates in Children with Cerebral Palsy: An Exploratory Study**

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Dissertação de Mestrado Integrado em Psicologia Clínica e da Saúde, Subespecialização em Intervenções Cognitivo-Comportamentais nas Perturbações Psicológicas e da Saúde, sob a orientação da Professora Doutora Maria Cristina Canavarro e Doutora Carla Crespo.

## **Qualidade de Vida e seus Correlatos em Crianças com Paralisia Cerebral: Um Estudo Exploratório**

A investigação recente tem mostrado um interesse crescente na avaliação da Qualidade de Vida (QdV) em crianças e adolescentes com condições crónicas de saúde, como uma medida de percepção subjectiva de saúde. No entanto, a QdV na população pediátrica com paralisia cerebral (PC) foi ainda pouco estudada, com escassas pesquisas a avaliar a QdV e as suas associações com outras variáveis psicológicas. A presente investigação analisou auto-relatos de Qualidade de Vida Relacionada com a Saúde (QdVRS) em 64 crianças e adolescentes com PC. Os resultados mostraram que uma maior QdVRS (genérica e específica para condições crónicas de saúde) se encontrava significativamente relacionada com níveis mais baixos de sintomas psicopatológicos, níveis mais elevados de comportamento pró-social e uma menor necessidade de actividades sociais. O género moderou a relação entre comportamento pró-social e QdVRS (específica para condições crónicas de saúde), que foi significativa para o género feminino, mas não para o masculino. Para as raparigas, mas não para os rapazes, níveis mais elevados de comportamento pró-social estavam relacionados com níveis mais elevados de QdVRS. Finalmente, a necessidade de actividades sociais mediou as associações entre sintomas psicopatológicos e QdVRS. Crianças e adolescentes com PC e com níveis mais elevados de sintomas psicopatológicos apresentavam uma maior necessidade de integrar actividades sociais, o que por sua vez se associava a uma avaliação mais negativa da sua QdVRS.

Palavras chave: Paralisia Cerebral; Qualidade de Vida; Sintomas Psicopatológicos; Comportamento Pró-social; Necessidade de Actividades Sociais.

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## **Lista das Abreviaturas**

CP – Cerebral Palsy

HRQoL – Health Related Quality of Life

PC – Paralisia Cerebral

QoL – Quality of Life

QdV – Qualidade de Vida

QdVRS – Qualidade de Vida Relacionada com a Saúde

WHO – World Health Organization

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**Figure 2.** The mediating role of need for social activities on the link between psychopathological symptoms and HRQoL (generic).

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**Table I.** Means, Standard Deviations, and Intercorrelations for the Study Variables

### **Introdução**

Tem-se assistido a um crescente interesse pela avaliação da Qualidade de Vida (QdV) em crianças e adolescentes, mas pouco se tem ainda estudado no campo da Paralisia Cerebral (PC) e a investigação é escassa relativamente às associações entre estas variáveis e outros indicadores de adaptação psicológica.

A PC é a deficiência motora mais frequente nos países desenvolvidos. Trata-se de uma situação clínica complexa e heterogénea cuja etiologia remonta a problemas pré, peri e pós-natais, havendo incertezas na atribuição causal desta patologia (Andrada et al., 2009). É uma condição de saúde irreversível, que coloca grandes desafios a quem apresenta esta condição e às suas famílias, mas que pode ser alvo de intervenção de forma a lhes proporcionar uma melhor QdV (Monteiro, 2009). A PC envolve alterações dos movimentos e/ou do controlo da postura e função motora (Centro de Reabilitação de PC Caloust Gulbenkian, 2006). A criança com PC pode ter uma inteligência normal, acima da média, ou ter um atraso intelectual (que, por vezes, impede ou dificulta verbalizações), pelo que, durante anos, os investigadores investiram na avaliação de questões relacionadas com a QV e com outros constructos subjectivos através de cuidadores primários. No entanto, hoje em dia, alguns trabalhos de relevo (e.g. Varni et al., 2005) têm acentuado a importância de se usarem as verbalizações das próprias crianças. Hauser-Cram e Krauss (2004) referem que as investigações devem incluir os relatos dos adolescentes com deficiências desenvolvimentais, na medida em que são eles os detentores de informações-chave relativamente ao que se passa nas suas vidas a nível social, emocional e relacional. Para além do atraso mental, outros problemas têm vindo a ser associados à PC: epilepsia, problemas visuais e auditivos e problemas de comportamento (Bax & Tydeman, 2010). Investigações recentes têm referido que o prognóstico da PC se relaciona com variáveis tais como o ajustamento social e emocional destas crianças.

Para se tentar entender a forma como uma criança ou um adolescente com condições crónicas de saúde se adapta à sua doença, ao tratamento da mesma e às repercussões que esta terá na sua QdV, é imprescindível considerarmos as idiossincrasias de cada condição, adoptando uma perspectiva desenvolvimental, utilizando múltiplos informadores e múltiplos instrumentos de avaliação. Alguns modelos teóricos darão, sem dúvida, o seu contributo que é imprescindível para a compreensão da adaptação

individual e familiar a uma condição crónica de saúde. De facto, a identificação dos predictores de adaptação e adesão à terapêutica que sejam modificáveis permite o delineamento de estratégias de intervenção idiossincráticas. Um modelo teórico de referência nas questões de adaptação às condições crónicas é o de Pless e Pinkerton (1975), que foi dos primeiros a enfatizar o papel dos processos psicológicos, para além dos factores genéticos, sociais e familiares que determinariam (segundo o modelo) as características da criança. Todas estas variáveis interagiriam com parâmetros da doença (como a gravidade) e as reações e atitudes de familiares, professores e pares, determinando o auto-conceito e o estilo de *coping* da criança e, consequentemente, a sua adaptação. O funcionamento psicológico seria o resultado das interações estabelecidas anteriormente. Na tentativa de colmatar as lacunas deste modelo, e dos que se lhe seguiram, surge o Modelo, conceptual e integrador, de Wallander e Varni (1989, 1995) que descreve uma relação bidireccional entre factores de risco (i.e. gravidade da patologia, stressores psicológicos, etc.) e factores de resistência intrapessoais (e.g. temperamento, factores de competência), de processamento do stress (e.g. avaliação cognitiva dos recursos) e sócio-ecológicos (apoio social e recursos familiares). Assim, o referido modelo tem em consideração a forma como a própria criança avalia a sua condição e se adapta à mesma (Wallander et al., 1989; Wallander & Varni, 1995). É este o modelo teórico de partida para a presente investigação que procura compreender de forma mais aprofundada a QdV nesta população. O conhecimento dos factores protectores de adaptação psicológica, nomeadamente a QdV, poderá ter grandes implicações quer ao nível da prevenção quer da intervenção no âmbito da Paralisia Cerebral Pediátrica.

A presente tese será submetida, em formato de artigo, a uma revista de arbitragem científica. De seguida, encontra-se o manuscrito tal como será submetido.

## Abstract

Recent research has shown a growing interest in the assessment of Quality of Life (QoL) in children and adolescents with chronic health conditions as a subjective health outcome. However, QoL in the pediatric population with cerebral palsy (CP) is still understudied, with scarce research assessing self-reported QoL and its links with other psychological variables. The present research examined self-reported health related quality of life (HRQoL) in 64 Portuguese children and adolescents with CP. Results showed that higher HRQoL (generic and specific to chronic health conditions) was significantly related to lower levels of psychopathological symptoms, higher levels of prosocial behavior and a lower need for social activities. Gender moderated the link between prosocial behavior and HRQoL (specific to chronic conditions), which was significant for girls but not for boys. Finally, the need for social activities mediated the associations between psychopathology symptoms and both measures of HRQoL.

**Key Words:** Cerebral Palsy; Quality of Life; Psychopathological symptoms; Prosocial behaviour; Need for social activities.

Cerebral palsy (CP), a condition prevalent in an average of two per 1000 live births (Johnson, 2002), is characterized by a set of permanent characteristics such as impediments in movement, posture and motor function (Bax et al., 2005). This condition is the most frequent etiology of incapacity in developed countries (Winter et al., 2002) and the most common of all congenital disorders (Wiley & Renk, 2007). Growing up with CP is a challenge: these children must progressively cope with the psychological, social, and physical consequences related to this condition (Ivan & Glazer, 1994; Wiley & Renk, 2007). In addition, children with CP often present a variety of physical and psychosocial comorbidities, the most common being epilepsy; hearing, visual, behavioral and intellectual difficulties (Bax & Tydeman, 2010). Furthermore, some research has reported that children and adolescents with CP have a more deteriorated QoL (Varni et al., 2005; Viehweger et al., 2008). Most studies within the CP population so far privileged proxy reports (e.g. Davis et al., 2010; Parkes et al., 2010; Wiley & Renk, 2007) rather than



self-reports of QoL (for an exception see Varni, Burwinkle, & Lane, 2005). However, some authors have recommended that researchers and clinicians should allow individuals to report on their own well-being (Shikako-Thomas et al., 2009). Recent studies showed empirical evidence that researchers can and should hear “the voices of the children” with CP (Varni et al., 2005, p. 592). Despite this recognition, there is a significant lack of research in evaluating the impact of CP on children’s self-reported QoL (Livingston et al., 2007; The Disabkids Group, 2006).

Another area requiring more research is in the identification of psychosocial factors linked with QoL (generic and health-related) in children and adolescents with CP. There is insufficient knowledge about factors which account for better QoL in this population. Besides the scarcity of research in this area, the majority of studies also rely on proxy reports of QoL’s correlations (Varni et al., 2005). The present study intends to address the aforementioned lack of research by assessing the self-reports of children with CP who reported on their Health Related Quality of Life (HRQoL), prosocial behavior, psychopathological symptoms, and the need for social activities (as an indicator of satisfaction with social support).

### **Quality of Life**

QoL has been defined as the individual’s perception of their well-being and satisfaction with life which must be assessed in the context of their culture, personal values and expectations (WHO, 1995). Research shows inconsistent response agreement from children and proxy in their assessment of HRQoL in both children with chronic health conditions and healthy children (Varni et al., 1994). This is especially true when assessing emotional responses, where parent proxy-report and child self-report correlate only modestly (Eiser & Morse, 2001). In a study aimed at understanding the differences on HRQoL between proxy-reports and self-reports on children with CP, Gates, Otsuka, Sanders and Mcgee-Brown (2010) concluded that perceptions of adolescents and their parents differed significantly. Varni and colleagues (2005), using a sample of children with CP and their parents, found that 47% of the sample (69 participants) was able to provide self-reports and that 16 of those were between 5 and 7 years old. Results from this study also showed a low correlation between children self-reports and proxy-reports of the

child's emotional functioning. Another study aimed at evaluating the correlation between two QoL scales (the CP QOL-Child and the Kidscreen-10), Davis, Shelly, Waters and Davern (2010) found that there were higher correlations between the two instruments when self-reports, instead of proxy-reports, were used. Moreover, there were fewer floor and ceiling effects when the children reported their own QoL.

Comparative studies of children and adolescents' QoL present heterogeneous findings. There are studies which demonstrate that children with CP have a more deteriorated QoL and HRQoL (Varni et al., 2005; Viehweger et al., 2008). Varni et al. (2005) found that children with CP self-reported a significantly lower HRQoL than healthy children, and about the same to HRQoL for pediatric cancer patients receiving treatment. Morales (2005) and Russo and colleagues (2008) found that children with CP had lower levels of QoL than their healthy peers. However, some studies reported different results. In a study with 27 children with CP, Lim and Wong (2009) found that just 11.1% of them reported severely affected QoL, with 37% (the majority) reporting mildly affected QoL. In another study, Dickinson and colleagues (2007) found that children with CP had similar QoL compared to children in the general population. They suggested that these findings could be explained by the fact that, from birth, the child incorporated their impairment on their sense of self. This way, children can embrace growth, development and living with the same excitement of other young people. Along with the need of more descriptive and comparative studies, research in pediatric CP is yet to address factors associated with children and adolescents QoL.

### **Quality of Life Correlations**

#### **Prosocial behavior**

Prosocial behavior can be defined as a voluntary behavior with the intention to benefit another individual (e.g. Staub, 1979). Prosocial adolescents tend to be popular and well liked among peers, (Caprara et al., 2000), to have high self-esteem (Johnson et al., 1998) and academic success (Caprara, et al., 2000). According to Youniss (1980), prosocial behavior is a relevant concept because building relational bonds and helping another is something that adolescents give importance to.

Research has shown a link between psychopathological

symptoms and poor social adjustment during adolescence and adult psychopathology (East et al., 1992). A study with a sample of adolescents with either CP or spina bifida (Anderson & Clarke, 1982) found that 31% reported they did not see friends outside school, and concluded that social isolation was the most common source of stress for these youths. Yude, Goodman and McConachie (1998), examining the social experiences of 55 children with hemiplegia found that they had twice the risk, when compared to their peers, of being rejected and of having no or few friends, as well as being three times more likely to be victimized.

In a study about determinants of daily function in children with CP, Tseng and colleagues (2011) found that children with CP scored high on prosocial behavior and that those who scored higher had better capacity and performance of daily function than those who scored lower. In explaining their results, the authors suggested that children with high levels of prosocial behavior also had an increase in compliance with others, a higher willingness to see what others requested from them and to help them accordingly and thus, had more opportunities to practice daily life skills and improve their daily function.

### **Psychopathological symptoms**

According to Wallander and Varni (1989), chronically ill and handicapped children present an increased risk of developing adjustment problems, particularly those with chronic cerebral disorders compared to their non-disabled peers (Rutter et al., 1970). There is evidence which suggests that children from 4 to 18 years with chronic conditions involving the central nervous system are more likely to have behavioral problems (McDermott et al., 1996). This emotional and behavioral maladjustment could be due to negative social experiences (e.g. exclusion or bullying; Yude et al., 1998) or by a direct link between the brain and behavior (Goodman & Graham, 1996). Parkes and colleagues (2008) evaluated the profile of 818 children with CP aged between 8 and 12 years and found that approximately one quarter of the sample was located in the abnormal level of psychological problems. The most frequent disorders were hyperactivity (31%), and peer (32%) and emotional problems (29%). Parkes and McCusker (2008), in another study with chronically ill children or with disabilities found that they were at increased risk of emotional and behavioral disturbance and that this risk increased

if there were neurological defects implicated. Carlsson, Olsson, Hagberg and Beckung (2008) came to the conclusion that behavioral problems are common in children with CP, even more when they also have epilepsy. Goodman and Graham (1996)'s research with children with hemiplegic CP found that psychiatric disorders were present in more than half of the sample. They also pointed out that literature and previous studies have shown that children with CP and other chronic cerebral disorders have a significantly augmented rate of emotional and behavioral problems. Wiley and Renk (2007) concluded that literature shows a correlation between emotional and behavioral functioning and children's QoL in children with CP. With their sample of children with CP, these authors found that children's internalizing behavioral problems predicted significantly their QoL.

### **Social Support: The Role of Social Activities**

Social support has been indicated as an important resource for individuals with chronic disabilities (Almeida & Sampaio, 2005; Moos, 2002). Satisfaction with social support has been inferred as a source of health and well-being, being positively associated with several positive outcomes for children and adolescents such as mental health (Gaspar et al., 2009; Rodin & Salovey, 1989). The ways in which support is conveyed can be diverse. For instance, it can be emotional or they can engage in joint activities, this last one being of great relevance to children and adolescents. Davis et al., (2009) found that adolescents with CP, who had poorer functioning, also had more health issues, finding daily tasks more difficult. However, these adolescents communicated their need to participate and to try out new things even if it required extra adjustments to make it possible. Links between participation in activities related to social support and QoL was illustrated by the qualitative study developed by Shikako-Thomas and colleagues (2009) aiming at assessing the perspectives of adolescents with CP. Results showed that adolescents had specific representations about their QoL, which included being involved in activities chosen by themselves, namely participating in a variety of activities with their friends such as hanging out or talking to their friends. In this study, adolescents expressed the desire to participate in a wider range of activities than the ones they were involved in at the time. Authors concluded that even if very little is known about the specific factors that influence

participation of adolescents with disabilities, there was co-evidence that in order to be content with one's life satisfaction, it was important for them to pursue and participate in a wide variety of activities of their liking (Shikako-Thomas et al., 2009). This fact gains increased relevance as Parkes, McCullough, and Madden (2010) found that, when compared to their able-bodied peers, children with CP had significantly reduced frequency of participation in some activities, specifically social situations, community activities, games and sports, non-sporting activities and pursuing cultural events. The authors suggested that this lack of opportunities could make them feel more socially isolated, which is in tune with past literature identifying peer problems as a significant issue for children with CP (Parkes et al., 2008; Yude, Goodman & McConachie, 1998).

### **Psychopathological Symptoms and QoL: Examining the Role of Social Support**

Although there is an established link between emotional and behavioral problems and poorer QoL in children with CP, there is still little knowledge about the process underlying this association. One of the possible avenues by which psychopathological symptoms can affect children's QoL is through the perceptions of the quality and availability of social support from different sources. A piece of research conducted by Henriques and Lima (2003) showed that individuals with negative emotional states tend to evaluate negatively their social support, which is likely to have a negative impact on a range of outcomes. Rockhill and colleagues (2009) tested this hypothesis in a study examining the links between psychopathology and functional outcomes on a middle school sample (healthy adolescents). They found that low social competence and social support mediated the relationship between psychiatric symptoms (depression and conduct problems) and lower grades. These results indicate that the perception of the social world can be affected by emotional problems, according to the theoretical rationale that the early emotional development of the child is the basis for the child's later social development (Schaffer, 1996). Our research, presented next, intended to expand Rockhill and colleagues' research by assessing the aforementioned mediation hypothesis in a cerebral palsy pediatric sample, by examining QoL as an outcome and by using self-reported measures of the three intervening variables.

## Study Aims and Hypotheses

The present study aimed at examining correlates of HRQoL (generic and specific for chronic conditions) in a sample of 64 Portuguese children with CP. Drawing on Wallander & Varni's model, we identified, at the intrapersonal level, psychopathological symptoms as a possible risk factor and prosocial behavior as a possible resistance factor in regard to HRQoL. At the socio-ecological level, we considered the need for social activities as a risk factor for poorer HRQoL. Three goals were set. Firstly, the intention was to examine the links between psychopathological symptoms, prosocial behavior, the need for social activities, and HRQoL (generic and specific for chronic conditions). An hypothesis was made that higher levels of psychopathological symptoms would be associated with lower levels of prosocial behavior and HRQoL and with a higher need for social activities. In addition, it was expected that prosocial behavior would be linked to better HRQoL, whereas a need for social activities would be associated with poorer HRQoL in children with CP. Secondly, based on the acknowledged importance of assessing gender effects in this specific population (e.g. Bullinger et al., 2006), we examined if gender moderated the links between psychopathological symptoms, prosocial behavior, and a need for social activities and HRQoL. In the absence of previous literature on this topic, no specific hypothesis was posed. Finally, the goal was to evaluate the process by which psychopathological symptoms were associated with lower HRQoL. It was predicted that need for social activities mediated the associations between psychopathological symptoms, generic and chronic conditions-specific HRQoL. Specifically, a prediction was made that more emotional and behavioural problems would be linked to a lack of fulfilling and satisfactory activities with others, which subsequently would be associated with poorer HRQoL.

## Method

### Participants

Participants in this study consisted of 64 Portuguese children/adolescents<sup>1</sup> diagnosed with CP, aged between 8 and 18 ( $M=12.03$ ,  $SD=3$ ). The majority of the sample was male (51.6%).

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<sup>1</sup> The term children was chosen when referring to this study's sample which includes both children and adolescents.

The clinicians' assessment of the severity of the disability reported that the majority of participants (67.2%,  $n = 43$ ) had level I (Walks and climbs stairs, without limitation), 12.5% ( $n = 8$ ) had level II (walks with limitations), 9.4% ( $n = 6$ ) had level III (walks using a hand-held mobility device), 9.4% ( $n = 6$ ) had level IV (self-mobility with limitations; may use powered mobility) and 1.6% ( $n = 1$ ) had level V (transported in a manual wheelchair) according to GMFCS-CP (Palisano, et al. 2008). In terms of the CP type, the majority of participants (51.6%,  $n = 33$ ) had Unilateral Spastic CP Form, 37.5% ( $n = 24$ ) had Bilateral Spastic CP Form, 3.1% ( $n = 2$ ) had Dystonic, 1.6% ( $n = 1$ ) had Dyskinetic and 1.6% ( $n = 1$ ) had Ataxic CP. These children attend regular schools and live in the family context, but they came regularly to a rehabilitation center.

### **Procedure**

Participants were recruited at the outpatient services of the Coimbra Cerebral Palsy Association, Portugal, between September 2010 and February 2011. The children had to meet the following inclusion criteria in order to be included in this study: (a) aged between 8 and 18; (b) clinical diagnosis of CP by a qualified physician according to the international classification systems (ICD-10; WHO, 1993); (c) available consent form from children and their parents. Exclusions of children from this study were made according to the subsequent criteria: (a) children who refused to participate, regardless of their parents' previous consent; (b) significant developmental delay, interfering with the assessment of thoughts and emotions, the ability to understand questions and the maintenance of an adequate conversation.

The data collection process was authorized by the directive board of the aforementioned association. Informed consent forms were obtained from children and their parents. The protocols were filled in by the child in the presence of a research assistant in a consultation office provided for this purpose. The researcher assisted whenever there were difficulties in reading/interpreting or writing. Clinicians used the Gross Motor Function Classification System Expanded and Revised (Palisano et al. 2008) in order to assess participants' CP severity.

## **Measures**

### **Prosocial behavior and Psychopathological symptoms**

In order to assess psychopathological symptoms and prosocial behavior, we used the Portuguese version of the Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997; Fleitlich, Loureiro, Fonseca & Gaspar, 2005), a 25-item questionnaire which assesses the psychopathological symptoms of children in terms of emotional and behavioral problems. The items are divided into five subscales: one subscale assessed prosocial behavior and the remaining four subscales (emotional symptoms, behavioral problems, hyperactivity and relationship problems with peers) were summed and averaged to produce an overall index of Psychopathological symptoms. Participants answered on a 3-point Likert scale ranging from “not true”, “a little bit true” to “very true”. Examples of the items used are “I worry too much” (to evaluate the emotional symptoms); “I get angry and I lose my mind very often” (to evaluate behavior problems); “I’m always distracted. I have difficulty focusing myself” (to evaluate hyperactivity); and “Other children or young people mess with me, threaten me, intimidate me” (to evaluate relationship problems with peers). Examples of items used to evaluate the prosocial behavior are “I try to be nice to other people. I worry about what they might feel” or “I like to help when someone is hurt, upset or sick”. Carlsson, Olsson, Hagberg and Beckung, (2008), state that the SDQ should be used in children with CP and that it is an adequate instrument for children with milder motor impairments and communicative skills.

### **Need for social activities**

To evaluate the need for social activities we used the subscale of Need for Activities Connected to Social Support (Gaspar, Pais-Ribeiro, Leal, Matos, & Ferreira, 2009). This subscale is comprised of 5 items. Participants must answer on a Likert scale ranging from 1 “I totally agree” to 5 “I totally disagree”. Items are: “My friends do not come to see me as often as I would like”, “Sometimes I miss someone really close who understands me and with whom I can share personal issues”, “I’m with my friends as often as I want to be”, “I miss social activities that fulfill me” and “I would like to participate more in organized activities of (eg.



sports clubs, scouts, etc.)”. The use of this scale with Portuguese children and adolescents’ samples has been increasing and it has proved to be a psychometrically sound measure (Almeida & Sampaio, 2005).

### **Health-Related Quality of Life Generic**

The KIDSCREEN-10 was used (Ravens-Sieberer et al., 2010; Gaspar & Matos, 2008) for the assessment of generic HRQoL. The 10 items of the KIDSCREEN 10, (e.g. “Were you able to pay attention?”; “Did you have enough time for yourself?”) reported on the previous week’s frequency. The answers were on a 5-point Likert-type response scale (“never”, “rarely”, “sometimes”, “often”, “always”). The items of this assessment scale were standardized according to norms available for the Portuguese population (Gaspar & Matos, 2008).

### **Specific for chronic conditions**

The DISABKIDS Chronic Generic Module (European DISABKIDS Group, 2006; Carona, Bullinger & Canavarro, in press) was used for the assessment of HRQoL specific for chronic conditions. Participants had to report on the “past four weeks” on a Likert scale ranging from 1 (“never”) to 5 (“always”). They answered 37 items (e.g. “Do you feel confident about your future?”; “Are you able to do everything you want in spite of your health problem?”). This measure assesses the physical, psychological and social domains.

## **Results**

### **Descriptives and Zero-Order Correlations**

Means, standard deviations, Cronbach’s alphas and Pearson’s correlations among all the study variables are shown on Table 1. It was found that higher levels of psychopathological symptoms were associated with higher levels of the need for social activities,  $r = .46$ ,  $p < .01$ . and with poorer HRQoL,  $r_s = -.35$  and  $-.45$ ,  $ps < .01$ . Prosocial behavior was only significantly related to HRQoL (generic),  $r = .27$   $p < .05$ , and marginally related to generic HRQoL (chronic conditions). Gender was only related with

prosocial behavior, with girls reporting higher levels than boys. Finally, there were negative correlations between the need for social activities and HRQoL (generic) as well as HRQoL (chronic conditions),  $r_s = -.37$  and  $-.41$ ,  $p_s < .01$ . Age was only related to prosocial behavior and the need for activities.

In order to assess gender and age group differences, we performed a series of t-tests for psychopathological symptoms, prosocial behavior and the need for social activities and a MANOVA with HRQoL (generic) and HRQoL (chronic conditions) as dependent variables. We found only one significant gender difference in prosocial behavior: girls reported higher levels of prosocial behavior ( $M = 1.84$ ,  $SD = .27$ ) than boys ( $M = 1.63$ ,  $SD = .40$ );  $t(54.42) = -2.48$ ,  $p = .016$ ,  $d = .062$ .

### **Moderation Analyses**

In order to test the moderating effect of gender on the associations between psychopathological symptoms, prosocial behavior and the need for social activities as well as HRQoL, a series of hierarchical regressions were conducted. Only one significant interaction between prosocial behavior and gender was found. Next, using ModGraph, (Jose, 2008) this significant interaction was plotted (see Figure 1). Results showed that lower levels of prosocial behavior were associated with lower levels of HRQoL (chronic conditions), and that this association was particularly important for females. Post-hoc simple slope analysis was performed. It was verified that for girls HRQoL (chronic conditions) changed according to levels of prosocial behavior ( $B = 1.07$ ,  $t = 3.46$ ,  $p = .001$ ), whereas for boys this link was non-significant ( $B = .08$ ,  $t = .42$ ,  $p = .68$ ).

### **Mediation Analyses**

Two mediations were conducted using bootstrapping (Preacher, & Hayes, 2004, 2008) since this procedure does not require the assumption of normality of the sampling distribution of the indirect effects. Plus, it allowed a better control for a Type I error and higher statistical power (MacKinnon et al., 2004) being a more appropriate procedure in small samples (Preacher & Hayes, 2008). The bootstrapping procedure, a nonparametric resample statistic can be used in order to estimate indirect effects. The program repeats the process several times (in this case, 5000

bootstrap samples) in order to generate an empirical approximation of the sample distribution of the indirect effect, providing point estimates along with confidence intervals for this effect (Preacher & Hayes, 2004, 2008). The SPSS version of Preacher and Hayes's macro was used. The interpretation of the bootstrap data can be accomplished if zero is not comprehended in the 95% bias-corrected and accelerated confidence intervals (BCa 95% CI).

In Figures 2 and 3 the following effects are presented: IV (independent variable) on the proposed mediator (M; path a), the effects of M on the DV (dependent variable) partialling out the effect of IV (path b) and the direct effect of IV on the DV after controlling for M (path c') as well as the total effect of IV on DV (path c). The indirect effect of IV on DV through M ( $a \times b$ ) was calculated and it was found that the need for social activities significantly mediated the two links examined (see Figure 3): the link between psychopathological symptoms and HRQoL (generic), (point estimate =  $-.06$ , CI =  $-.11/-.01$ ); and the link between psychopathological symptoms and HRQoL (specific for chronic conditions), (point estimate =  $-.05$ , CI =  $-.13/-.02$ ). These analyses were re-run controlling for age and gender and results did not change significantly.

## Discussion

The main purpose of the study was to identify correlates of self-reported HRQoL on a CP pediatric sample. Specifically, we aimed at identifying psychopathological symptoms and the need for social activities as possible risk factors, and prosocial behavior as a possible resistance factor in regard to HRQoL (generic) and HRQoL (chronic conditions).

As predicted in the first hypothesis, a negative correlation between psychopathological symptoms and HRQoL (generic and specific for chronic conditions) was found. Literature suggests that psychopathological symptoms are important variables when studying children with CP, because they have an increased risk in having adjustment problems (McDermott et al., 1996; Parkes et al., 2008; Wallander & Varni, 1989). Plus, the results are in line with past research showing a link between emotional and behavioral functioning and children's QoL in children with CP (Wiley & Renk, 2007). Against predictions, no significant association between psychopathological symptoms and prosocial

behavior was found, which may be due to the small sample size not allowing identification of medium to small-size correlations.

As expected, when children had higher levels of psychopathological symptoms, they also reported a higher need for social activities given that satisfaction with social support is an important resource for well-being and improved mental health (Gaspar et al., 2009; Wallander & Varni, 1989). It is legitimate to consider that when a child presents more psychopathological symptoms, they might have a stronger subjective experience of isolation and thus, find themselves wishing for more activities where they can engage with others and the social world. These activities can be an important vehicle through which they feel supported by significant others in their life contexts like family and peers. This result is especially relevant for children with CP since it is known that the decrease in frequency of activities (Parkes et al., 2010) has a negative effect in the way they feel (eg. more isolation and peer problems; Yude et al., 1998; Parkes et al., 2008).

It was also found, as expected, that higher levels of prosocial behavior were linked to better HRQoL (both generic and specific for chronic conditions). As Anderson and Clarke (1982) pointed out, social isolation is linked to more stress and thus, young people, who engage in more prosocial behavior are more likely to feel better about themselves and their lives. We found that prosocial behavior was more strongly reported by girls than boys, a finding based on self-reports that is in tune with past research based on parents' reports: Tseng and colleagues (2011) in a study of parents with children with CP found that parents tended to rate girls higher than boys in terms of their social competence. Research shows that girls tend to have higher scores of prosocial behavior than boys, and that prosocial behavioral components like agreeableness and conscientiousness are typically considered as female characteristics (Pursell et al., 2008). These results could be due to gender differences in the altruistic (cf. Pursell et al., 2008), but also from gender differences in social contexts that could be responsible for influencing girls' prosocial behavior (Zakriski et al., 2005). Concerning the need for social activities, it was identified, as expected, that when children reported a higher need, they also reported poorer HRQoL, both generic and specific for chronic conditions. A way to look at this finding is to consider a higher need for social activities as a sign that children are not currently satisfied with an important part of their lives, which is

reflected on the less positive way they appraise their own HRQoL.

In regard to the second goal, it was found that only one of the hypothesized links was moderated by gender, which is the link between prosocial behaviour and HRQoL. For girls, but not for boys, higher levels of prosocial behaviour were linked to higher HRQoL. These findings can be interpreted in light of socialization of gender roles. In their friendships, girls reveal more empathy, a greater need for nurturance, and the desire for and ability to sustain intimate relationships (Galambos, 2004). According to this perspective, children develop specific gender roles according to what they observe and also to what is expected from them, i.e., there are tasks and roles that people expect more from girls than from boys. If the social world, and significant others, expect girls to be more attentive to other's needs and available to help them, it is likely that girls, compared to boys, place a higher value on this dimension. Thus, when they perceive to be engaging in prosocial behavior, girls might feel that an important part of their lives is working out as expected and might receive positive feed-back about their behavior from others, which will contribute to feeling better about themselves and their lives.

Finally, it was found that the need for social activities mediated the associations between psychopathology symptoms and HRQoL (generic) and also HRQoL (chronic conditions), as predicted in the third hypothesis. Children with CP with more adjustment problems experience a greater need to be engaged in activities with others, which in turn, is associated with a lower subjective appraisal of their life, i.e, their HRQoL. Literature tells us that social development is affected by children's emotional development (Rockhill et al., 2009; Schaffer, 1996; Varni et al., 1994), an approach which allows an understanding of how adjustment problems can lead to difficulties in engaging with others and an overall lack of rewarding and frequent social activities. Children who don't think they are involved in sufficient social activities are likely to feel disconnected from others, which has a negative impact in their quality of life. Children with CP might be especially vulnerable given that they have less autonomy in organizing and introducing change to their daily lives, a task that parents and formal caregivers usually take responsibility for.

### **Limitations of the Study**

This study's main limitation was the reduced sample size. It is likely that other small to medium significant effects (mainly gender and age) and associations could have been identified with a larger number of participants. In addition, given the reduced participants' diversity, we were not able to assess the effect of this condition's type and gross motor impairment. Furthermore, participants were recruited at the same institution, which can raise questions concerning the generalization of the present results, however, they came from different districts in Portugal (around 1/3 of the national districts are included). Finally, the cross-sectional nature of our data determines that the results of the mediation hypothesis should be interpreted with caution. Although it was possible to clarify part of the process by which psychopathological symptoms were linked to HRQoL's in this sample, it is also possible that a third, higher-order variable could explain variability in psychopathological symptoms and the need for social activities and also their links to HRQoL's.

### **Conclusion**

Despite previous considerations, the present study has several strengths. First of all, it relied on self-reports and not on proxy reports as the majority of the studies with this population. As Hauser-Cram and Krauss (2004) pointed out, research designs should include "...adolescents with developmental disabilities as key informants about their lives. (...) [they] have much to teach us about how they view their own development socially and emotionally and about how their relationships with their parents, siblings, and peers change..." (p.714). Overall, the study reaffirms the importance of assessing children with CP own perceptions about their subjective experiences and the need to use reliable and valid child self-report instruments such as the DISABKIDS and the KIDSCREEN.

Secondly, this research addressed some issues currently being discussed in the field of pediatric CP, examining children's HRQoL's correlates and identifying if poorer adjustment was linked to poorer HRQoL (generic) via the need for social activities. In addition, the findings of this study have important implications for practice. The results show that children with CP benefit greatly from social activities and feel happier about their

lives when they feel they are engaged in frequent and satisfactory activities with family and peers. Furthermore, children with adjustment problems seem to be especially at risk of decreased social support provided by social activities, a result which highlights the relevance of interventions targeted at promoting these activities for all children with CP and, especially, for those with more adjustment difficulties. Some authors have defended the notion that the inclusion of children with disabilities in regular schools could improve their social participation and support networks outside school. However, more research is needed to establish an evidence base to support this claim (Schenker, Coster & Parush, 2005). In conclusion, the field of pediatric CP will benefit from more studies, with larger samples and self-reports based on assessing which factors, under which conditions can promote HRQoL in children and adolescents facing this challenging condition.

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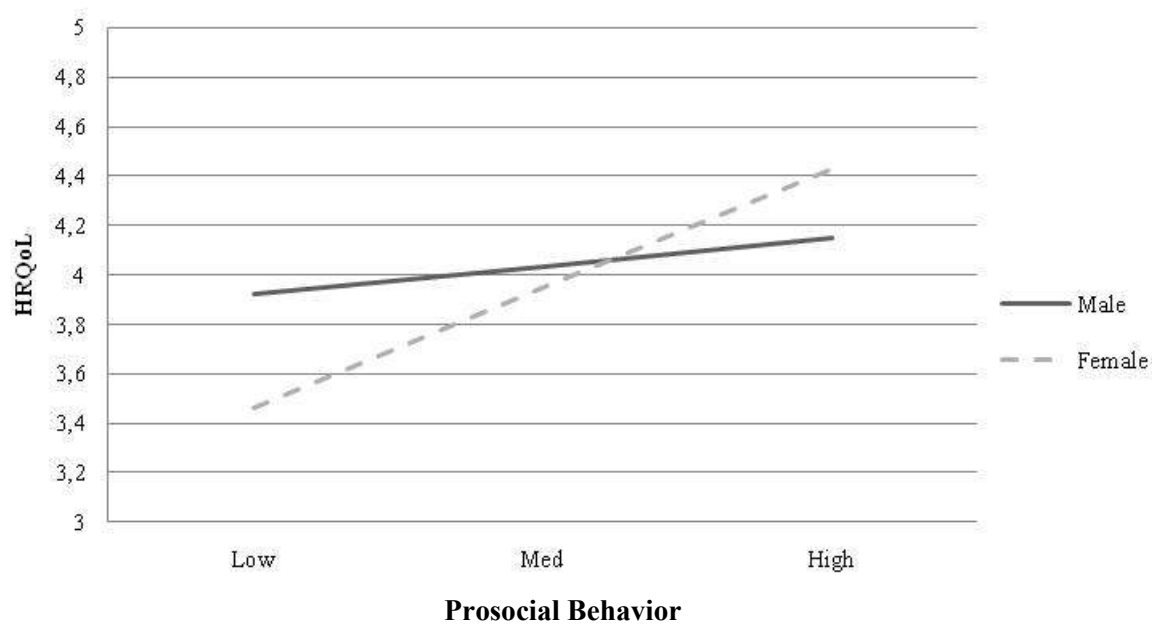
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**Table I.** Means, Standard Deviations, and Intercorrelations for the Study Variables

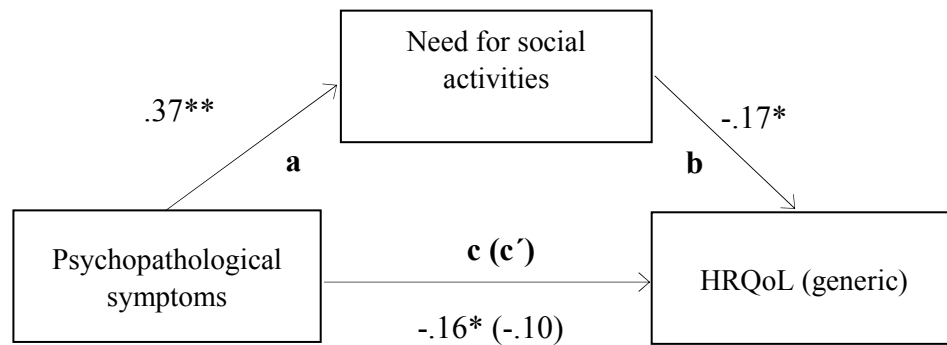
<b>Variables</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>1. Prosocial behavior</b>	--					
<b>2. Psychopathological symptoms</b>	-.22	--				
<b>3. Need for social activities</b>	.05	.46**	--			
<b>4. HRQoL (Generic)</b>	.27*	-.35**	-.37**	--		
<b>5. HRQoL (Chronic conditions)</b>	.25~	-.45**	-.41**	.66**	--	
<b>6. Age</b>	-.26*	.15	-.26*	-.13	-.11	--
<b>7. Gender</b>	.30*	-.11	-.07	.05	.02	
<b><i>M</i></b>	1.73	2.84	2.23	4.06	4.00	12.03
<b><i>SD</i></b>	.36	1.28	1.02	.57	.52	3.00
<b><i>α</i></b>	.74	.70	.78	.74	.89	

*Note.* *N* = 64

\**p* < .05; \*\**p* < .01; ~*p* = .06



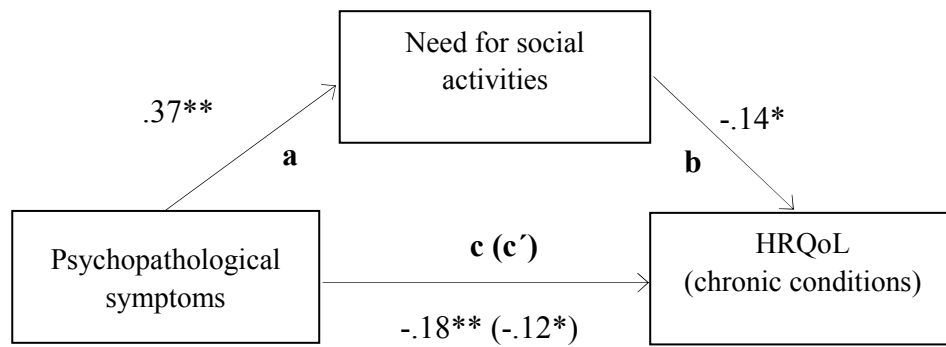
**Figure 1.** The moderating effect of gender on the association between Prosocial behavior and HRQoL (chronic conditions).



Note. Numbers shown are the unstandardized regression coefficients. The value inside parentheses represents the direct effect of IV on DV after controlling for mediator (path c'). \* $p < .05$  \*\* $p < .01$

Figure 2. The mediating role of need for social activities on the link between psychopathological symptoms and HRQoL (generic).





*Note.* Numbers shown are the unstandardized regression coefficients. The value inside parentheses represents the direct effect of IV on DV after controlling for mediator (path c'). \* $p < .05$  \*\* $p < .01$

Figure 3. The mediating role of need for social activities on the link between psychopathological symptoms and HRQoL (chronic conditions).

### Conclusões Finais

O principal objectivo deste estudo foi o de **identificar variáveis que se relacionam com a QdVRS (genérica e específica para condições crónicas de saúde), através de auto-relatos de crianças e adolescentes com PC**. Mais especificamente, objectivou a *identificação de sintomatologia psicopatológica* e da *necessidade de actividades sociais* como possíveis factores de risco e o *comportamento pró-social* como um factor de resistência no que concerne à QdVRS.

Estudos como este podem ter um importante impacto nas medidas tomadas pelos técnicos e serviços de saúde, ajudando a orientar a sua intervenção e prevenção, bem como os apoios específicos e necessários para a definição de estratégias promotoras da QdV e Saúde Mental de crianças e adolescentes com PC.

Vejamus esta questão mais pormenorizadamente: no nosso estudo, encontramos uma correlação negativa entre sintomatologia psicopatológica e QdVRS; e uma correlação positiva entre sintomatologia psicopatológica e necessidade de actividades sociais. Um resultado relevante, e que (do nosso conhecimento) não foi encontrado até agora nesta população, foi o papel mediador das necessidades de actividades sociais na associação entre sintomatologia psicopatológica e QdVRS. Uma vez que estas crianças têm um maior risco em desenvolver sintomatologia psicopatológica (McDermott et al., 1996; Parkes et al., 2008; Wallander & Varni, 1989), os profissionais de saúde, que com esta população trabalham, devem não só prestar mais atenção a possíveis manifestações a fim de as detectar precocemente, como actuar a fim de as prevenir de forma eficaz.

Sabe-se que altos níveis de sintomas psicopatológicos se relacionam com altos níveis de necessidades de actividades sociais e que uma diminuição na frequência de actividades se relaciona com mais sintomas negativos em crianças com PC (como o isolamento ou problemas com os pares; Yude et al., 1998; Parkes et al., 2008). A inclusão destas crianças em actividades pode ter um papel preventivo ou mesmo “remediativo”, fazendo-as sentir que têm apoio por parte dos outros e encontrando formas que proporcionem a interacção com o seu ambiente social. Perceber se as crianças e adolescentes com PC recebem apoio para lidar com as suas dificuldades, se têm cuidados diários suficientes, se recebem atenção e apoio das pessoas próximas (e.g. familiares e amigos), se estão bem

ajustados na escola e na comunidade ou se se sentem marginalizados, são algumas questões pertinentes sobre as quais os clínicos poderão continuar a reflectir quando estão perante uma criança ou adolescente com PC. Estes resultados abrem, ainda, brechas importantes para o trabalho a nível da prevenção primária com estas crianças (mesmo em contexto escolar ou comunitário). Poder-se-iam, por exemplo, criar protocolos com exercícios que promovam o comportamento pró-social. Há a necessidade de se articularem os serviços de saúde mental, as escolas e a comunidade na promoção da saúde e bem-estar dos jovens. O trabalho do psicólogo com estas crianças deve centrar-se, também, nos aspectos positivos e não apenas na sintomatologia psicopatológica. Deve ser feita uma intervenção biopsicossocial e de cariz multi-disciplinar que respeite as várias áreas de vida dos indivíduos e que integre diferentes profissionais.

No entanto, os nossos resultados devem ser lidos à luz das suas limitações. Trata-se de um estudo com uma amostra de apenas 64 participantes. Apesar de se tratar de uma amostra muito especial e de difícil “alcance”, com uma maior amostra poder-se-iam ter em atenção outras questões, especialmente se se conseguisse um número equitativo de participantes com diferentes graus de gravidade ou representativa dos diversos tipos de PC. Deve ter-se ainda em atenção que o presente estudo, dado o seu carácter transversal, não pôde identificar a direcção da causalidade da associação entre as diversas variáveis (encontradas no nosso estudo).

Apesar das limitações, a presente investigação tem vários pontos fortes, dos quais se salientam dois, um ao nível da metodologia de avaliação das variáveis e outro ao nível dos resultados. Em relação ao primeiro, consideremos a definição de QdVRS (conceito multidimensional e multideterminado): trata-se de uma percepção individual de bem-estar e satisfação com a vida, que deve ser avaliada tendo em conta o contexto, a cultura, os valores e as expectativas pessoais (WHO, 1995). Na nossa investigação, utilizámos questionários de auto-avaliação com a finalidade de avaliarmos a perspectiva da criança e do adolescente, e não a opinião dos seus cuidadores. Existem questões importantes que podem e devem ser avaliadas também pelos pais e outros cuidadores, (e.g. a perspectiva económica, questões de interacção familiar) e que devem ser usadas quando a criança não tem outra forma de comunicar. No entanto, para avaliarmos algo tão subjectivo e pessoal, como as variáveis

utilizadas neste estudo, em situações nas quais as crianças têm capacidades e meios para o fazer, ninguém melhor para responder aos questionários do que elas próprias. Acreditamos que este estudo reforça a ideia de que se deve ter em conta determinantes da saúde percebida pelos próprios jovens, quer na PC, quer noutras condições crónicas de saúde.

Em relação aos resultados, esta investigação atestou a evidência empírica (muito escassa nesta população) das relações entre QdVRS e as diversas variáveis em estudo. Não temos conhecimento de outros estudos portugueses que tenham abordado simultaneamente estas variáveis específicas na nossa população-alvo, e esperamos ter ajudado à compreensão e divulgação destas questões nos meios académicos e científicos.

Investigações futuras deverão contornar as questões levantadas pelas limitações do nosso estudo, mas também deverão ter em conta múltiplas fontes de informação complementares; incluir outras variáveis como a resiliência, os estilos de *coping*, o QI ou o estigma social; e avaliar se essas ou outras são variáveis mediadoras (excepto o QI) e/ou moderadoras da relação entre QdV e Saúde Mental. A estigmatização social pode ser uma variável de estudo importante, na medida em que poderá levar a um maior isolamento e menor comportamento pró-social, acarretando, conseqüentemente, as dificuldades que temos vindo a enumerar. Seria pertinente analisar a comorbilidade com outras doenças e o impacto que estas têm nas medidas de adaptação psicológica e investir-se no estudo das dimensões positivas que permitem compreender a adaptação a uma condição de saúde pediátrica.

Acreditamos, sobretudo, que o nosso estudo pode demonstrar aos profissionais de saúde e, principalmente aos pais de crianças e adolescentes com PC, que é possível promover factores positivos e trajectórias adaptativas que influenciem o ajustamento psicológico e o bem-estar desta população.

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