

# Do Clinical And Psychosocial Factors Affect Health-Related Quality of Life in Adolescents with Chronic Diseases?

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## Abstract

Living with a chronic disease in adolescence can have an impact on the perception of Health-related Quality of Life (HRQoL). Facing the increasing relevance of psychosocial dimensions and also considering the interaction with clinical variables, this study aimed to measure the impact of clinical and psychosocial factors (separated and combined) on adolescent's reported HRQoL.

A cross-sectional study was conducted in a clinical population of 135 adolescents with chronic diseases (n=70 boys), average age: 14±1.5 years old. Through a self-reported questionnaire, HRQoL (KIDSCREEN-10), socio-demographic, clinical variables (diagnostic; time of diagnosis; self-perceived pain; disease severity proxy; disease-related medication intake/use of special equipment), and psychosocial variables (psychosomatic health; resilience; self-regulation; social support) were assessed.

Separately, clinical and psychosocial variables showed a significant impact in HRQoL, 27.9% and 62.4%, respectively. Once combined, the previously identified variables had a significant impact (64.2%), but a different contribution from clinical and psychosocial variables was revealed: when first entering the clinical variables (model 1) the variance only reaches 30%, and much more from psychosocial variables seems to explain the total (64.2%); inversely, when first integrating psychosocial variables (model 2), the clinical ones added a small significance to the model (0.6%).

The present study underlined the association of clinical ("disease-related") and psychosocial ("non-disease-related") factors on HRQoL. Furthermore, it reinforced the need to focus more on psychosocial dimensions, highlighted the potential role of psychosomatic health, resilience, self-regulation and social support. It can be suggested that the identification of impaired psychosocial domains may help professionals to better plan, and achieve effective interventions of psychosocial care.

**Keywords:** adolescents, chronic disease, clinical variables, psychosocial variables, health-related quality of life

## 1. Introduction

In the last 40 years, advances in pediatric medicine have reduced the mortality rates of many fatal chronic diseases, increasing the survival of youths into adolescence and adulthood (Sattoe et al., 2015). However, living with chronic disease in adolescence still have a significant high risk for poor Quality of Life (QoL) and health-related quality of life (HRQoL) (Alba et al., 2013; Elsenbruch, Schmid, Lutz, Geers, & Schara, 2013; Mellion et al., 2014),

particularly in psychological functioning (Moreira et al., 2013; Santos, Matos, Simões, & Machado, 2015; Williams, Sharpe, & Mullan, 2013) and social dimensions (Carona, Moreira, Silva, Crespo, & Canavarro, 2014; Compas, Jaser, Dunn, & Rodriguez, 2012). HRQoL is generally conceptualized as a multidimensional psychological construct including physical, mental, social and spiritual areas of life and general well-being (Eiser & Morse, 2001; Ravens-Sieberer et al., 2001; 2005). The adolescent-friendly health service concept (WHO, 2012) suggests the need to also include physical, psychological, and social perspectives in HRQL conceptualizations. Relying on the World Health Organization's (WHO) definitions of health (WHO, 1978), QoL and HRQoL are important constructs given their implications for health outcomes, well-being and a successful daily life in adolescents (Gaspar, Ribeiro, Matos, Leal, & Ferreira, 2012; Suris, Michaud, & Viner, 2004).

The aspects comprising HRQoL in chronically ill adolescents can be divided into two factors: disease-related factors (age of onset, disease severity, complications, treatment, sense of normality and positive attitude towards the disease), and non-disease-related factors (age, gender, socioeconomic status, support of parents, social wellbeing and support) (Sawyer, Spurrier, Kennedy, & Martin, 2001). Recent literature has enlightened disease-specific determinants of HRQoL, such as physical ability, pain, subjective burden of medication use (Haverman et al., 2012), diagnosis (Herzer, Denson, Baldassano, & Hommel, 2011; J. Wang, Y. Wang, L. B. Wang, Xu, & Zhang, 2012; Zashikhina & Hagloff, 2014), severity of the disease (Mellion et al., 2014; Vanhalst et al., 2013; Zashikhina & Hagloff, 2014), school absence (Cortina et al., 2010; Haverman et al., 2012) and illness perception (Williams et al., 2013). In addition, non-disease factors were also considered determinants for HRQoL, namely anxiety/depression (Velasco, Martín, Díez, Pérez, & Amigo, 2012), gender (Williams et al., 2013; Zashikhina & Hagloff, 2014), age (Alba et al., 2013; Moreira et al., 2013; Zashikhina & Hagloff, 2014), socioeconomic status (Herzer et al., 2011; Zashikhina & Hagloff, 2014), quality of peer relationship (Rassart et al., 2012), social interaction/social support (Carona et al., 2014; Elsenbruch et al., 2013; Vanhalst et al., 2013) and parents' support (Békési et al., 2011; Williams et al., 2013).

In youths, perceptions of HRQoL can be influenced by a dynamic interdependence between several demographic, personal and social factors (The KIDSCREEN Group Europe, 2006; Ravens-Sieberer et al., 2001; 2005; Houtrow, Jones, Ghandour, Strickland, & Newacheck, 2012). Nevertheless, as a child advances in age, psychosocial elements seem to be more important for self-perceived QoL, than biomedical/physical ones (Payot & Barrington, 2011). Thus, psychosocial variables can assume a crucial role, more than the presence, per se, of the physical dimensions of a health condition (Denny et al., 2014; Mackner, Bickmeier, & Crandall, 2012; Olsen et al., 2012). As a result, chronic disease's assessment should be less focused on diagnostic categories (more prone to variability), and more centered on the impact that the disease might have on the socialization process, emotional health, and general limitations in ordinary activities (Denny et al., 2014; van der Lee, Mookink, Grootenhuis, Heymans, & Offringa et al., 2007). Supporting this idea, clinical settings have been progressively recognizing the need to complement traditional health indicators with psychosocial factors (Health, 2013; Watson, 2014), which requires a routinely assessment in pediatric contexts (Mellion et al., 2014; Moreira et al., 2013). Moreover, to include such factors in clinical decision making and research is necessary, mainly once to manage symptoms and to improve psychosocial care are nowadays primary goals of interventions (Elsenbruch et al., 2013; Health, 2003; Marmot et al., 2012; Pulkki-Råback et al., 2015; Watson, 2014).

Facing the increasing relevance of psychosocial dimensions, but also taking into account the interaction with clinical variables, this study aimed to measure the impact of clinical and psychosocial factors (first separated; and afterwards combined) on adolescent's reported HRQoL.

## 2. Method

### 2.1 Participants, Design and Procedure

This cross-sectional study included 135 chronically ill adolescents ( $n=70$  boys) with a mean age of 14 ( $SD=1.5$ ) years old, attending a clinical appointment in the paediatric outpatient department of Centro Hospitalar Lisboa Norte – CHLN EPE (North Lisbon Central Hospital). The majority of the adolescents had Portuguese nationality ( $n=132$ ), lived in Lisbon ( $n=114$ ) and attended the 7th-9th school grades ( $n=72$ ). The adolescents were diagnosed with neurologic diseases, or allergic diseases, or diabetes mellitus, and the focus on these chronic diseases was based on the evidence of their high prevalence in adolescence (Barros, 2009).

Prior to data collection, ethical approval for this study was obtained from The Ethics Committee for Health from CHLN-EPE, the institution's ethical committees (Compliance with Ethical Standards: Reference PCA-12 Nov.2012-0785). Accordingly with the World Medical Association Declaration of Helsinki's guidelines (WMA, 2013), the description of the study's aims and participants' rights was delivered. The participation was voluntary, and the agreement and informed consent required by the ethical committee was filled by both adolescents and their

parents. Participants were then selected and during the medical appointments they were directly approached by their health professionals (physicians and/or nurses). Health professionals (paediatricians) helped to identify the inclusion criteria for this study: 1) to have diagnosis of specific chronic disease, such as diabetes mellitus, or allergic diseases, or neurologic diseases); 2) to be between 12 and 16 years old at the time of the study, including both age groups of young teens (12–14 years old) and teenagers (15–17 years old), defined by the Centers for Disease Control and Prevention – CDC (CDC, 2016); 3) to have cognitive skills that allow to fill the questionnaire autonomously. Data was collected using a self-reported questionnaire, either after or before the medical appointment according to the most convenient moment. Research assistance was available to provide support whenever necessary.

## 2.2 Measures

The self-reported questionnaire was completed by adolescents, including HRQoL, socio-demographic, clinical and psychosocial variables. Socio-demographic variables comprised age, gender, geographic region, nationality, education level of adolescents, and educational level of adolescent's parents (a proxy for socioeconomic status). Clinical variables consisted of diagnosis, time since diagnosis, self-perceived pain, disease-related use of special equipment, and the following 3 items: 1) disease-related medication intake; 2) “Does your long-term illness, disability or medical condition affect your attendance and participation in leisure activities with friends, classmates (PLTF)? No/Yes”; 3) “Does your long-term illness, disability or medical condition affect your attendance and participation at school (PSCH)? No/Yes”. These three items are included in the international study Health Behaviour in School-aged Children - HBSC/WHO (Matos & Equipa Aventura Social, 2000–2014; Roberts et al., 2009) and items 1 and 3 constitute its optional package The Chronic Condition Short Questionnaire - CCSQ (Mazur et al., 2013). Focused on the disease's consequences (missing school classes, medication), such items permit to assess the impact of a chronic health condition on the adolescents' activities, helping to understand its psychosocial impact. In addition, they seem to show considerable strengths over a single, open-ended item, and co-existing problems related to medication intake, and/or missing school classes are reported as good indicators of severity (Mazur et al., 2013). Thus, all of these items together were considered in the present study as a proxy for disease's severity. To assess Self-perceived Pain, it was used a combination of the most common Pain's Perception Analogic Scales suggested in the literature (Cohen et al., 2007; Jensen, 2008; von Baeyer & Spagrud, 2007), namely the Visual Analogue Scale (VAS), the Numerical Rating Scale (NRS) (Breivik, Björnsson, & Skovlund, 2000; Hollen et al., 2005), and the Faces Scale of Wong-Baker (Wong & Baker, 1988), which are also in accordance with the recommendation of the Portuguese Health Ministry (DGS, 2010). Due to the small size of the sample, the adolescents were grouped not by categories of disease's intensity, but according to feeling or not feeling pain.

The psychosocial variables (described in detail in Table 1) included Health-related Quality of Life - HRQoL (KIDSCREEN-10 Index), Symptoms Check-List (Psychosomatic Health Complaints - SCL), Resilience (Scale Healthy Kids Resilience Assessment Module - RES), Self-regulation (Scale Adolescent Self-Regulatory Inventory - ASRI, SR), and Social Support (Scale of Satisfaction with Social Support - SSSS).

Table 1. Psychosocial Variables

Name	Psychosocial Measure	Abbreviation (in this study)	Short Description
KIDSCREEN-10 Index (Gaspar & Matos, 2008; Ravens-Sieberer et al., 2010; Matos et al., 2006, 2010).	Health-related quality of life – HRQoL	KIDS-10	<ul style="list-style-type: none"> <li>• Short version of KIDSCREEN-52;</li> <li>• Used in the HBSC/WHO Study (Currie et al., 2001; Roberts et al., 2009).</li> <li>• 10 items, on a 5-point Likert-type scale;</li> <li>• Ranges from 0 to 100;</li> <li>• Lower values reflect feelings of unhappiness, dissatisfaction and inadequacy. Higher values show feelings of happiness, perception of adequacy and satisfaction within adolescent's life contexts.</li> <li>• <math>\alpha = .83</math></li> </ul>

Symptoms Check List (SCL-HBSC) (Ravens-Sieberer et al., 2008; Ravens-Sieberer et al., 2009)	Psychosomatic complaints (unidimensional latent trait).	SCL	<ul style="list-style-type: none"> <li>Used in the HBSC/WHO Study ((Currie et al., 2001; Roberts et al., 2009).</li> <li>8 items focusing on subjective physical and psychological health complaints;</li> <li>Each item answered on a 5-point Likert-type response scale;</li> <li>Resulting values between 1 (worst health) and 5 (best health);</li> <li>Ranges from 8 to 40.</li> <li><math>\alpha = .78</math></li> </ul>
Healthy Kids Resilience Assessment Module (Austin, Bates & Duerr, 2013; Martins, 2005)	Resilience (2 dimensions: external and internal resources).	RES	<ul style="list-style-type: none"> <li>The present study only used the internal resources;</li> <li>18 items answered on a 4-point scale;</li> <li>Ranges from 18 to 72;</li> <li>Higher scores indicate higher levels of competences, protection and resilience to adversity.</li> <li><math>\alpha = .0.72^1</math></li> </ul>
Adolescent Self-Regulatory Inventory – ASRI (Moilanen, 2007)	Self-regulation (2 dimensions: Short term-SR-ST and Long term-SR-LT).	SR	<ul style="list-style-type: none"> <li>In this study the instrument was translated from the original English version into Portuguese language (and back translation). It was then revised by a group of specialized experts within the area and a pre-test in schools with a group of students was conducted.</li> <li>36 items answered on a 5-point Likert scale;</li> <li>Ranges from 36 to 180.</li> <li>Higher values indicate better competences of self-regulation.</li> <li><math>\alpha = .0.79^1</math></li> </ul>
Scale of Satisfaction with Social Support (Gaspar,Ribeiro, Matos, Leal & Ferreira, 2009; Ribeiro, 1993)	Satisfaction with social support (2 dimensions: Satisfaction with Social Support-SSS; and Need for Activities connected to Social Support-NASS).	SSSS	<ul style="list-style-type: none"> <li>Translation and adaptation for children and adolescents of a Satisfaction with Social Support Scale for adults;</li> <li>12 items answered on a 5-point scale;</li> <li>Ranges from 18 to 72;</li> <li>Higher scores indicate higher satisfaction with social support (SSS) or higher satisfaction for not feeling the need to have more social support activities (NASS).</li> <li><math>\alpha = .85^1</math></li> </ul>

<sup>1</sup> Value for the total score of the scale.

### 2.3 Statistical Analysis

Descriptive statistics (means, standard deviation and percentage) were used to characterize the sample. All data were tested for normality prior to any analyses using Shapiro-Wilk and Kolmogorov-Smirnov tests, as well as Levene's test for the homogeneity of the variance. In a first moment, multiple linear regressions were used to assess,

separately, the extent to which clinical and psychosocial variables were associated with health-related quality of life (HRQoL) for the total group of adolescents. Later, two more multiple linear regressions (model 1 and model 2) were conducted only using the previously identified significant clinical and psychosocial variables. Model 1 comprised two steps: in the first step, the clinical variables were included; and in the second step, the psychosocial were added; in model 2 both steps were entered inversely. Multiple linear regressions were controlled for age and gender. The categorical variables were transformed into dummy variables. All statistical analyses were completed using IBM Statistical Package for Social Sciences (SPSS), version 22.0. The significance level was set at  $p < 0.05$ .

### 3. Results

The socio-demographic and the clinical variables included in the study for the total group of adolescents are presented in Table 2.

Table 2. Participant's socio-demographic and clinical characteristics

<b>Socio-Demographic Variables</b>	<b>Total Group (N=135)</b>
<b>Age (years) (M±SD)</b>	14.0±1.5
<b>Gender (%)</b>	
Boy	51.9
Girl	48.1
<b>Geographic Region (%)</b>	
Lisbon	84.4
Rest of the Country	15.6
<b>Nationality (%)</b>	
Portuguese	97.8
Others	2.2
<b>Educational Level – Adolescents (%)</b>	
Basic 2 <sup>nd</sup> Level (5 <sup>th</sup> -6 <sup>th</sup> Grades)	21.5
Basic 3 <sup>rd</sup> Level (7 <sup>th</sup> -9 <sup>th</sup> Grades)	53.3
Secondary Level (10 <sup>th</sup> -12 <sup>th</sup> Grades)	25.2
<b>Educational Level – Father<sup>1</sup> (%)</b>	
Basic Level (1 <sup>st</sup> -9 <sup>th</sup> Grades)	64.6
Secondary Level (10 <sup>th</sup> -12 <sup>th</sup> Grades)	23.6
Superior (or more) Level (Universitary, Post-Graduate)	11.8
<b>Educational Level – Mother<sup>1</sup> (%)</b>	
Basic Level (1 <sup>st</sup> -9 <sup>th</sup> Grades)	53.8
Secondary Level (10 <sup>th</sup> -12 <sup>th</sup> Grades)	29.5
Superior (or more) Level (Universitary, Post-Graduate)	16.7

HRQoL – Health-related Quality of Life; KIDS-10 - KIDSCREEN; PSCH - “chronic condition affects/not affects participation and attendance at school”; PLTF - “chronic conditions affects/not affects participation in leisure time with friends”; RES - Resilience; SCL - Symptoms Check List; SR - Self-regulation; SSSS – Scale of Satisfaction with Social Support.

<sup>1</sup> Considered as a proxy of socioeconomic status.

<sup>2</sup> Considered as a proxy of disease's severity.

Table 2. Participant's socio-demographic and clinical characteristics (Continued)

<i>Clinical Variables</i>	
<b>Chronic Condition diagnosis (%)</b>	
Diabetes	31.9
Allergic Diseases	46.7
Neurologic Diseases	21.5
<b>Time since diagnosis (years) (M±SD)</b>	7.5±4.7
<b>Self-perceived pain (%)</b>	
No	43.0
Yes	57.0
<b>Disease-related use of special equipment (%)</b>	
No	61.5
Yes	38.5
<b>Disease-related medication intake<sup>1</sup> (%)</b>	
No	34.8
Yes	65.2
<b>Chronic Condition affects SCHOOL (PSCH)<sup>2</sup>? (%)</b>	
No	82.2
Yes	17.8
<b>Chronic Condition affects LEISURE TIME WITH FRIENDS (PLTF)<sup>2</sup>? (%)</b>	
No	86.7
Yes	13.3
<i>Psychosocial Variables (M±SD)</i>	
SCL	35.6±4.8
RES	58.4±7.8
SR	119.9±14.4
SSSS	45.1±8.6
<i>HRQoL (M±SD)</i>	
KIDSCREEN - 10	79.7±12.5

HRQoL – Health-related Quality of Life; KIDS-10 - KIDSCREEN; PSCH - “chronic condition affects/not affects participation and attendance at school”; PLTF - “chronic conditions affects/not affects participation in leisure time with friends”; RES - Resilience; SCL - Symptoms Check List; SR - Self-regulation; SSSS – Scale of Satisfaction with Social Support.

<sup>1</sup> Considered as a proxy of socioeconomic status.

<sup>2</sup> Considered as a proxy of disease's severity.

This study included 135 adolescents having three diagnosed chronic diseases: diabetes (n=43), allergic diseases (n=63), or neurologic diseases (n=29). The adolescents had a mean time of diagnosis of 7.5 (SD=4.7) years, the majority took medication (n=88) and generally did not use special equipment (n=83) related to the chronic disease. Most of them felt that living with a chronic disease did not affect school participation - PSCH (n=111), nor social participation - PLTF (n=117).

Table 3 shows the results of the multiple linear regression analysis, separately, for clinical and psychosocial variables, for the total group of adolescents with chronic diseases, adjusted by age and gender.

Table 3. Summary of multiple linear regression results between HRQoL and clinical and psychosocial variables (separately), in adolescents with chronic disease, adjusted by age and gender.

	Clinical Included Variables	<i>B</i>	<i>SE B</i>	$\beta$	
HRQoL	Diagnostic (asthma disease)	2.519	4.372	0,101	
	Diagnostic (neurologic disease)	4.346	4.036	0.144	
	Diagnostic (diabetes)	-2.519	4.372	0.566	
	Time since diagnostic (years)	-0.100	0.219	-0.038	
	Disease-related medication intake <sup>1</sup>	0.741	2.707	0.028	
	Disease-related use of special equipment <sup>2</sup>	2.518	3.537	0.098	
	Self-perceived Pain <sup>3</sup>	-5.192	1.940	-0.206**	
	PSCH <sup>4</sup>	-9.456	2.835	-0.291***	
	PLTF <sup>5</sup>	-7.968	3.352	-0.218*	
		<i>R</i> <sup>2</sup>			27.9%
	<i>F</i>			6.157***	
	Psychosocial Included Variables	<i>B</i>	<i>SE B</i>	$\beta$	
HRQoL	SCL	0.761	0.161	0.295***	
	RES	0.285	0.105	0.183**	
	SR	0.126	0.056	0.149*	
	SSSS	0.595	0.100	0.412***	
	Educational Level - Father	-0.391	0.866	-0.032	
	Educational Level - Mother	-0.523	0.864	-0.042	
		<i>R</i> <sup>2</sup>			62.4%
		<i>F</i>			26.917***

Note. *B* (unstandardized coefficient) and *SE* (standard error);  $\beta$ : standardized coefficients.

\*\*\* $p \leq .001$ ; \*\* $p \leq .01$ ; \* $p \leq .05$

Analysis were adjusted for age and gender.

<sup>1</sup> No Use of medication was used as the reference group.

<sup>2</sup> No Use of special equipment was used as the reference group.

<sup>3</sup> No self-perceived pain was used as the reference group.

<sup>4</sup> Not affecting SCH was used as the reference group.

<sup>5</sup> Not affecting LTF was used as the reference group.

HRQoL – Health-related quality of life; PLTF - “chronic conditions affects/not affects participation in leisure time with friends”; PSCH - “chronic condition affects/not affects participation and attendance at school”; SCL – Symptoms Check-List; SSSS - Satisfaction with Social Support; SR – Self-regulation; RES – Resilience.

A model was achieved for clinical variables [F(10,123)=6.157,  $p < 0.001$ ,  $R^2 = .279$ ]. The variables self-perceived pain and the items PSCH and PLTF had a significantly association: the adolescents that did not have Self-Perceived Pain, nor felt that the disease affected PSCH, tended to have a higher perception of their HRQoL. No differences were found for the variables: time since diagnosis, disease-related use of special equipment or medication intake.

A model was also achieved for the psychosocial variables [F(8,117)=26.917,  $p < 0.001$ ,  $R^2 = .624$ ]. The variables SCL, RES, SR and SSSS had a significantly association: adolescents with better psychosomatic health (reporting

less symptoms), higher levels of resilience, self-regulation and social support were more likely to perceive their HRQoL as more satisfying. No differences were found for the educational level (father or mother).

Table 4 shows the summary of results between HRQoL and the previously identified significant clinical and psychosocial variables (model 1), when first entering the clinical variables (step 1), and afterwards the psychosocial variables (step 2).

Table 4. Summary of multiple linear regression results between HRQoL and the previously identified significant clinical (step 1) and psychosocial variables (step 2), in adolescents with chronic disease, adjusted by age and gender (Model 1).

<b>Model 1</b>								
<b>(Step 1 - Clinical Variables)</b>					<b>(Step 2 - Clinical and Psychosocial Variables)</b>			
	<b>Variables</b>	<b>B</b>	<b>SE B</b>	<b><math>\beta</math></b>	<b>Variables</b>	<b>B</b>	<b>SE B</b>	<b><math>\beta</math></b>
<b>HQoL</b>	Self-perceived Pain <sup>1</sup>	-5.182	1.883	-.206**	Self-perceived Pain <sup>1</sup>	0.483	1.510	0.019
	PSCH <sup>1</sup>	-9.380	2.747	-.288***	PSCH <sup>1</sup>	-2.322	2.208	-0.071
	PLTF <sup>1</sup>	-7.172	3.082	-.196*	PLTF <sup>1</sup>	-0.384	2.323	-0.011
					SCL <sup>2</sup>	0.723	0.179	0.280***
					RES <sup>2</sup>	0.300	0.102	0.188**
					SR <sup>2</sup>	0.101	0.056	0.116
					SSSS <sup>2</sup>	0.589	0.100	0.408***
	<b>R<sup>2</sup></b>			.300	<b>R<sup>2</sup></b>			.642
	<b>F</b>			12.472***	<b>F</b>			27.744***

Note. B (unstandardized coefficient) and SE (standard error);  $\beta$ : standardized coefficients.

\*\*\*p $\leq$ .001; \*\*p $\leq$ .01; \*p $\leq$ .05

Analysis were adjusted for age and gender.

<sup>1</sup> Clinical Variables

<sup>2</sup> Psychosocial Variables

HRQoL – Health-related quality of life; PLTF - “chronic conditions affects/not affects participation in leisure time with friends”; PSCH - “chronic condition affects/not affects participation and attendance at school”; SCL – Symptoms Check-List; SSSS - Satisfaction with Social Support; SR – Self-regulation; RES – Resilience.

Table 5 shows the summary of results between HRQoL and the previously identified significant clinical and psychosocial variables (model 2), when first entering the psychosocial variables (step 1), and afterwards the clinical variables (step 2).



Table 5. Summary of multiple linear regression results between HRQoL and the previously identified significant psychosocial (step 1) and clinical variables (step 2), in adolescents with chronic disease, adjusted by age and gender (Model 2).

Model 2								
(Step 1 - Psychosocial Variables)					(Step 2 – Psychosocial and Clinical Variables)			
	Variables	B	SE B	$\beta$	Variables	B	SE B	$\beta$
HQoL	SCL <sup>2</sup>	.859	.148	.333***	SCL <sup>2</sup>	.723	.179	.280***
	RES <sup>2</sup>	.274	.101	.171**	RES <sup>2</sup>	.300	.102	.188**
	SR <sup>2</sup>	.100	.053	.116	SR <sup>2</sup>	.101	.056	.116
	SSSS <sup>2</sup>	.636	.094	.440***	SSSS <sup>2</sup>	.589	.100	0.408***
				Self-perceived Pain <sup>1</sup>	0.483	1.510	0.019	
				PSCH <sup>1</sup>	-2.322	2.208	-0.071	
				PLTF <sup>1</sup>	-0.384	2.323	-0.011	
	$R^2$			.636	$R^2$			.642
	F			59.509***	F			27.744***

Note. B (unstandardized coefficient) and SE (standard error);  $\beta$ : standardized coefficients.

\*\*\*p $\leq$ .001; \*\*p $\leq$ .01; \*p $\leq$ .05

Analysis were adjusted for age and gender.

<sup>1</sup> Clinical Variables

<sup>2</sup> Psychosocial Variables

HRQoL – Health-related quality of life; PLTF - “chronic conditions affects/not affects participation in leisure time with friends”; PSCH - “chronic condition affects/not affects participation and attendance at school”; SCL – Symptoms Check-List; SSSS - Satisfaction with Social Support; SR – Self-regulation; RES – Resilience.

In the step 1 of Model 1 in Table 4 an adequate model was achieved [F(5,129)=12.472, p=0.000, R<sup>2</sup>=.300]. Self-perceived pain and the items PSCH and PLTF had a significant association: the adolescents that did not have Self-Perceived Pain, nor felt that the disease affected PSCH, tended to have a higher perception of their HRQoL. An adequate model was also achieved in the step 1 of Model 2 in Table 5 [F(4,130)=59.509, p=0.000, R<sup>2</sup>=.636]. The psychosocial variables SCL, RES and SSSS had a significant association: the adolescents reporting higher scores for psychosomatic health, resilience and social support had a tendency to perceive a higher HRQoL, and no differences were found for SR.

In step 2 of both Models in Tables 4 and 5 an adequate model was achieved [F(9,125)=27.744, p<0.001, R<sup>2</sup>=.642]. The psychosocial variables SCL, RES and SSSS had a significant association: the adolescents reporting higher scores for psychosomatic health, resilience and social support had a tendency to perceive a higher HRQoL. No differences were found for Self-Perceived Pain, PSCH/PLTF and SR.

#### 4. Discussion

The present study aimed to measure the impact of clinical and psychosocial factors (separated and combined) on adolescent’s reported HRQoL.

A brief overlook of the results shows that, separately, both clinical and psychosocial variables have a significant association with the perception of HRQoL, showing high values of explained variance (respectively 27.9% and 62.4%). Self-perceived pain and the items PSCH/PLTF (proxy for disease’s severity) were the significant clinical variables impacting HRQoL, whereas SCL, RES, SR and SSSS were the most significant psychosocial ones. These findings are in accordance with literature, which indicated that perceptions of HRQoL could be influenced by several factors (The KIDSCREEN Group Europe, 2006; Ravens-Sieberer et al., 2001; 2005; Houtrow et al., 2012. Also reinforce the suggestions in the literature to assess both disease related and non-disease-related factors (Sawyer et al., 2001), including physical, psychological and social perspectives (WHO, 2012), as well as limitations in ordinary activities (Denny et al., 2014; van der Lee et al., 2007). In addition, these results highlight that adolescents living with a chronic condition may have a high risk for poor perceptions of HRQoL, also pointed

out in previous research (Alba et al., 2013; Elsenbruch et al., 2013; Mellion et al., 2014; Payot & Barrington, 2011; Varni et al., 2007).

Interestingly, when combining the above identified significant clinical and psychosocial variables in a multilinear regression models (Model 1 and Model 2, step 2), a significant association with a high value of explained variance was obtained (64.2%). Clinical variables were no longer significant and the psychosocial variables SCL, RES and SSSS (with exception of SR) maintain their association with HRQoL's perception. To achieve such result, a different contribution from both clinical and psychosocial variables was revealed (Model 1 and Model 2, step 1). When first entering the clinical variables the variance only reaches 30% (Model 1, step 1) and much more from psychosocial variables seems to explain the total of 64.2% (Model 1, step 2); inversely, when first entering the psychosocial variables the variance reaches 63.6% (Model 2, step 1), and the clinical ones add a small significance to the model (only 0.6%) (Model 2, step 2).

Such findings suggest a dynamic interdependence between these different variables, as stressed out in the literature (The KIDSCREEN Group Europe, 2006; Houtrow et al., 2012; Ravens-Sieberer et al., 2001; 2005), although pointing out a higher relevance of non-disease-related factors. Thus, these results support the suggestions in the literature emphasizing more the importance to focus on the disease's impact on psychosocial dimensions, and less on the diagnostic categories/physical dimensions (Denny et al., 2014; Mackner et al., 2012; van der Lee et al., 2007). In addition, the results underline previous research recommendations, namely the need to include psychosocial factors in complement of health indicators (Health, 2013; Watson, 2014), and the relevance of routinely conduct its assessment in clinical and pediatric settings (Mellion et al., 2014; Moreira et al., 2013; Williams et al., 2013). However, it may be suggested somehow a relationship between SR, the educational level of parents and the clinical variables (that need to be studied with more detail), considering that this psychosocial variable was no longer significant in the step 1 of Model 1 and in step 2 of both Model 1 and Model 2.

The observed significance of psychosocial variables in the present study can also be understood taking into account The Asset Model (Morgan & Ziglio, 2007), which draws attention to the role of protective factors that can predict positive health outcomes and improve coping skills, in chronically ill adolescents (Maslow & Chung, 2013). Additionally, the results of the present research are in line with previous studies reporting the importance of such protective factors, namely psychosomatic health (Suris, Bélanger, Ambresin, Chabloz, & Michaud, 2011), resilience (Guilera, Pereda, Paños, & Abad, 2015; Helgeson, Reynolds, Siminerio, Becker, & Escobar, 2014; Matos et al., 2012), self-regulation (Gois et al., 2012) and social support (Békési et al., 2011; Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013). Resilience, social support, symptom's control and self-management may allow a good adaptation in adolescents, while facing adverse health conditions and potentially stressful new situations, and help to reduce stress, increase control and improve outcomes in HRQoL. Therefore, these variables can be considered promising candidates for future interventions (Chao, Whitemore, Minges, Murphy, & Grey, 2014; Gaspar et al., 2012; Guilera et al., 2015; Helgeson et al., 2014). Moreover, because literature has previously indicated that adolescents with chronic conditions who need to develop more disease-related skills (e.g. insulin assessment/intake) and adhere to multiple complex daily tasks, require high levels of self-management and regulation competencies (Chao et al., 2014).

Facing these results, the present study accentuates a higher relevance of non-disease-related factors, supporting the suggestions in the literature to emphasize more the disease's impact on the psychosocial dimensions and less on the diagnostic categories/physical dimensions (Denny et al., 2014; Mackner et al., 2012; van der Lee et al., 2007). In addition, it also underlines previous research recommendations, proposing that in the specific period of adolescence (Carona et al., 2013; Carona, Silva, & Moreira, 2015), it is crucial to include psychosocial dimensions in complement of traditional health indicators (Health, 2013; Watson, 2014, Pulkki-Råback et al., 2015; Varni et al., 2007) and to routinely conduct its assessment in clinical and pediatric settings (Mellion et al., 2014; Moreira et al., 2013). Furthermore, to identify the impaired psychosocial domains, can give potentially useful suggestions, that better help to plan and guide interventions aiming to improve an integral perspective that represents the holistic care for these adolescents (Alba et al., 2013; Elsenbruch et al., 2013; Mazur & Małkowska-Szcutnik, 2010; Marmot et al., 2012).

#### *4.1 Limitations and Strengths*

This study had some limitations. This was a clinical convenience sample; therefore probable generalizations should take that into account. Recall bias might be introduced through self-report, and some adolescents were under-represented, due to the group's heterogeneity (different diseases/limitations). The cross-sectional design of the study precludes inferences concerning causality, and longitudinal data would be needed. However, this study has numerous strengths, namely including self-reports from adolescents and the use of well-developmentally

appropriate measures (WHO, 1993) for HRQoL, psychosomatic health, resilience, and social support. In addition, it focuses on potentially protective factors for health outcomes, as suggested in the literature.

In forthcoming research it would be important to replicate these variables in a larger sample and in specific populations, in order to conduct more valid analyses for the included clinical/psychosocial variables and for additional ones. This aims to increase the understanding of the potential differences in these groups. Also due to the cross-sectional design of the present study, more research is needed to highlight the interaction and reciprocal potentially effects of chronic disease and adolescent developmental changes, once the disease can affect this age process but the reverse is also true (Suris et al., 2004).

#### *4.2 Conclusion*

The present research supports the suggestions in the literature that underlined the relevance of assessing psychosocial domains as a complement to traditional health indicators. In addition, it draws attention to potential protective factors for health outcomes. To identify impaired psychosocial domains in adolescence and to conduct further research on these variables may reveal crucial strategies used by successfully adapted adolescents, which may help planning psychosocial care for those who struggle. Furthermore, to have knowledge on such impaired psychosocial domains and successful strategies can also better help professionals in their work to address adolescent's needs and to design and adjust interventions, increasing their cost-effectiveness.

#### **Abbreviations**

CHLN EPE: Centro Hospitalar Lisboa Norte

HRQoL: Health-related Quality of Life

KIDS-10: KIDSCREEN Index

QoL: Quality of Life

RES: Healthy Kids Resilience Assessment Module

SCL: Symptoms Check List-HBSC-SCL (Psychosomatic Complaints)

SR: Adolescent Self-Regulatory Inventory (ASRI)

SSSS: Scale of Satisfaction with Social Support

WHO: World Health Organization

WMA: World Medical Association

#### **Ethical approval**

All procedures in the present study were performed in accordance with the ethical standards of the institutional and/or national research appropriate committee (The Ethics Committee for Health from CHLN-EPE, Reference PCA-12 Nov.2012-0785), and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Written informed consent was obtained from all individual participants included in the study (both adolescents and their parents/legal guardians). For this type of study, formal consent from adolescents under 14 years old was not required.

#### **Author's Contributions**

TS and MGM conceived the study, participated in its design and coordination, draft and authored the manuscript. AM helped to perform statistical analyses, participated in interpretation of data and helped to draft manuscript revisions. CS participated in the study design, interpretation of the data, and helped to draft manuscript revisions. IL and MCM participated in the study design and helped to draft manuscript revisions. All authors have read and approved the final manuscript.

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### Competing Interests Statement

None of the authors reported any financial interests or potential conflicts of interest.

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