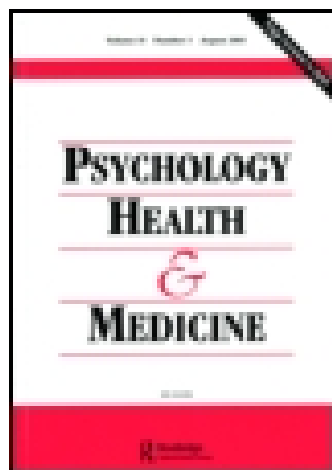


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Health-related quality of life in paediatric asthma: Children's and parents' perspectives

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This study aimed to describe the quality of life of a group of Portuguese children with asthma, to explore the association between health-related quality of life (HRQL), asthma severity, child's characteristics and parental psychopathology. Additionally, the concordance between the children's HRQL self-report and the parents' HRQL proxy was assessed. Fifty children with asthma (7–13 years) and their primary caregiver participated in the study by filling out the DISABKIDS-37 and other self-report questionnaires. Results for the DISABKIDS-37 supported a good internal consistency and associations between the facets and the global score, in the two versions of the questionnaire. Children and their caregivers scored the child's HRQL positively. Parents of children with an asthma diagnosis for a longer period reported better HRQL. The distribution of the HRQL scores in the child's version showed differences across categories of subjective severity rated by children and across categories of asthma control assessed by the physician. The group with uncontrolled asthma obtained lower HRQL scores than the other groups. There was a lack of convergence between self-report and parent's report of HRQL, with the exception of the physical limitation facet. Asthma severity assessed by the child and parental psychopathology explained 28% of the variance in the children's self-rated HRQL. Findings reinforce that children and caregivers' reports are complementary to each other and support the recommendation to use both information sources.

Keywords: paediatric asthma; quality of life; DISABKIDS-37; asthma control

Introduction

Asthma is the most frequent chronic condition in children and a major cause of hospitalization in Portugal (Direcção-Geral da Saúde [DGS], 2007; Gaspar, Almeida, & Nunes, 2006). As a long-term illness with large variations in symptoms severity and composite treatments, asthma interferes with everyday activities (Laster, Holsey, Shendell, Mccarty, & Celano, 2009; Trollvik & Severinsson, 2005) and can impact on family life and lead to a decrease in the child's quality of life (Laster et al., 2009; Sawyer et al., 2001, 2005; Silva, 2009; van Gent et al., 2007).

Asthma control can be achieved by self-management programmes implemented by patients and caregivers, with the aim of minimizing symptoms, preventing exacerbations and, thus, reducing the impact on daily activities and the need for emergency visits and hospital admissions (Kumar & Gershwin, 2006). Families have to adapt to a daily life in which asthma management or supervision by parents, becomes essential.

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Asthma management by the family entails that parents and children make management decisions and take actions to prevent and control symptoms (Bacharier et al., 2008; Meng & McConnell, 2002). Caregivers' asthma management strategies proved to be associated with asthma-related quality of life (Raymond, Fiese, Winter, Knestel, & Everhart, 2012). If the family fails to control asthma symptoms, children are likely to experience a reduced level of quality of life (Everhart & Fiese, 2009; Guilbert et al., 2011). Perceived burden of family's asthma management practices was linked to children's well-being, through its effects on mother-child interaction patterns (Fiese, Winter, Anbar, Howell, & Poltrock, 2008). In addition, the burden experienced by parents as primary caregivers, affected their perceptions of the family environment and both their quality of life and their children's quality of life (Crespo, Carona, Silva, Canavarro, & Dattilio, 2011).

Health-related quality of life (HRQL), defined as the perceived impact of health on an individual's well-being, has recently emerged as an important outcome measure in paediatric chronic diseases (Upton, Lawford, & Eiser, 2008; Wilson et al., 2012). Asthma-related quality of life is an important dimension of asthma outcomes (Wilson et al., 2012), and its improvement is one of the main goals of treatment (Chang, 2006). Implementation of adequate treatment can significantly reduce asthma impact and enhance patients and caregivers' quality of life. Measures of HRQL have been used both in the assessment of the effectiveness of interventions delivered as part of routine clinical care (Sawyer et al., 2005) and for clinical research (Wilson et al., 2012). HRQL is a multidimensional construct, and incorporates subjective and objective evaluations of dysfunction caused by an illness and its treatment (Spieth & Harris, 1996). HRQL instruments aim to measure patients' personal perceptions of the impact of the disease on the quality of their lives (Wilson et al., 2012).

Evidence that parents' and children's reports of the child's HRQL are not consistent (Sawyer et al., 2005; Upton et al., 2008) has led to the development of measures integrating both children's reports and parent's reports, acting as proxy informants (Sawyer et al., 2005; Wilson et al., 2012). Parents and children can have different opinions on the impact of the disease on the child's life (Wilson et al., 2012). A review conducted by Upton et al. (2008) confirms the existence of differences between parent's proxy-report and child's self-report mean scores, although only two of the studies reported significant differences. The child's inclusion as a source of information of his HRQL has been emphasized as children are unique informants about their own experience, namely about internalizing symptoms (Everhart & Fiese, 2009; Wilson et al., 2012). However, parent's perception of their child's HRQL is one of the determinants of the utilization of healthcare services (Upton et al., 2008). Therefore, several instruments of HRQL include a version to the child and one to the caregiver, as proxy-informant, allowing for the comparison of the two perspectives (Upton et al., 2008).

A developmental approach to HRQL emphasizes the need for children's specific measures with an appropriate level of abstraction and the inclusion of areas specifically relevant to children and adolescents (Spieth & Harris, 1996). Within a developmental approach, the DISABKIDS project has the main goal of developing and promoting the use of standardized instruments to assess HRQL in children and adolescents with chronic conditions (Bullinger, Schmidt, Petersen, & The DISABKIDS Group, 2002). This project proposed several HRQL assessment instruments, "The DISABKIDS Questionnaires", and tested these instruments in several European countries (Baars et al., 2006; Petsios et al., 2011), including Portugal (Carona, Bullinger, & Canavarro, 2011; Carona et al., 2013).

Previous studies have shown that HRQL is associated with patients' psychological variables, with emotional problems being associated with lower quality of life in adolescents (Vila et al., 2003) and in adults with asthma (Kolawole et al., 2011).

On the other hand, parents' mental health problems were found to be associated with poorer child's HRQL in paediatric cancer (Yağc-Küpel, Akyüz, Küpel, & Büyükpamukçu, 2012), spinal cord injury (Garma, Kelly, Daharsh, & Vogel, 2011) or ADHD (Riley et al., 2006). Parental psychopathology (depressive and anxiety symptoms) also showed a negative impact on HRQL in children and adolescents with epilepsy (Abiodun, 2006; Ferro, Avison, Campbell, & Speechley, 2011). Specifically in patients with asthma, caregiver's negative affect was associated with the report of quality of life (Price, Bratton, & Klennert, 2002) and with symptoms reports (Bender & Zhang, 2008). Josie, Greenley, and Drotar (2007) found that high levels of parental distress were a risk factor for poor HRQL of children with asthma in a group of inner-city African-American people. A relationship between parental mental health problems and the parents' reports of asthma attacks in children was also found (Ortega, Goodwin, McQuaid, & Canino, 2004). Caregivers' psychiatric symptoms revealed an association with greater frequency of asthma-related hospitalizations of the child (Brown et al., 2006) and maternal depressive symptoms showed a detrimental effect on child asthma morbidity (Otsuki et al., 2010).

This study aims to describe the quality of life of a sample of Portuguese children with asthma and to explore the association between HRQL, asthma severity and socio-demographic characteristics of the child. A second objective is to assess the agreement level between the children's HRQL self-report and the parents' HRQL proxy-report, comparing asthma's impact on the child's quality of life as perceived by these two types of informants. In addition, we intend to evaluate the association between parental psychopathology and parents' proxy-report and children's self-report of HRQL.

Method

Participants

Caregivers of children between 7 and 13 years old with a diagnosis of persistent asthma and disease duration of at least six months, attending an outpatient paediatric allergology division of two Portuguese hospitals, were invited to participate in the study during admission to medical appointments. Children with significant developmental delay or other chronic conditions implying significant medical care were excluded. The final sample included 50 children and their primary caregivers.

Procedures

After formal authorizations were obtained from the Ethics Committees of both hospitals, data collection was carried out. Following a comprehensive description of the project, parents signed an informed consent form and children gave their verbal approval. Socio-demographic and clinical information was collected at that time, including age at initial asthma diagnosis, prescribed medication, number of hospitalizations and asthma exacerbations. The allergist reviewed the medical history.

Measures

DISABKIDS-37 (DISABKIDS chronic generic measure)

The Generic DISABKIDS questionnaire (Bullinger et al., 2002; Carona et al., 2011) is designed to assess HRQL in children and adolescents with any chronic condition, aged between 8 and 18 years. The DISABKIDS-37 includes a self and a proxy version with similar items. The questions relating to the child's global functioning and well-being during the previous four weeks are grouped into six facets: independence, emotion, social inclusion, social exclusion, physical limitation and treatment. The questionnaire uses a five-point Likert scale, with endpoints: "never" to "always". A mean global score based on all responses is computed to indicate the measure of reported quality of life by the child and by the parent.

Level of asthma control

The child's physician assesses asthma control according to GINA guidelines (GINA, 2006), into three categories: controlled, partly controlled or uncontrolled. The level of asthma control refers to the control of clinical manifestations of the disease and represents a global composite index including: asthma symptoms (daily and nightly symptoms), activity limitations due to asthma, use of reliever medication and pulmonary function (FEV1). Asthma is classified as clinically controlled if the child has had no or few symptoms per week, a normal lung function and no asthma exacerbation during the last year (GINA, 2006). The level of asthma control is considered a reliable measure of the child's clinical state (GINA, 2006).

Subjective evaluation of asthma severity

Parents and children were asked to rate the perceived severity of their child's/their asthma during the last year (*How severe was your child's/your asthma during the last year?*), using a five-point ordinal response scale (*nothing serious* to *extremely serious*).

Brief symptom inventory (BSI)

BSI (Derogatis, 1982/1993; Canavarro, 2007), a short version for SCL-90, was used to screen for parents' emotional disturbance. BSI is a 53-item self-report scale used to measure nine symptom dimensions (Somatisation, Obsessive-compulsive behaviour, Interpersonal sensitivity, Depression, Anxiety, Hostility, Phobic anxiety, Paranoid ideation and Psychoticism), and three global indices [global severity index, positive symptom distress index (PSDI) and positive symptom total]. In the Portuguese validation, most subscales revealed good internal consistency, between .7 and .8 α , except for Phobic anxiety and Psychoticism, which both had lower alphas of .62 (Canavarro, 2007). BSI also demonstrated good temporal stability (Pearson's coefficient between .81 and .63 for the nine dimensions, and .45 for PSDI) (Canavarro, 2007). Emotionally disturbed individuals revealed higher levels of psychopathology than individuals in the general population, for all BSI scales and three global indices. A PSDI score ≥ 1.7 is likely to correspond to emotionally disturbed people (Canavarro, 2007). In the statistical analyses, we used the PSDI as a summary score.

Analysis

Data analyses were performed using the Statistical Package for Social Sciences (SPSS, version 19.0). Mean values for the six facets and the overall HRQL score were calculated for the two versions of DISABKIDS-37. Internal consistency of the questionnaires was assessed with Cronbach's α . Parent-child concordance was assessed with intraclass correlations (ICC) for average measurements within a two-way mixed model (absolute agreement type).

Global mean score in the parents' version of DISABKIDS-37 followed a normal distribution (Shapiro-Wilk test: $sw = .96$, $p = .074$), however not all the facets had a normal distribution. *T*-tests were used to compare global mean score in the DISABKIDS proxy version when groups revealed a normal distribution. Global mean score in the child's version of DISABKIDS-37 did not follow a normal distribution (Shapiro-Wilk test: $sw = .89$, $p = .000$). Consequently, we used non-parametric tests in the analyses of the child's version. Spearman's correlation coefficients were computed in order to assess scale intercorrelations, and the non-parametric Mann-Whitney *U*-test and Kruskal-Wallis test were used to compare means between small independent groups, according to the number of groups. Relationships between DISABKIDS-37 scores and the subjective evaluation of asthma severity made by parents and children were assessed by Kendall's tau coefficient. A hierarchical multiple regression was used to assess the relative contribution of children's subjective estimate of asthma severity and of parental psychopathology in children's DISABKIDS-37 total scores. Statistical analyses were conducted for a confidence interval of 95%.

Results

Sample characteristics

Fifty children with asthma and their primary caregivers (44 mothers, five fathers and one grandmother) participated in the study. Children's mean age was 10.5 years (25 children 7–10 years; 25 children 11–13 years; $SD = 2.07$), 58% were boys. All children had asthma for a period of more than 6 months, and 76% for more than 5 years. Eighty-eight percent were prescribed daily asthma medication, specifically anti-inflammatory agents.

Caregivers' ages ranged between 29 and 54 years ($M = 40.20$; $SD = 5.29$) and their educational level ranged from elementary school ($n = 2$) to a college degree ($n = 13$), with the majority (62%) having at least high school completion. Most caregivers (86%) were married or lived together. Eighteen caregivers reported having chronic health conditions, asthma and rhinitis were the most referred.

Children attended the outpatient service for a period of 1 month–11 years ($M = 3.95$; $SD = 3.09$). Twenty-six percent of caregivers evaluated their child's asthma as nothing serious, 18% as somewhat serious, 40% as more or less serious and the other 16% as quite serious. Clinicians' assessment of asthma control classified 38% of children as having controlled asthma, 36% as having partly controlled asthma and the remaining 24% of children as having uncontrolled asthma.

Health-related quality of life (HRQL)

DISABKIDS-37 questionnaires (self-report: $\alpha = .89$; proxy: $\alpha = .90$) and the six facets (self-report: $\alpha = .78$; proxy: $\alpha = .78$) revealed good internal consistency in this sample.

Both children and their caregivers scored their HRQL relating to the previous four weeks, showing a tendency towards the positive end of the scale (Table 1). The mean value in the six facets of DISABKIDS-37 ranged between 3.99 (social inclusion) and 4.67 (social exclusion) in the child's version and between 3.92 (limitation) and 4.62 (social exclusion) in the parents' version. Parents showed higher scores in global HRQL and in the independent and social inclusion facets, and children scored higher in the physical limitation, emotion, social exclusion and treatment facets.

Parent/child concordance

ICC coefficients were calculated to assess parent–child agreement and showed no significant correlations between the children's global score and the parents' version or between facet mean scores of the two versions (ICC ranged from .008 in independence to .363 in social inclusion), with the exception of the physical limitation facet where a significant correlation ($ICC = .45$; $p = .02$) was found, indicating a convergence between self-report and parent's report of HRQL in this domain.

Scale intercorrelations

The correlations between subscales and the total score of the child and proxy versions of DISABKIDS-37 questionnaires (Table 2) showed a high association between all facets and the total score of HRQL. The lowest correlation was obtained in the treatment facet in the child version and in the independence facet in the parents' version. The strongest positive correlation obtained for the two versions was between total score and emotion.

On the other hand, the correlation coefficients between the various facets varied widely (Table 3). The treatment facet revealed low or lack of correlation with other facets of the DISABKIDS-37, more so in the child version (treatment was only significantly correlated with emotion). In the caregivers' version, the physical limitation facet showed no significant correlation with the independence and social inclusion facets.

Discrimination between gender and age groups

No gender differences were found for the total score in the parents' version ($t[47] = .11$, $p = .917$), as well as in the child's version ($U = 238.5$; $W = 644.5$; $p = .385$). However, the distribution of the mean score in the limitation facet in the child's version was different between genders (for $p = .044$), with boys obtaining a lower score, namely reporting more physical limitations due to their asthma.

Table 1. Total scores and facet scores of child and proxy versions of DISABKIDS.

DK facets	Child		Caregivers	
	Mean (SD)	Min–max	Mean (SD)	Min–max
Independence	4.19 (.60)	2.50–5.00	4.36 (.41)	3.33–5.00
Emotion	4.29 (.70)	1.57–5.00	4.24 (.70)	2.14–5.00
Social exclusion	4.67 (.53)	2.33–5.00	4.62 (.38)	3.83–5.00
Social inclusion	3.99 (.72)	2.33–5.00	4.33 (.54)	2.67–5.00
Limitation	4.06 (.62)	2.33–5.00	3.92 (.59)	2.17–5.00
Treatment	4.22 (.77)	1.83–5.00	4.01 (.75)	1.83–5.00
Total score	4.24 (.46)	2.78–4.81	4.25 (.40)	3.32–4.84

Table 2. Correlation coefficients between total score and the six facets of DISABKIDS-37.

Total score Facet	Child version Spearman coefficient (Sig.)	Parent version Spearman coefficient (Sig.)
Independence	.721 (.000)	.575 (.000)
Limitation	.723 (.000)	.638 (.000)
Emotion	.766 (.000)	.846 (.000)
Social exclusion	.647 (.000)	.709 (.000)
Social inclusion	.633 (.000)	.690 (.000)
Treatment	.409 (.004)	.724 (.000)

Note: Sig.= Significance level.

Table 3. Intercorrelations between subscales for the child and proxy versions of DISABKIDS-37.

	Independence Self/proxy	Emotion Self/proxy	Social exclusion Self/proxy	Social inclusion Self/proxy	Limitations Self/proxy
Emotion	.377**/.402**				
Social exclusion	.406**/.322*	.554**/.577**			
Social inclusion	.607**/.450**	.326*/.454**	.357*/.467**		
Limitations	.460**/.222 NS	.474**/.619**	.388**/.446**	.370**/.195 NS	
Treatment	.100 NS/.233 NS	.372**/.488**	.081 NS/.372**	-.137 NS/.429**	.154 NS/.292*

Note: NS, not significant.

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

No differences were found in the DISABKIDS-37 child's version between age groups (7–10 years, 11–13 years) ($U = 238.5$; $W = 644.5$; $p = .358$, for global mean score), except in the social inclusion facet ($U = 202.5$; $W = 637.5$; $p = .044$), with older children reporting better values. No significant differences were found in the facets and global score in the parents' version across age categories ($t[47] = 1.05$; $p = .300$, for global mean score).

Duration of the disease

Parents of children with an asthma diagnosis for a longer period of time (more than 4 years) reported a better child global HRQL mean score than parents of children with a more recent asthma diagnosis ($t[47] = -2.64$, $p < .011$). However, an independent-samples Mann–Whitney U test showed no significant differences between these two groups in the HRQL mean score in the child's self-report ($U = 222.5$; $W = 888.5$; $p = .877$).

Relationship with asthma severity

We found a significant negative correlation between the children's subjective evaluation of asthma severity and their global mean score in DISABKIDS-37 ($\tau = -.34$, $p = .003$). The distribution of the global mean score ($kw(3) = 10.13$; $p = .017$) and the physical

limitations ($kw(3) = 17.09$; $p = .001$), emotion ($kw(3) = 8.92$; $p = .030$) and social exclusion ($kw(3) = 8.51$; $p = .037$) facets was different across categories of subjective severity rated by children. However, there was no significant association between parents' subjective rating of asthma severity and the global mean score in the parents version of DISABKIDS ($\tau = -.171$, $p = .122$). In this version, only the physical limitations facet showed a different distribution across subjective severity rated by parents ($kw(3) = 10.62$; $p = .014$).

Discrimination between asthma control categories

The distribution of the global score and the facet mean scores in the child's version of DISABKIDS-37 across categories of asthma control, assessed by the physician, showed significant differences only in the global mean score ($kw(2) = 6.49$; $p = .039$) and in the limitation facet ($kw(2) = 9.79$; $p = .007$), with the group with uncontrolled asthma obtaining lower mean scores than other groups (Figure 1).

In contrast, the distribution of the total score and the facet mean scores in the parents' version did not show significant differences across the asthma control categories (independent-samples Kruskal-Wallis test, $p > .05$).

Relationship with parental psychopathology

No association was found between the HRQL global mean score reported by parents and the PSDI of the BSI ($\rho = -.09$, $p = .540$). There were no differences in the distribution of the global mean score in DISABKIDS-37 proxy version, between parents with a PSDI under or over the cut-off ($t[46] = -.75$, $p = .457$). However, the global mean score in the child version of DISABKIDS-37 showed a small but significant negative correlation with parents' PSDI ($\rho = -.36$, $p = .013$), with a higher level of parental psychopathology associated with a lower level of children's self-reported HRQL. Yet, no significant differences in the children's global mean score were found between children with parents under or over the cut-off in the BSI ($U = 132.5$; $p = .099$).

Taking in consideration the previous results, an hierarchical multiple regression was used to assess the ability of parental psychopathology (PSDI) to predict levels of children's HRQL (total score on child version of DISABKIDS-37), after controlling for the influence of asthma severity perceived by children. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. Asthma severity was entered at Step 1, explaining 21% of the variance in perceived HRQL. After entering the PSDI of BSI at Step 2, the total variance explained by the model as a whole was 28%. Parental psychopathology explained an additional 7% of the variance in HRQL, after controlling for perceived asthma severity (Table 4).

Discussion

DISABKIDS-37 confirmed good internal consistency and high associations between the facets and the global score of HRQL, for parent and child versions. In both versions, the strongest association was obtained between the global score and the emotion, revealing a strong relationship between emotional problems and concerns with health condition and global HRQL. The treatment facet revealed a low correlation with other facets

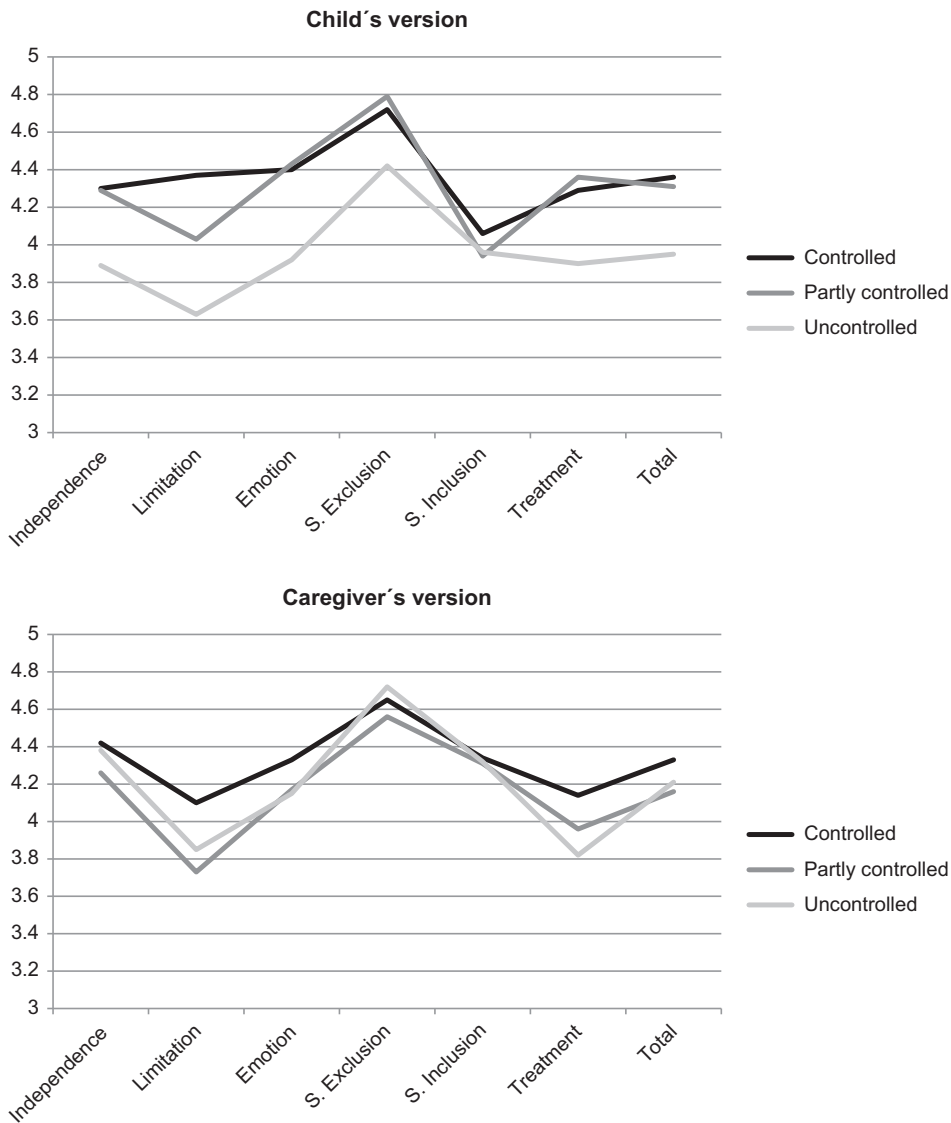


Figure 1. The DISABKIDS facets mean scores (0–5) of children with asthma by level of asthma control rated by the physician.

of the DISABKIDS-37, mainly in the child's version, suggesting that the impact of pharmacological treatment is modestly associated with other dimensions of HRQL. Similarly, in a study using the DISABKIDS in a population of European children and adolescents with asthma (Baars et al., 2006) treatment revealed the lowest associations with other facets, namely independence, social exclusion and social inclusion. In a large Portuguese sample of children and adolescents with asthma or epilepsy, treatment also showed the lowest correlations with other facets (Carona et al., 2013).

Children and their caregivers scored their HRQL relating to the previous four weeks positively, revealing an overall good quality of life and mean scores in HRQL were

Table 4. Hierarchical multiple regression of the contribution of children's subjective estimate of asthma severity and of parental psychopathology in children's HRQL.

	<i>B</i>	<i>SE B</i>	β
Step 1			
Constant	169.26	4.01	
Asthma severity	-8.63	2.49	-.46*
Step 2			
Constant	185.29	8.67	
Asthma severity	-6.29	2.66	-.34**
Parental psychopathology	-12.49	6.04	-.29**

Note: $R^2 = .21$ for Step 1; $\Delta R^2 = .07$ for Step 2 ($ps < .05$).

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

similar between self and proxy versions of the DISABKIDS-37. Other studies confirmed that most children with asthma estimate their HRQL towards the positive end of the scale (Rydström, Dalheim-Englund, Holritz-Rasmussen, Möller, & Sandman, 2005). In the caregivers' version, the physical limitation and treatment facets revealed the lowest mean scores. In the child's version, the social inclusion and physical limitation facets presented the lowest mean scores. This finding is consistent with previous research demonstrating that children reported more impairment in the activities domain than in emotions and symptoms (Rydström et al., 2005).

Regarding concordance between informants, we found a lack of agreement between parent and child HRQL assessment, with the exception of the physical limitation facet. This lack of agreement reveals different interpretations of asthma impact on the child's quality of life. Other studies with DISABKIDS questionnaires confirmed some lack of agreement between child self-report and parent proxy-report on HRQL (Carona et al., 2011), with parents overestimating HRQL of their children with asthma (Petsios et al., 2011). A lack of correspondence between child and parent reports was found with other HRQL measures in children with asthma (Annett, Bender, DuHamel, & Lapidus, 2003) and in healthy children (Rajmil, López, López-Aguilà, & Alonso, 2013; Theunissen et al., 1998). A large study with Portuguese children and adolescents with asthma or epilepsy found moderate levels of agreement between caregiver and child/adolescent reports (Carona et al., 2013). The agreement of child and parent assessment in physical limitation is probably due to this domain being more directly observable, and similar results were found in other studies (Rajmil et al., 2013). A systematic review of the agreement between ratings of children's HRQL made by parents and children also found a greater agreement for observable functioning domains (Eiser & Morse, 2001). These discrepancies are comparable to the differences between parents and children's assessment of children's psychopathology (De Los Reyes & Kazdin, 2005).

There were no gender differences in HRQL, both for proxy and child versions, with the exception of the physical limitations facet in the child's version where boys reported lower values, namely more physical limitations. This result can be due to a higher valuing of physical activity by males in this age group, but needs further exploration. In the study lead by Baars et al. (2006), with a sample of children and adolescents (8–17 years), girls scored significantly lower on the limitation facet. In the Portuguese validation study, DISABKIDS-37 self and proxy versions did not discriminate between gender categories (Carona et al., 2011).

DISABKIDS-37 questionnaires did not differentiate between age groups (7–10 years, 11–13 years) with the exception of social inclusion, with older children reporting a better HRQL in this dimension. Previous research also found differences between age groups in the social inclusion (Baars et al., 2006; Carona et al., 2011) and independence facets (Carona et al., 2011), with children aged 8–12 scoring significantly lower than adolescents.

Regarding the duration of the disease, we found no significant differences in the HRQL mean score in the child's self-report. However, parents of children with an asthma diagnosis for a longer period reported a better HRQL, which may indicate that parents consider that the impact of paediatric asthma on the child's HRQL decreases over time. This is supported by the results of a two-year study conducted by Sawyer et al. (2005) that found a significant improvement in HRQL scores of children with asthma reported by parents.

Children's report of HRQL was associated with their subjective evaluation of asthma severity, particularly in physical limitations, emotion and social exclusion. Parents' report of child HRQL only showed a different distribution across asthma subjective severity categories in the physical limitations facet of DISABKIDS. Surprisingly, these findings seem to reflect a greater congruence between children's assessment of asthma severity and their evaluation of their HRQL, comparatively with parents' assessments, and needs further confirmation.

No differences were found across the asthma control categories assessed by physicians in the parents' version of DISABKIDS-37, with the exception of the physical limitation facet that showed a slight difference. By contrast, differences were found in the child's version in the global score and in the physical limitations, social exclusion and independence facets, with the group with uncontrolled asthma obtaining lower mean scores. This difference is stronger in the limitation facet, reflecting a greater impact of the disease on daily activities of the child when asthma is not controlled, as expected. These results seem to indicate that children's assessment of their HRQL is more consistent with the physician's evaluation of the clinical aspects of asthma, than the parents' assessment of HRQL. Recent research has pointed out that asthma control is associated with health-related quality of life in adult patients (Doz et al., 2013; Sullivan et al., 2013) and in children and adolescents (Guilbert et al., 2011). A Portuguese study also found that asthma severity assessed by clinicians was negatively linked to children's HRQL (Crespo et al., 2011).

We found no association between parents' emotional disturbance and their report of child's HRQL. However, HRQL assessed by the children was moderately correlated with parental emotional disturbance, explaining 7% of the variance in HRQL after controlling for asthma severity perceived by children. This finding could be related to the association of maternal psychopathological symptoms to children's asthma symptoms (Ortega et al., 2004; Otsuki et al., 2010), but deserves further investigation. In the model proposed by Annett, Turner, Brody, Sedillo, and Dalen (2010) to understand child and parent perceptions of asthma quality of life, family functioning predicted the child's psychological functioning, and child psychological functioning predicted both the long-term asthma control, as well as the child's perceived quality of life. The authors found a strong correlation between family functioning and child psychological functioning that may help to explain the relationship between parental psychological variables and HRQL self-report by children (Annett et al., 2010).

Limitations

This study contributes to paediatric asthma HRQL assessment in Portugal. However, some limitations should be highlighted. This is a small sample of children followed in two specialized asthma outpatient departments, and it is unclear whether our participants are representative of children across these departments.

The cross-sectional design is another limitation of this study because adjustment to a chronic condition is an ongoing dynamic process that cannot be fully understood with this design. A longitudinal design would provide a more comprehensive model of HRQL in children with asthma.

Implications

Children with uncontrolled asthma report a lower HRQL as compared to children with controlled or partly controlled asthma. These findings reinforce the importance of obtaining long-term asthma control in order to ensure a good HRQL in children with asthma.

Findings reinforce that children and caregivers' reports are complementary to each other and support the recommendation to use both information sources. Parents are an important source of information on their children's HRQL, particularly in cases where children are unable to report about their own experience. Parents' subjective experience of their child's HRQL has a main effect on whether they seek or do not seek healthcare services for their child. Additionally, if parents are not sufficiently aware of the impact of the disease on their child's quality of life, they may not engage in the necessary efforts to improve their child's clinical condition.

However, our findings also indicate that children have a different awareness of the impact of the disease on their quality of life, revealing a greater consistency with clinical variables. Accordingly, children should be included as a prime source of information about their HRQL.

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