

Why the (dis)agreement? Family context and child-parent perspectives on health-related quality of life and psychological problems in pediatric asthma

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Abstract

Introduction. Children's health-related quality of life (HrQoL) and psychological problems are important outcomes to consider in clinical decision making in pediatric asthma. However, children's and parents' reports often differ. The present study aimed to examine the levels of agreement/disagreement between children's and parents' reports of HrQoL and psychological problems and to identify socio-demographic, clinical and family variables associated with the extent and direction of (dis)agreement. **Method.** The sample comprised 279 dyads of Portuguese children with asthma who were between 8 and 18 years of age ($M = 12.13$; $SD = 2.56$) and one of their parents. The participants completed self- and proxy-reported questionnaires on pediatric generic HrQoL (KIDSCREEN-10), chronic-generic HrQoL (DISABKIDS-37) and psychological problems (Strengths and Difficulties Questionnaire). Children's and parents' perceptions of family relationships were measured with the Family Environment Scale and the caregiving burden was assessed using the Revised Burden Measure.

Results. The child-parent agreement on reported HrQoL and psychological problems was poor to moderate (intraclass correlation coefficients between .32 and .47). The rates of child-parent discrepancies ranged between 52.7% (psychological problems) and 68.8% (generic HrQoL), with 50.5% and 31.5% of the parents reporting worse generic and chronic-generic HrQoL, respectively, and 33.3% reporting more psychological problems than their children. The extent and direction of disagreement were better explained by family factors than by socio-demographic and clinical variables: a greater caregiving burden was associated with increased discrepancies in both directions and children's and parents' perceptions of less positive family relationships were associated with discrepancies in different directions. **Conclusion.** Routine assessment of pediatric HrQoL and psychological problems in healthcare and research contexts should include self- and parent-reported data as complementary sources of information, and also consider the family context. The additional cost of conducting a more in-depth assessment of pediatric adaptation outcomes can be offset through more efficient allocation of health resources.

Keywords

Caregiving burden • Child-parent (dis)agreement • Family relationships • Health-related quality of life • Pediatric asthma • Psychological problems

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Introduction

Health-related quality of life (HrQoL) and psychological problems have emerged as important health outcomes to consider in clinical decision making and research related to pediatric chronic conditions, such as asthma, because managing symptoms and improving psychosocial adaptation are now the primary goals of interventions (Clarke & Eiser, 2004; Le Coq, Boeke, Bezemer, Colland, & van Eijk, 2000). The assessment of pediatric populations poses particular methodological challenges, namely the reliability of children's self-reports and the advantages/disadvantages of using their parents as proxies (Bullinger, Schmidt, Peterson, & Ravens-Sieberer, 2006; Matza, Swensen, Flood, Secnik, & Leidy, 2004). Parents' reports are essential when children are too young or unable to report their own experiences (Eiser & Morse, 2001; Wallander, Schmitt, & Koot, 2001), and these reports play an important role in decision making about treatment and healthcare use (Annett, Bender, DuHamel, & Lapidus, 2003; Matza et al., 2004) and in detecting clinical changes over time (Le Coq et al., 2000). Nevertheless, the World Health Organization (WHO, 1993) recommends assessing children's individual perceptions of their quality of life (QoL) whenever possible. In addition, children's reports are more sensitive than their parents' in detecting minor emotional and behavioral disturbances (Becker, Hagenberg, Roessner, Woerner, & Rothenberger, 2004; Van Roy, Groholt, Heyerdahl, & Clench-Aas, 2010). Therefore, a multi-informant approach that includes both children's and parents' reports has been widely recommended to enable a comprehensive assessment of pediatric adaptation outcomes (Eiser & Morse, 2001; Van Roy et al., 2010).

Over the last few years, several instruments with self- and proxy-reported forms for assessing pediatric HrQoL and psychological problems have been developed (Bullinger et al., 2006; Goodman, 2001). Despite the common assumption that the reports from children and parents should be similar, most studies have found low to moderate levels of agreement on HrQoL (e.g., Sattoe, van Staa, Moll, & On Your Own Feet Research Group, 2012; White-Koning et al., 2007) and psychological problems (e.g., Ender, Stachow, Petermann, & Tiedjen, 2011; Van der Meer, Dixon, & Rose, 2008), with lower rates for social and emotional domains than for physical symptoms and observed behaviors (Becker et al., 2004; Eiser & Morse, 2001).

Children's health status seems to impact both the degree to which children and parents agree/disagree [the extent of (dis)agreement] and whether parents are more likely to over or underrate pediatric HrQoL and psychological problems (the direction of disagreement). Higher levels of agreement have been reported between parents and children with chronic conditions, compared with healthy controls (Russell, Hudson, Long, & Phipps, 2006). Research on pediatric chronic conditions has found that parents reported significantly lower HrQoL (Sattoe et al., 2012; White-Koning et al., 2007) and more psychological problems (Becker et al., 2004) than the children

themselves, which is the opposite of the directional pattern of disagreement found in the general population (Cremeens, Eiser, & Blades, 2006; Gaspar, Matos, Batista-Foguet, Pais-Ribeiro, & Leal, 2010; Sawyer, Baghurst, & Mathias, 1992; Theunissen et al., 1998). Moreover, Upton, Lawford, and Eiser, (2008) stated that the levels of agreement would also depend on the relevance of different domains for a specific clinical group because parents would be most alert to the frailest domains of their children's HrQoL. This argument is supported by research that shows positive associations between the extent of agreement and disease severity and length (April, Feldman, Platt, & Duffy, 2006; Petsios et al., 2011).

Children's developmental characteristics have also been investigated in the child-parent (dis)agreement research, which has produced inconsistent findings to date. Some studies have found higher levels of agreement for older children, supporting the hypothesis that the levels of agreement depend on cognitive and communication skills (e.g., Petsios et al., 2011). Conversely, other studies have described greater agreement between parents and younger children, suggesting that increasing independence in adolescence may limit the sharing of experiences with parents (e.g., April et al., 2006; Jokovic, Locker, & Guyatt, 2004). Children's and parents' genders have also been suggested as important determinants of (dis)agreement (Eiser & Morse, 2001; Upton et al., 2008); however, few empirical studies have addressed the role of these variables (e.g., Theunissen et al., 1998) and no clear findings have emerged.

The examination of family-related factors remains an important gap in (dis)agreement research in general and in pediatric asthma in particular. There is, nonetheless, some evidence suggesting that the study of family relationships may add valuable contributions to our current understanding of the extent and direction of child-parent (dis)agreement (De Civita et al., 2005). For example, White-Koning and colleagues (2007) described a significant association between higher levels of parenting stress and parents' underrating the HrQoL of their children with cerebral palsy. Family relationships characterized by poor parental engagement and communication have also been linked to an increased likelihood of disagreement on reports of emotional and behavioral problems, most often with children reporting more problems than their parents (Van Roy et al., 2010). In addition, in a pediatric asthma study, the illness-related burdens experienced by parents were negatively associated with parents' reports of pediatric HrQoL (Annett et al., 2003), which may contribute to child-parent disagreement.

In the context of pediatric asthma, the present study aimed to examine the (dis)agreement between child- and parent-reported adaptation outcomes (HrQoL and psychological problems) and to identify the socio-demographic, clinical and family variables that may account for the extent and direction of disagreement. Three hypotheses were formulated: (H1) child-parent agreement on reports of adaptation outcomes will be moderate; (H2) parents will report lower HrQoL and more psychological problems than children; (H3) the extent of disagreement, particularly in parents'

underrating of adaptation outcomes, will be associated with the clinical characteristics of their child's asthma (i.e., lower severity and a shorter time since diagnosis), with less positive family relationships and with greater caregiving burden.

Method

Participants and procedure

The participants (279 dyads of children with asthma and one of their parents) were enrolled between March 2010 and February 2012 in the outpatient services of three Portuguese public hospitals (Coimbra University Hospitals, Coimbra Pediatric Hospital and Leiria Saint Andre Hospital) after the study had been approved by the institutions' ethic committees. Using a non-probabilistic convenience sampling method, the children were selected based on their medical files, according to the following criteria: (1) age between 8 and 18 years; (2) diagnosis of asthma according to the International Classification of Disease (ICD-10) for at least 1 year; (3) absence of other chronic conditions; and (4) accompanied by the parent self-identified as the primary caregiver. The participants' socio-demographic and clinical characteristics are presented in Table 1.

Table 1 | Socio-demographic and clinical characteristics of the sample

	Children (<i>n</i> = 279)	Parents (<i>n</i> = 279)
Socio-demographic characteristics		
Age (in years), <i>M</i> (<i>SD</i>)	12.13 (2.56)	41.33 (5.90)
Age group ^a , <i>n</i> (%)		
Children	162 (58.1%)	
Adolescents	117 (41.9%)	
Gender, <i>n</i> (%)		
Male	175 (62.7%)	41 (14.7%)
Female	104 (37.3%)	238 (85.3%)
Socio-economic level ^b , <i>n</i> (%)		
Low		168 (60.2%)
Medium		78 (28.0%)
High		20 (7.2%)
Missing		13 (4.7%)

^a The pediatric sample was divided into two age groups based on The DISABKIDS Group Europe's (2006) categories: children (8-12 years old) and adolescents (13-18 years old). For simplicity, we adopted the term children to refer to the pediatric sample, which includes both age groups. ^b Socio-economic level was determined using a classification system for the Portuguese context based on the parents' jobs and educational levels (Simões, 1994).

Table 1 | Socio-demographic and clinical characteristics of the sample (cont.)

	Children	Parents
<i>Clinical characteristics</i>		
Asthma severity ^c , <i>n</i> (%)		
Intermittent	157 (56.3%)	
Mild persistent	73 (26.2%)	
Moderate persistent	41 (14.7%)	
Severe persistent	8 (2.9%)	
Age (in years) at the time of diagnosis, <i>M</i> (<i>SD</i>)	4.74 (3.89)	
Time (in years) since asthma diagnosis, <i>M</i> (<i>SD</i>)	7.64 (4.04)	
Using medication, <i>n</i> (%)	273 (97.8%)	

^c Asthma severity was classified by physicians, according to the Global Initiative for Asthma [GINA] (2008) guidelines. Due to the heterogeneous distribution of asthma severity in our sample, this variable was dichotomized and dummy-coded [0 – intermittent asthma, *n* = 157; 1 – persistent asthma (mild, moderate and severe), *n* = 122].

The pediatric sample was mainly composed of boys and most of the children had intermittent asthma, which is consistent with the prevalence of asthma by gender and with the distribution of asthma severity levels typically observed in the Portuguese pediatric population (Gaspar, Almeida, & Nunes, 2006). The great majority of caregivers was female and had low/medium socio-economic status, reflecting the users' profile in public pediatric healthcare services in Portugal.

Informed consent was obtained from all parents and adolescents older than 13 years, and informal assent was obtained from younger children. The protocols were completed by the children and parents in the health institution they attended, under the supervision of a trained research assistant who ensured that no information was exchanged between the children and their parents.

Measures

Children's adaptation outcomes

The children's HrQoL was measured by the Portuguese self- and proxy-reported versions of the KIDSCREEN-10 Index (Ravens-Sieberer et al., 2010; Portuguese version: Matos, Gaspar, & Simões, 2012) and the DISABKIDS-37 Chronic-Generic Module (The DISABKIDS Group Europe, 2006; Portuguese version: Carona et al., 2013). The KIDSCREEN-10 provides a general index of subjective health and well-being, whereas the DISABKIDS-37 assesses the impact of the chronic condition on six facets of the children's QoL: Independence, Emotion, Social inclusion, Social exclusion, Physical limitation and Treatment. Both questionnaires were answered using a five-point Likert scale ranging from 1 (*never*) to 5 (*always*), with higher scores indicating better HrQoL.

Psychological problems were assessed using the Difficulties scale of the Portuguese self- and parent-rated versions of the Strengths and Difficulties Questionnaire (Goodman, 2001; Portuguese version: Fleitlich, Loureiro, Fonseca, Gaspar, 2005). This scale comprises 20 items that were

clustered into Internalizing and Externalizing problems (Goodman, Lamping, & Ploubidis, 2010) and answered using a Likert-type response scale with three options (0 = *not true*, 1 = *somewhat true* and 2 = *certainly true*). Higher values indicated more psychological problems. The Cronbach's alpha values found in our sample for each measure are presented in Table 2.

Family variables

The overall quality of family relationships was assessed by the children and parents using the Portuguese version of the Family Relationships Index (Moos, 1990). This scale is comprised of the Cohesion, Expressiveness and Conflict dimensions of the Family Environment Scale (Moos & Moos, 1986), which assess how involved family members are in their family and how openly they express both positive and negative feelings, using 27 items scored on a six-point Likert scale ranging from 1 (*completely disagree*) to 6 (*completely agree*), with higher scores indicating better perceived family relationships. In the current sample, the Cronbach's alpha values were .86 and .85 for children's and parents' reports, respectively.

The caregiving burden was measured using the Portuguese version of the Revised Burden Measure (Montgomery & Kosloski, 2006; Portuguese version: Carona, Silva, & Canavarro, 2011). This scale assesses the parents' perceptions of changes in dyadic parent-child relationships (Relationship burden), time constraints resulting from caregiving activities (Objective burden) and generalized negative affect (Subjective burden), with 16 items scored on a five-point Likert scale ranging from 1 (*not at all*) to 5 (*a great deal*), with higher values indicating a greater caregiving burden. Good internal consistency was observed for our sample (Cronbach's alpha = .93).

Statistical analyses

Statistical analyses were performed with SPSS 17.0 (SPSS Inc., Chicago, IL, USA). The child-parent (dis)agreement on adaptation outcomes was examined at the individual and the group levels (Sneeuw, Sprangers, & Aaronson, 2002), by using, respectively, intraclass correlation coefficients (ICC) [two-way mixed model, absolute agreement, 95% confidence interval (CI)] and analyses of covariance for repeated measures (univariate analyses for the total scores and multivariate analyses for the six facets of chronic-generic HrQoL and for the two dimensions of psychological problems). Absolute and directional discrepancies were computed as dyadic indexes of the extent and direction of disagreement, respectively (Kenny, Kashy, & Cook, 2006). Directional discrepancies were categorized into three groups ("child-report > parent-report", "agreement" and "child-report < parent-report") based on the threshold for clinically important differences in QoL (Norman, Sloan, & Wyrwich, 2003). Thus, agreement was defined as an absolute child-parent difference that was lower than or equal to half of the standard deviation (SD) of the score with the greatest variability. In order

to identify the clinical, socio-demographic and family-related variables associated with the extent and direction of child-parent discrepancies, hierarchical multiple regression analyses and multinomial logistic regression analyses using “agreement” as the reference category were respectively performed (Field, 2009). For multinomial logistic regressions, the goodness-of-fit of the overall model was evaluated using likelihood ratio tests and the statistical significance of individual predictors was evaluated by calculating the Wald statistic and the odds ratio (OR) with a 95% CI.

Results

Child-parent (dis)agreement

At the individual level, there were poor to moderate correlations between children’s and parents’ reports of pediatric HrQoL and psychological problems (Table 2). At the group level, after controlling for socio-demographic and clinical variables, the results indicated a multivariate effect of the informant on chronic-generic HrQoL, Wilks’ Lambda = .95, $F_{(6, 258)} = 2.13$, $p = .05$, and on psychological problems, Wilks’ Lambda = .96, $F_{(2, 268)} = 5.30$, $p = .01$. However, as shown in Table 2, no univariate effects reached statistical significance.

The examination of the child-parent discrepancies indicated rates of agreement ranging from 31.2% (generic HrQoL) to 47.3% (psychological problems). Overall, the parents tended to score pediatric HrQoL lower and psychological problems higher than did the children (Figure 1).

Regression analyses explaining the extent of disagreement

The regression analyses showed that children’s age and gender explained only a small portion of the variance in child-parent absolute discrepancies. After controlling for clinical and socio-demographic variables, the family variables explained a significant portion of the variance (Table 3). Specifically, better family relationships were negatively associated with the extent of disagreement in HrQoL reports and a greater caregiving burden was positively associated with the extent of disagreement in the reported HrQoL and psychological problems.

Table 2 | Descriptive statistics, intraclass correlation coefficients, ANCOVA for repeated measures, and absolute and directional discrepancies

	Child-report		Parent-report		ICC ^a	ANCOVA for repeated measures ^b		Discrepancy	
	M (SD)	α	M (SD)	α		F	p	Absolute ^c	Directional ^d
Generic HrQoL	4.26 (0.55)	.80	4.01 (0.57)	.78	.38	0.23	.63	0.79 (0.41)	0.26 (0.60)
Chronic-generic HrQoL	4.25 (0.48)	.91	4.21 (0.49)	.93	.47	0.72	.40	0.77 (0.34)	0.05 (0.50)
Independence	4.23 (0.58)	.73	4.31 (0.57)	.77	.33	2.76	.10	0.72 (0.45)	-0.08 (0.66)
Emotion	4.26 (0.71)	.86	4.22 (0.73)	.91	.37	0.94	.33	0.80 (0.54)	0.05 (0.81)
Social inclusion	4.26 (0.58)	.64	4.22 (0.59)	.70	.32	2.88	.09	0.81 (0.45)	0.03 (0.68)
Social exclusion	4.66 (0.48)	.71	4.60 (0.53)	.81	.41	0.23	.63	0.47 (0.50)	0.06 (0.54)
Physical limitation	3.87 (0.65)	.68	3.70 (0.67)	.77	.41	< 0.01	.96	0.89 (0.47)	0.17 (0.71)
Treatment	4.16 (0.81)	.81	4.14 (0.79)	.84	.36	2.75	.10	0.91 (0.62)	0.04 (0.91)
Psychological problems	0.53 (0.25)	.75	0.59 (0.30)	.81	.40	0.07	.79	0.49 (0.19)	-0.06 (0.30)
Internalizing	0.47 (0.28)	.62	0.52 (0.34)	.71	.37	2.39	.12	0.50 (0.23)	-0.05 (0.35)
Externalizing	0.58 (0.34)	.75	0.66 (0.38)	.78	.46	3.48	.06	0.49 (0.24)	-0.08 (0.37)

^a Intraclass correlation coefficients reference values: ICC < .40 = poor agreement, ICC between .41 and .60 = moderate agreement, ICC between .61 and .80 = good agreement, ICC > .81 = excellent agreement (Landis & Koch, 1977). All ICCs were statistically significant at the .01 level. ^b Univariate analyses of covariance for repeated measures, entering the informant (child vs. parent) as the within-subject factor and the socio-demographic and clinical variables (children's age and gender, parents' gender, asthma severity and time since diagnosis) as covariates. ^c $\sum (|\text{child score} - \text{parent score}|) / \text{number of items for each dimension}$. ^d $\sum (\text{child score} - \text{parent score}) / \text{number of items for each dimension}$.

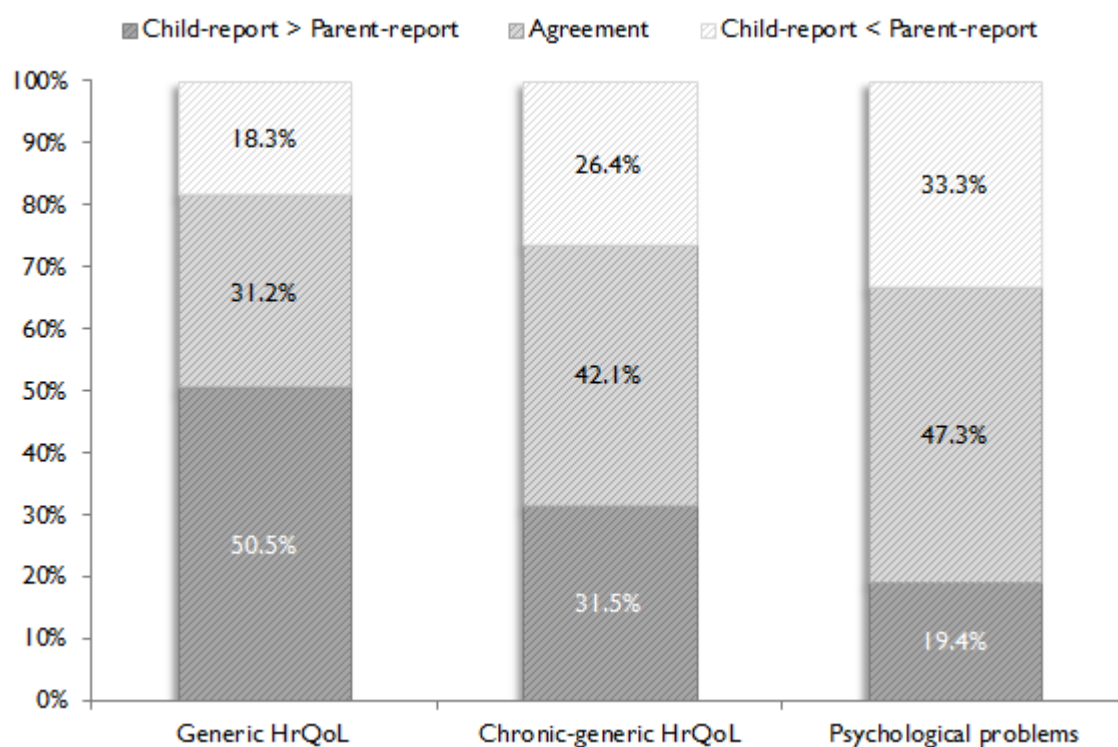


Figure 1 | Distribution of child-parent directional discrepancies on generic HrQoL, chronic-generic HrQoL and psychological problems

Note. Agreement was defined as an absolute difference between the child's and parent's scores that was lower than or equal to half of the *SD* of the score with the greatest variability.

Regression analyses explaining the direction of disagreement

The results from the multinomial logistic regression analyses examining “child-report > parent-report” and “child-report < parent-report” vs. “agreement” are presented in Table 4. The socio-demographic and clinical variables were not significantly associated with the direction of disagreement. A greater caregiving burden was associated with an increased likelihood of disagreement in both directions: parents’ overrating of generic HrQoL and psychological problems and children’s overrating of chronic-generic HrQoL. Family relationships had varying associations with the direction of disagreement: when children perceived less positive family relationships, they were more likely to report worse HrQoL and more psychological problems than their parents; when parents perceived less positive family relationships, they reported worse HrQoL; and when parents perceived better family relationships, they reported fewer psychological problems than the children.

Table 3 | Hierarchical regression model explaining the extent of the child-parent discrepancies

	Absolute child-parent discrepancies ^a					
	Generic HrQoL $R^2 = .19; F_{(8, 257)} = 7.62^{***}$		Chronic-generic HrQoL $R^2 = .35; F_{(8, 252)} = 16.69^{***}$		Psychological problems $R^2 = .18; F_{(8, 257)} = 6.90^{***}$	
First step: <i>Socio-demographic and clinical variables</i>	$\Delta R^2 < .01; F_{(5, 260)} = .17$		$\Delta R^2 = .06; F_{(5, 255)} = 3.00^*$		$\Delta R^2 = .04; F_{(5, 260)} = 1.89$	
	β	t	β	t	β	t
Children's age	-.03	-0.44	-.18	-2.65**	-.16	-2.40*
Children's gender ^b	.02	0.36	.14	2.25*	-.09	-1.51
Parents' gender ^b	.04	0.56	-.03	-0.55	-.05	-0.73
Asthma severity ^c	.02	0.31	.11	1.77	-.02	-0.29
Time since asthma diagnosis	-.01	-0.11	.09	1.38	.12	1.84
Second step: <i>Family variables</i>	$\Delta R^2 = .19; F_{(3, 257)} = 19.97^{***}$		$\Delta R^2 = .29; F_{(3, 252)} = 37.37^{***}$		$\Delta R^2 = .14; F_{(3, 257)} = 14.74^{***}$	
	β	t	β	t	β	t
Children's age	.04	0.63	-.10	-1.67	-.09	-1.38
Children's gender ^b	.02	0.30	.13	2.56*	-.10	-1.81
Parents' gender ^b	.02	0.33	-.06	-1.23	-.07	-1.13
Asthma severity ^c	.04	0.71	.13	2.56*	-.01	-0.15
Time since asthma diagnosis	-.02	-0.37	.08	1.34	.10	1.68
Family relationships (children)	-.11	-1.65	-.19	-3.21**	-.09	-1.39
Family relationships (parents)	-.18	-2.83**	-.20	-3.39**	-.06	-0.96
Caregiving burden	.30	4.88***	.35	6.32***	.33	5.30***

^a Hierarchical multiple regression analyses, entering the clinical and socio-demographic variables in the first block and the family variables in the second block of the regression equation. ^b Reference group: 0 = male; ^c Reference group: 0 = intermittent asthma.

*** $p < .001$, two-tailed. ** $p < .01$, two-tailed. * $p < .05$, two-tailed.

Table 4 | Multinomial logistic regression model explaining the direction of the child-parent discrepancies

	Directional child-parent discrepancies ^a					
	Generic HrQoL		Chronic-generic HrQoL		Psychological problems	
	$R^2_{(Cox \& Snell)} = .13$; $R^2_{(Nagelkerke)} = .14$ Model $\chi^2_{(16)} = 35.60^{**}$		$R^2_{(Cox \& Snell)} = .24$; $R^2_{(Nagelkerke)} = .27$ Model $\chi^2_{(16)} = 69.85^{***}$		$R^2_{(Cox \& Snell)} = .12$; $R^2_{(Nagelkerke)} = .14$ Model $\chi^2_{(16)} = 35.28^{**}$	
	B (SE)	Odds Ratio	B (SE)	Odds Ratio	B (SE)	Odds Ratio
Child-report < Parent-report vs. Agreement						
Children's age	.03 (.08)	1.03 (0.88/ 1.21)	-.14 (.07)	0.87 (0.75/ 1.00)	-.03 (.07)	0.97 (0.85/ 1.10)
Children's gender ^b	.04 (.38)	1.04 (0.49/ 2.20)	-.32 (.33)	0.73 (0.38/ 1.39)	.07 (.30)	1.07 (0.60/ 1.93)
Parents' gender ^b	.68 (.47)	1.98 (0.79/ 4.98)	.52 (.42)	1.69 (0.74/ 3.84)	-.68 (.46)	0.51 (0.21/ 1.26)
Asthma severity ^c	.05 (.38)	1.05 (0.50/ 2.20)	.20 (.32)	1.22 (0.65/ 2.29)	.23 (.29)	1.25 (0.71/ 2.22)
Time since asthma diagnosis	-.07 (.05)	0.93 (0.85/ 1.03)	.03 (.04)	1.03 (0.95/ 1.12)	.04 (.04)	1.04 (0.97/ 1.13)
Family relationships (children)	-.65 (.32)*	0.52 (0.28/ 0.99)	-.84 (.29)**	0.43 (0.25/ 0.76)	.45 (.26)	1.56 (0.94/ 2.60)
Family relationships (parents)	.40 (.39)	1.49 (0.69/ 3.20)	-.08 (.31)	0.93 (0.50/ 1.71)	-.35 (.28)	0.70 (0.41/ 1.21)
Caregiving burden	.61 (.30)*	1.84 (1.02/ 3.35)	.31 (.28)	1.36 (0.78/ 2.37)	.51 (.23)*	1.66 (1.06/ 2.60)
Child-report > Parent-report vs. Agreement						
Children's age	.03 (.07)	1.03 (0.90/ 1.17)	-.01 (.08)	0.99 (0.86/ 1.15)	-.15 (.08)	0.86 (0.74/ 1.00)
Children's gender ^b	.29 (.30)	1.33 (0.74/ 2.39)	-.34 (.34)	0.71 (0.37/ 1.37)	-.25 (.35)	0.78 (0.39/ 1.56)
Parents' gender ^b	-.64 (.43)	0.53 (0.23/ 1.23)	-.75 (.54)	0.47 (0.17/ 1.35)	.58 (.44)	1.79 (0.75/ 4.25)
Asthma severity ^c	-.28 (.29)	0.75 (0.43/ 1.34)	-.09 (.33)	0.92 (0.48/ 1.75)	-.22 (.34)	0.80 (0.41/ 1.57)
Time since asthma diagnosis	-.04 (.04)	0.96 (0.89/ 1.04)	-.02 (.04)	0.98 (0.90/ 1.07)	.03 (.05)	1.03 (0.94/ 1.13)
Family relationships (children)	.32 (.26)	1.38 (0.83/ 2.29)	.53 (.30)	1.70 (0.95/ 3.06)	-.77 (.30)*	0.47 (0.26/ 0.83)
Family relationships (parents)	-.76 (.29)*	0.47 (0.26/ 0.83)	-.69 (.32)*	0.50 (0.27/ 0.94)	.84 (.36)*	2.32 (1.15/ 4.71)
Caregiving burden	.41 (.24)	1.50 (0.94/ 2.41)	1.35 (.28)**	3.85 (2.23/ 6.65)	.26 (.28)	1.29 (0.75/ 2.24)

^a Multinomial logistic regression analyses, using "agreement" as the reference category and entering the child's and parent's genders and the child's asthma severity as categorical factors and the child's age, time since diagnosis and family factors as covariates. ^b Reference group: 0 = male; ^c Reference group: 0 = intermittent asthma.

*** $p < .001$, two-tailed. ** $p < .01$, two-tailed. * $p < .05$, two-tailed.

Discussion

To our knowledge, this is the first study examining the role of family relationships and caregiving burden in explaining the extent and direction of child–parent (dis)agreement. Three main findings should be considered. First, most of the children with asthma and their parents differed in their perceptions of pediatric adaptation outcomes. Second, although disagreement occurred in both directions, the parents were more likely to report worse HrQoL and more psychological problems than the children. Finally, the extent and direction of disagreement were better explained by family-related factors than by socio-demographic and clinical variables. The strengths of this research include the use of developmentally appropriate instruments for assessing HrQoL and psychological problems with strictly parallel versions for children and parents and the adoption of a multi-informant approach; both children and parents reported on family relationships, and the physicians reported on asthma severity.

The low to moderate levels of agreement found at the individual level confirmed our first hypothesis and coincide with previous studies (e.g., Ender et al., 2011; White-Koning et al., 2007). These results can be understood within a cognitive-developmental framework, which suggests that children and adults differ in their understanding of the concept of illness, its causes and the effects of treatment (Bibace & Walsh, 1980). Although the instruments used to assess children’s adaptation outcomes have been semantically and psychometrically validated for children as young as 8 years and for family caregivers, children and parents may support their answers with different experiences (Davis et al., 2007). At the group level, no significant differences were found between child and parent-reported adaptation outcomes, regardless of the domains being assessed, which refutes the hypothesis raised by Upton and colleagues (2008).

Consistent with most of the previous research conducted with clinical samples (e.g., Becker et al., 2004; Sattoe et al., 2012; White-Koning et al., 2007) and as predicted in our second hypothesis, when disagreement occurred, it was likely to be in the direction of parents reporting worse HrQoL and more psychological problems. These results may reflect, on the one hand, the children’s tendency to emphasize the positive aspects of adaptation (Oeffinger et al., 2007). On the other hand, parents may be more reliable in identifying the most strongly affected areas of their children’s functioning and the so-called “hidden morbidities” (Varni, Burwinkle, & Lane, 2005). Therefore, a dyadic child–parent approach to assessing pediatric outcomes may provide unique information about the children’s risk factors and resilience.

The extent and direction of child–parent disagreement on adaptation outcomes were primarily explained by family-related factors. Children’s and parents’ perceptions of less positive family relationships were significantly associated with greater disagreement on HrQoL reports. These findings suggest that a family context that is characterized by high levels of cohesion and low

levels of conflict, which allows children to openly express their worries and feelings, might be more important in explaining child–parent (dis)agreement than developmental characteristics and communication skills. Regarding the direction of disagreement, we observed a tendency for children and parents underrate the pediatric adaptation outcomes when they also perceived family relationships as less positive. These findings may reflect informant biases, but they could also indicate that individual perceptions of family relationships may affect how each family member evaluates the children’s health status. Furthermore, a greater caregiving burden was significantly associated with increased disagreement, regardless of its direction. Parents’ perceptions of caregiving tasks and asthma management routines as overly demanding and burdensome have been associated with negative mother–child interactions (Fiese, Winter, Anbar, Howell, & Poltrock, 2008), which may limit the exchange of information between children and parents. Moreover, the caregiving burden is also likely to negatively affect children’s and parents’ perceptions of the family environment (Crespo, Carona, Silva, Canavarro, & Dattilio, 2011) and thus contribute indirectly to child–parent disagreement on adaptation outcomes.

Two main limitations should be acknowledged in the present study. First, the non-probabilistic sampling strategy may have influenced the levels of agreement because parents who participated were more involved in pediatric healthcare than parents in the general population. In addition, the low frequency of children with severe asthma required the dichotomization of the asthma severity variable and increased the intragroup variability. Furthermore, the sample of caregivers included mostly mothers, which limited the ability to assess the potential role of the caregivers’ gender in explaining the extent and direction of child–parent disagreement. Second, the study’s cross-sectional design precluded causal inferences among the variables. Given the possibility that the associations between family-related factors and child–parent disagreement are bidirectional, longitudinal studies should further investigate this hypothesis.

Despite the aforementioned limitations, our findings have important implications for pediatric asthma research and clinical practice. The tendency for parents to report worse HrQoL and more psychological problems than children suggests, on the one hand, that parents may underestimate children’s abilities to adapt to adverse circumstances and, on the other hand, that they may be more aware of children’s current and future functional limitations. Moreover, parents assume important responsibilities in asthma management and healthcare decision making. Child–parent disagreement may influence the way parents respond to children’s healthcare and emotional needs, which may influence their adaptation over time. Therefore, routine assessment of children’s adaptation outcomes should include both children’s and parents’ perspectives as complementary sources of information and should also consider the family factors that are likely to influence child–parent (dis)agreement. The additional cost of conducting a more in-depth assessment of adaptation outcomes can be offset by more efficiently allocating health resources and implementing clinical

interventions.

Key messages

- The agreement between children with asthma and their parents on pediatric adaptation outcomes was low to moderate.
- Parents were more likely to report worse pediatric HrQoL and more psychological problems than children themselves.
- Both the extent and direction of child-parent disagreement were better explained by family relationships and caregiving burden than by clinical or socio-demographic variables.
- When possible, information about children’s adaptation outcomes should be collected from both children and parents, while also consider the family context.
- An in-depth assessment of pediatric adaptation outcomes can enhance a more efficient allocation of health resources.

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