

Understanding Quality of Life in Children with Asthma and their Parents: Family Resources and Challenges

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Abstract

The present research investigated the links between caregiver burden, family environment, and quality of life in 97 pairs of children with asthma and one of their parents (the primary family caregiver). Using structured equation modelling, within-participant analyses showed that family environment was positively linked to quality of life for both children and parents respectively. Across-participant analyses demonstrated that parents' positive perceptions of family environment were associated with parents' and children's improved quality of life. In addition, parents' perceptions of family environment mediated the link between caregiver burden and parents' and children's quality of life. Implications for intervention with families are discussed in light of this study's important results.

Keywords

Quality of life • Asthma • Family environment • Caregiver burden

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Asthma is the most common chronic disease in childhood, affecting a significant number of children and their families worldwide (Shohat, Graif, Garty, Livne & Green, 2005; Streisand & Tercyak, 2004). Living with asthma poses challenges of different sorts: to children and the other family members individually, as well as to the family as a whole (Kazak, 1989). A growing body of research (Brown, Gan, Jeffress, Wood & Mille, 2008; Everhart, Fiese & Smyth, 2008; Marsac, Funk & Nelson, 2006; Van Gent et al., 2007) consistently shows that children with asthma and their parents/caregivers are at risk for decreased psychological functioning, well-being, and quality of life (QoL). Despite the evidence underscoring that this health condition can be associated with a wide range of impairments of functioning and well-being and the consensual view that asthma can be best understood within a family-contextual approach (Fiese, Winter, Anbar, Howell, & Poltrock, 2008; Josie, Greenley, & Drotar, 2007), the majority of research has examined parents' and children's adaptation separately (Annett, Turner, Brody, Sedillo & Dalen, 2010). Although this line of inquiry has provided valuable insights into the specific vulnerabilities of children with asthma and their caregivers, the interdependence of family members who influence each other has prompted researchers to ask new questions and implement novel study designs. Mirroring the shift occurring in the wider field of parent/child relationships (Laursen & Collins, 2009; Sameroff & Fiese, 2000) only recently has asthma research adopted a more integrative approach by examining the bidirectional influences between children and their parents (i.e., the impact that children variables have on parents' outcomes and vice-versa) (Sales, Fivush & Teague, 2008).

The major goal of the present study is to strengthen the efforts to bring this shift to the context of cases involving pediatric asthma. Adopting the transactional framework presented by Fiese and colleagues (2008), which allows examining family influences on individual adaptation in the context of a chronic health condition, we specifically aim to do the following: (1) analyze the individual and dyadic links between perceptions of whole-family environment and QoL in a sample of children with asthma and their parents/ primary family caregivers; and (2) assess whether the burden of providing care to a child with asthma influences parents' and children's QoL via their effects on the family's environment as a whole. This contribution will both expand the knowledge about the links between entire family processes and individual adaptation in the specific context of asthma and provide new relevant information to professionals working with these families and seeking to develop a best practice approach.

Quality of Life in Children with Asthma and Their Parents/Caregivers

Growing up with asthma is associated with higher risk of recurrent hospitalizations, emergency room visits, and school absence (Shohat et al. 2005). Professionals and researchers in the

field of pediatric asthma have long recognized that together with the physical, there are also psychological and social consequences of having this condition. A well established fact is that asthma has a significant impact on the children's quality of life (e.g. Gibson, Henry, Vimpani & Halliday, 1995; Hesselink et al., 2004; Van Gent et al., 2007). Reflecting the tendency for the assessment of negative outcomes that has largely dominated research on adaptation to asthma during previous decades, a considerable amount of research consistently showed an increased risk for the development of psychopathology in children with asthma (Marsac et al., 2006). In terms of psychological adjustment, anxiety disorders, behavior problems, and lower self-esteem have been systematically reported as more prevalent in children and adolescents with asthma (Vila et al., 2003). Higher levels of internalizing symptoms, such as depressive thinking and worry, school absenteeism and academic underachievement have also been observed for this group (French, 2001; Klinnert, McQuaid, McCormick, Adinoff & Bryant, 2000; Moonie, Sterling, Figgs & Castro, 2008; Van Gent et al., 2007). Asthma severity has been inconsistently related to adaptation outcomes, with some studies reporting an association between asthma severity and poor outcomes (e.g. De Lira & Da Silva, 2005; Josie et al., 2007), and others reporting no significant association at all (e.g. Goldbeck, 2006; Vila et al., 2003). In a recent systematic review, Everhart and Fiese (2009) found that in nine out of 14 studies, asthma severity was related to children's QoL.

Parents of children with a chronic health condition, such as asthma, are also at risk for negative outcomes such as depression (Brown et al., 2006; Waxmonsky et al., 2006), anxiety about the child's health and emotional distress (Frankel & Wamboldt, 1998). Goldbeck (2006) found that, compared with parents of healthy children, the parents of children with a chronic health condition reported a persistent impairment in most dimensions of perceived parental quality of life. Links between the severity of the disease and caregiver's QoL to date have been grossly under examined. Although caregivers' QoL seems to be worse when the severity of asthma severity is higher (Everhart et al., 2008; Halterman et al., 2004) this is likely due to the fact that many studies rely for the most part on caregivers' self-reported assessment of symptom severity. Thus, researchers have called for the use of external measures to assess the severity of the disease.

Finally, the links between parents' and children's QoL have been seldom researched, however there is some evidence that these variables are positively associated (Vila et al., 2003; Wood et al., 2007). In sum, there is evidence to support the increased vulnerability to psychological maladjustment and QoL impairment of children with asthma and their parents. From an applied point of view, however, more important than descriptive comparisons of families with asthma with healthy families, is the focus on families with asthma and their resources, namely the need to assess which factors account for the variability of the effects of the disease on family members' outcomes. This study also addresses two of those important factors, family environment and caregiver burden.

Family's Influences on QoL: Whole-family and Individual Variables

Family environment

Research comparing the family functioning and environment of families with a chronically ill child and healthy families presents contradictory evidence (Barlow & Ellard, 2006). While some studies stress the poorer outcomes of families who have a child with a chronic condition (e.g. Quittner, Opiari, Regoli, Jacobsen, & Eigen, 1992), others do not find differences between these two groups (e.g. Kazak, 1987). A third cluster stresses the better results that may be found for those families. Goldbeck (2006), for instance, found that parents who had children with chronic conditions (and reported poorer parental QoL in several domains) were significantly more satisfied with their family situation compared to parents of healthy children. Another study by Thornton and colleagues (2008) found that families of children with epilepsy were found to score significantly higher on family involvement dimension, reflecting a positive impact of epilepsy on the family. Thus, in families with children with a chronic health condition, despite the evidence that family members present poorer QoL and that parents are exposed to more sources of stress, the overall functioning of the family system does not seem to be as negatively affected (at least in an unequivocal and consistent way). This gains an increased relevance given the consensus that a positive, warm and cohesive family system is considered a protective factor for parents and children with a chronic condition (e.g. Kazak, 1989; Krulik et al., 1999; Wallander & Varni, 1989). Specifically, with regard to children, Josie and colleagues (2007), found that by testing a cumulative risk model for children and adolescents with asthma, family functioning was the strongest contributor to the youths' health related QoL. With regard to parents/caregivers' QoL, a study by Everhart and colleagues (2008) found significant associations between perceived family burden and stress. Altogether, these results seem to indicate that family environment, besides not being as permeable to the negative effects of the disease as other variables, also has a positive effect on family members' QoL, making it a worthwhile route for future research aiming to inform for practical interventions.

A major gap of research in this field involves the lack of studies addressing the parents-children mutual influences in these whole family variables. Although some studies in asthma research have already demonstrated how parents and children influence each other (e.g. Waxmonsky et al, 2006; Fiese et al., 2008), there is still significant information requiring empirical examination. For instance, there are no studies that we are aware of, addressing the transactional influences of whole-family processes and their links to well-being. Our research addresses the aforementioned gap in the literature.

Caregiver burden

A chronic illness in a child/adolescent is not restricted to the individual inflicted, but rather affects everyone in the family (Kazak, 1989). Although parents caring for a child with an illness might generally perceive family life as stressful, the stressors they report seem to be specific to the

caregiving demands of the illness (Quittner, Glueckauf & Kackson, 1990). In these families, parenting and caregiving go hand in hand as parents are also the main informal caregivers. Providing daily care to children is a part of every parent's role. However, providing the high level of care required by a child with a chronic health condition can become burdensome and may have an impact upon both the physical and psychological health of the caregiver (Raina et al., 2004). Parents of children with such conditions are responsible, not only for the physical care of their children, but for dealing with medical, educational, and other service providers, for helping children cope with the physical and emotional demands of their condition, and for balancing competing family needs (Silver, Westbrook & Stein, 1998).

A good avenue to understand the negative impact of asthma on adaptation of parents and children is to investigate the burden of caregiving (i.e., the caregiver's perceived responsibilities and limitations inflicted upon the self and family) (Canning, Harris & Kelleher, 1996). Research has mainly addressed caregiver burden effects in indirect ways, namely, assessing the negative impact of time constraints in opportunities for family interactions and leisure activities (Quittner et al., 1992; Turner-Henson, Holaday & Swan, 1992) or the consequences of burden such as stress and depression, found to be predictors of inflammatory markers in children with asthma (Wolf, Miller & Chen, 2008). However, very little research has addressed the impact of parents' own perceptions of caregiver burden. This is a relevant aspect, as for instance, Canning and colleagues (1996) found that it was caregivers' reports of burden, not physician reports of parental burden that predicted caregivers' distress. Another study (Fiese, Wamboldt & Anbar, 2005) found that the perceived burden of routine asthma care was negatively linked to both parents and children's QoL. Fiese et al. (2008) additionally found that the perceived burden of routine asthma care was indirectly associated with higher anxiety and children's lower QoL through their effect on mother-child interaction patterns (mother criticism and rejection of the child). In our study, we advance the current research by examining how perceived caregiver burden, as an individual-level variable, affects the manner in which parents perceive their family as a whole and also their, and their children's, quality of life.

Hypotheses

Four main hypotheses were devised for the present study. It was predicted that associations between family environment and QoL would be positive for both parents and children respectively (within-participants effects). It was also predicted that parents' perceptions of family environment would be positively associated with better QoL in children and that children's perceptions of family environment would be linked to better QoL in parents (across-participants effects). These predictions spawn from past research that consistently shows that a positive family environment and a sense of connectedness is one of the main factors that predicts both children and adolescents' and

their caregivers' well-being (Everhart et al., 2008; Josie et al., 2007). In addition, based on the transactional model's assumption that both parents and children are active agents who continuously influence each other (Fiese et al., 2008), it was anticipated that children's and parents' positive perceptions of the family would positively influence each other's appraisals of life.

Next, based on past research stressing the negative consequences of burden due to providing care to a family member (e.g. Fiese et al., 2008; Raina et al., 2004), it was hypothesized that higher levels of caregiver burden would be associated with less positive family environment and worse QoL for both family members (hypothesis 3). In addition, we hypothesised that family environment would have a mediating role on the links between caregiver burden and parents' and children's QoL (hypothesis 4). More precisely, we expected that, when parents experienced higher levels of caregiver burden, their views on the family would be less positive, which in turn, would lead to a decrease in their, and their children's, QoL. This hypothesis is based on Fiese et al.'s (2008) finding that the perceived burden of routine asthma care negatively affected children's QoL through dyadic mother-child interaction (rejection/criticism). This study aimed at expanding these results by specifically assessing if caregiver burden affected not only children's but also parents' QoL directly and/or via their effect on the overall family environment. Finally, we examined the links between the aforementioned variables and age, gender, and asthma levels of severity but made no specific predictions in this regard.

Method

Participants

Participants were 97 parent-child/adolescent¹ pairs: children had diagnosed asthma and parents were their primary family caregiver (i.e., the parent who currently assumes the primary role in informal healthcare issues). Children's ages ranged between 8 and 18 ($M=12.52$, $SD= 2.48$), the majority (91) being between the ages of 9 and 16 years. Fifty nine percent of the sample was male. According to clinicians' assessment of the disease's severity, the majority of participants (63%) had level one asthma (intermittent), 25% had level two (mild persistent), 10% had level three (moderate persistent) and 2% level four (severe persistent). Caregivers' ages ranged from 30 to 59 ($M=41.77$, $SD= 5.62$). The great majority (85) of caregivers were mothers, 11 were fathers, and in one dyad this information was missing. The majority of dyads came from low socio-economic status (SES) background (65%), followed by 25% from medium SES and 10% high SES, a distribution consistent

¹ For simplicity, we opted to use the term children when referring to this study's sample comprised of both children and adolescents.

with the users' profile for the attendance of public health services in Portugal.

Procedure

Sample collection was conducted at the outpatient services of three public hospitals (Coimbra University Hospitals, Coimbra Pediatric Hospital, and Santo André Hospital) between February 2009 and July 2010. Children and adolescents were included in this study if they met the following inclusion criteria: (1) age between 8 and 18; (2) clinical diagnosis of asthma according to the international classification systems (ICD-10) by a physician; (3) illness duration of at least one year; (4) available consent form from them and/or their parents. Individuals were excluded from this study according to these criteria: (1) children (younger than 14 years old) who refused to participate, regardless of their parents' previous consent; (2) significant developmental delay, interfering with the ability to understand questions, assess thoughts and emotions, and maintain an adequate conversation with an adult; (3) severe psychiatric comorbid disorder.

For data collection, formal authorizations were obtained from the Ethics Committees of the aforementioned institutions. Informed consent forms were obtained by young people (when over 14) and their parents. Assessment protocols were filled in by the child and their parent/caregiver in an institution's room provided for this purpose in the presence of a research assistant. Children and adolescents with reading difficulties were personally aided by the research assistant. Asthma severity, following Everhart et al.'s (2008) and Everhart and Fiese's (2009) recommendation, was assessed by the child's clinician.

Measures

Family environment

Family environment was a latent variable based on two subscales of The Family Environment Scale (Moos & Moos, 1986; Portuguese version: Matos & Fontaine, 1992), a questionnaire designed and used in this study for both parents and children. The two subscales Cohesion (9 items) and Expressiveness (9 items) assessed perceptions of family relationships (e.g. "Family members really help and support one another" and "Family members often keep their feelings to themselves"). Participants' responses were on a Likert-type scale ranging from 1 "completely disagree" to 6 "completely agree".

Children's Quality of life

Children's QoL was assessed as a latent variable comprised of two indicators, the self-report versions of the DISABKIDS Chronic Generic Module (European DISABKIDS Group, 2006) and the

KIDSCREEN-10 (Ravens-Sieberer et al., 2010; the Portuguese version for the extended version: Gaspar & Matos, 2008). These two scales were both designed for assessing health-related quality of life in children and adolescents between 8 and 18, however, while the DISABKIDS was specifically designed for children and adolescents with chronic health conditions, the KIDSCREEN has a broader scope and can be applied to both healthy and chronically ill children. With regard to the DISABKIDS scale, participants answered 37 items (e.g. “Are you able to do everything you want to do even though you have your condition?”; “Do you worry about your condition?”), reporting to the “the past four weeks”, on a Likert response scale ranging from 1 (“never”) to 5 (“always”). The KIDSCREEN 10 items reported to the previous week’s frequency (e.g. “Have you felt full of energy?”; “Have you had fun with your friends?”) and were also on a 5-point Likert-type response scale (“never” – “always”; “not at all” – “extremely”). KIDSCREEN items were standardized according to norms available for the Portuguese population (Gaspar & Matos, 2008).

Parents’ Quality of life

Parents’ QoL was assessed with the Psychological scale of the World Health Organization Quality of Life [WHOQOL-BREF] (WHOQOL Group, 1998; Portuguese version: Vaz-Serra et al., 2006). This scale was comprised of six items (e.g. “How much do you enjoy life?”). A latent variable was developed composed of two parcels containing 3 items each. All of these items were answered on a 5-point Likert-type response scale, in terms of intensity (“not at all” – “extremely”), capacity (“not at all” – “completely”), frequency (“never” – “always”) or evaluation (“very dissatisfied” – “very satisfied”).

Caregiver burden

A caregiver burden latent variable was constructed with three indicators corresponding to the subscales of The Revised Burden Measure (Montgomery & Colleagues, 2006): Relationship, Objective, and Subjective burden. In total, participants answered 16 items according to a 5-point Likert-type scale ranging from 1 “not at all” to 5 “a great deal”. The Relationship burden subscale (5 items) assessed the negative psychological state that results from demands for care and attention over and above the level that the caregiver perceives is warranted by the care receiver’s condition (e.g. “Have your caregiving responsibilities increased attempts by your relative to manipulate you?”). The Objective burden subscale (6 items) assessed the negative psychological state that results from the interference of caregiving activities on the caregiver’s life (e.g. “Have your caregiving responsibilities decreased time you have for yourself?”). The Subjective burden (5 items) referred to a generalized form of negative affect that results from caregiving, but not as a result of any specific event, task, or interaction (e.g. “Have your caregiving responsibilities caused you to worry?”).

Asthma severity

Asthma severity was assessed by clinicians according the Global Initiative for Asthma Program (GINA, 2008) guidelines. Asthma severity was evaluated based on the level of symptoms, airflow obstruction, and lung function variability, into four categories: intermittent, mild persistent, moderate persistent or severe persistent. Due to the low frequencies of participants in each group of asthma severity, this variable was dichotomized and then “dummy coded” in order to perform correlation analyses. The final two categories for asthma severity were intermittent ($n=60$) vs. persistent (mild, moderate and severe persistence; $n=36$).

Data Analysis

Descriptives and zero-order correlations were performed using SPSS 17. Structural equation modeling (SEM) was constructed with AMOS 16 (Arbuckle, 2006). We used raw data and the full information maximum likelihood estimation method. In order to assess the goodness of fit of the models, we used the maximum-likelihood χ^2 statistic, the Comparative Fit index (CFI), and the Root Mean Square Error of Approximation (RMSEA). Following Hu & Bentler’s guidelines (1999), a model was considered to fit the data well if the maximum likelihood χ^2 was non-significant, the Comparative Fit Index (CFI) had a value of .95 or higher and the Root Mean Square Error of Approximation (RMSEA) had a value of .06 or lower. We started by testing the measurement model (i.e., we constructed a confirmatory factor analysis (CFA) model with the hypothesized links among latent variables and their observed indicators). This step was taken to ensure the latent constructs operationalization was appropriate (Anderson & Gerbing, 1988). We subsequently constructed two structural models, model 1 testing the bidirectional links among parents’ and children’s family environment and QoL and model 2 testing the mediating role of family environment on the links between caregiver burden and parents’ and children’s QoL. In this last model, bootstrap procedures were used to examine the significance of the indirect effects (MacKinnon, Lockwood, & Williams, 2004; Preacher & Hayes, 2008).

Results

The Measurement Model

Means, standard deviations, Cronbach’s alphas, and factor loadings for the main constructs and/or their indicators are presented in Table I.

Table 1. Means, standard deviations and Cronbach's alphas

Variables (range)	M(SD)	α	Factor loadings
Parents			
Family environment (18-108)	85.84 (11.75)	.87	
Cohesion (9-54)	43.68 (6.32)	.76	.81
Expressiveness (9-54)	41.76 (6.77)	.74	.87
Psychological QoL (6-30)	23.27 (3.63)	.80	
Parcel 1 (3-15)	12.27 (1.92)	.68	.85
Parcel 2 (3-15)	11.00 (2.09)	.70	.74
Caregiver burden (16-80)	29.45 (10.82)	.92	
Relationship burden (5-25)	8.03 (3.64)	.84	.79
Objective burden (6-30)	11.41 (4.68)	.85	.79
Subjective burden (5-25)	10.34 (4.19)	.81	.90
Children			
Family environment (18-102)	83.15 (13.71)	.87	
Cohesion (9-54)	43.49 (8.28)	.87	.92
Expressiveness (9-54)	39.67 (6.34)	.60	.80
Quality of life (47-235)	196.80 (22.96)	.94	
Health-related (Chronic conditions) (37-185)	155.11 (18.72)	.93	.80
Health-related (General) (20-100)	83.57 (11.62)	.82	.80

Alphas for all the scales, except one (family expressiveness assessed by children) were above .70. Initially a CFA was performed with five latent variables (family environment and QoL reported by both parents and children, and caregiver burden reported by parents) and their observed indicators, which were established subscales for all variables, except for the psychological QoL's two parcels. In this model, all the latent variables were allowed to correlate. The items that had the highest loading were fixed as the reference points for model identification (Schmitt & Kuljanin, 2008). All factor loadings were significant ($p < .01$) and fit indexes for the overall model were very good: $\chi^2(34, n = 97) = 42.93$; $p > .05$; CFI = .98; RMSEA = .05.

Zero-order correlations among all the variables in the SEM models are presented in Table 2. Asthma severity was negatively linked to children's QoL, however, the association with parents' QoL and caregiver burden was non-significant. There was a marginal negative link between asthma severity and children's' (but not parents') perceptions of family environment. Associations between parents' and children's family environment and QoL were, as predicted, significant and positive, both within (for parents and young people separately as predicted in hypothesis 1) and across family members (for associations among parents' and children's variables as predicted in hypothesis 2). As expected (hypothesis 3), caregiver burden was negatively related to parents' and children's QoL; caregiver burden was also negatively related to parents' and children's perceptions of family environment (although these were marginally significant associations). Children's gender and age

were not significantly correlated to any of the study variables. SES was significantly linked ($r = .25$, $p < .05$) with parents' perception of family environment.

Table 2. Matrix of inter-correlations among model constructs for parents and children

	Parents			Children	
	1	2	3	4	5
Parents					
1. Family environment					
2. Quality of Life	.43**				
3. Caregiver Burden	-.19~	-.28**			
Children					
4. Family environment	.36**	.31**	-.21~		
5. Quality of life	.36**	.31**	-.32**	.60**	
Clinical variable					
6. Asthma severity*	.12	.12	.12	-.18~	-.23*

* Dummy-coded variable: 0=intermittent; 1= persistent.

** $p < .01$; * $p < .05$; ~ $p \leq .08$

Structural Equation Models

Model 1. Parents and young people's family environment and QoL: Associations within and across family members.

Figure 1 depicts the final model constructed to test hypotheses 1 and 2. We used a model-generation application of SEM (Jöreskog, 1993, described in Kline, 2005): after testing the hypothesized model, this was trimmed by removing non-significant paths. The model had a very good fit: $\chi^2(15, n = 97) = 15.13$; $p > .05$; CFI = 1; RMSEA = .01. More positive perceptions of family environment were linked to better QoL for parents and children (within-participants paths), supporting hypothesis 1. With regard to the cross-lagged paths, we verified that, parents' family environment was linked to children's QoL, partially confirming hypothesis 2. However, against predictions (hypothesis 2), children's QoL was not linked to parents' QoL. The R^2 for parents' QoL was .37 and for children's QoL was .58. We re-ran the final model controlling for children's gender, age, SES, and asthma severity and found similar results.

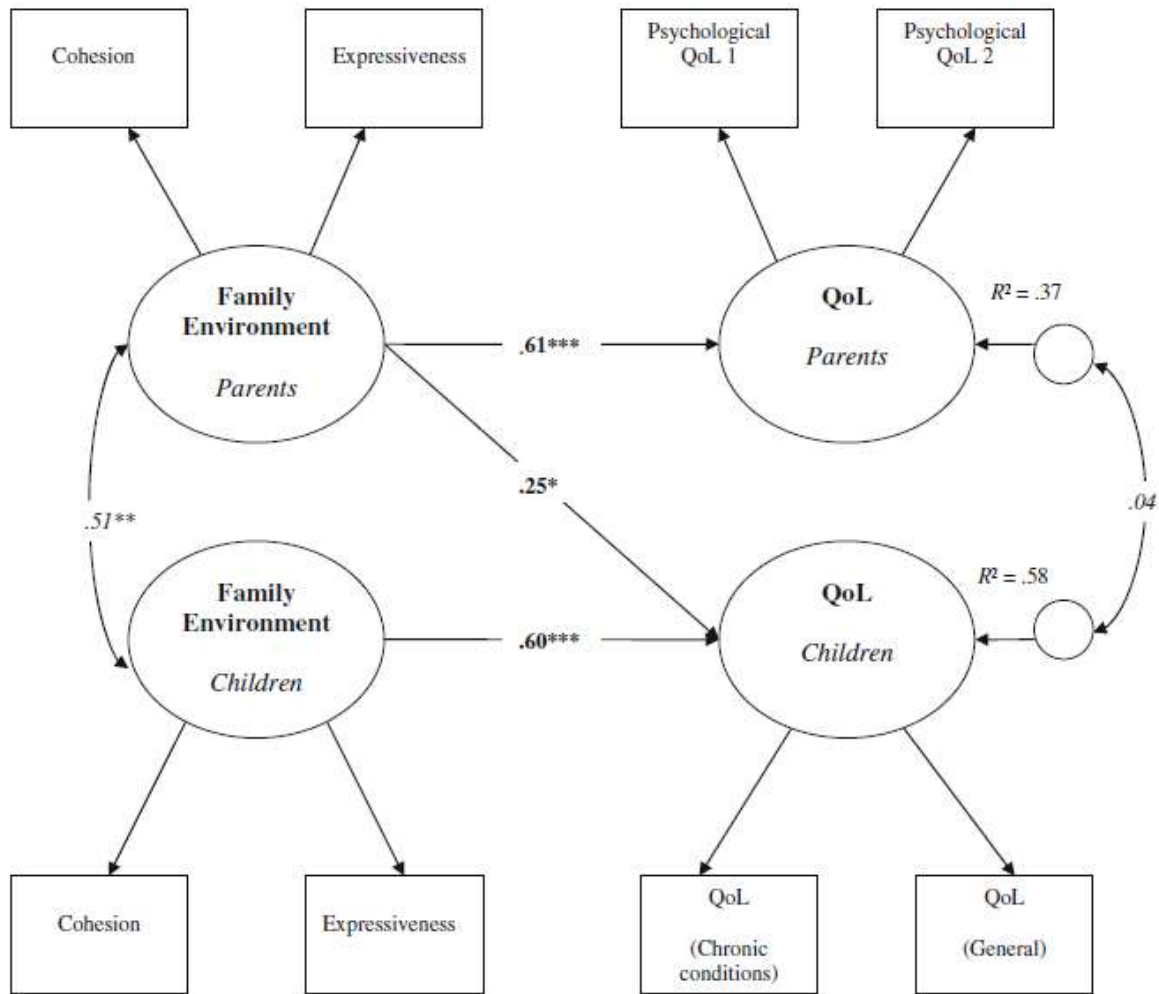


Figure 1. Structural equation model testing the links between family environment and quality of life. Bold figures represent standardized coefficients; non-bold figures represent Pearson correlation coefficients. For simplicity, measurement error terms are not shown; *** $p \leq .001$; ** $p \leq .01$; * $p \leq .05$.

Model 2. Parents' perceptions of family environment as a mediator between caregiver burden and parents' and children's QoL.

Figure 2 depicts the hypothesized mediation model, which yielded a good fit to the data: $\chi^2(22, n = 97) = 20.77$; $p > .05$; CFI = 1; RMSEA = .00. We opted not to include in the final model the direct path from caregiver burden to parents' QoL as this was only marginally significant ($\beta = -.20$, $p = .10$). However, when we compared these two nested models (the depicted model where this path was set to zero and an alternative model where it was set free) we verified that the difference between them was non-significant ($\Delta \chi^2[1] = 2.71$), suggesting that with a larger sample size, this direct path could reach significance (as verified in the zero-order correlations). To assess whether indirect effects were statistically significant, the bias-corrected (BC) bootstrap 90% confidence intervals (CIs) with 5000 bootstrap samples procedure was used (see Preacher & Hayes, 2008). Both

indirect effects were significant: the standardized indirect effect of caregiver burden on parents' QoL was $-.15$ ($CI = -.20/-.01$) and on children's QoL was $-.11$ ($CI = -.93/-.08$). The R^2 for parents' QoL was $.34$ and for children's QoL was $.28$. This model held when we sequentially controlled for children's gender, age, SES, and disease severity.

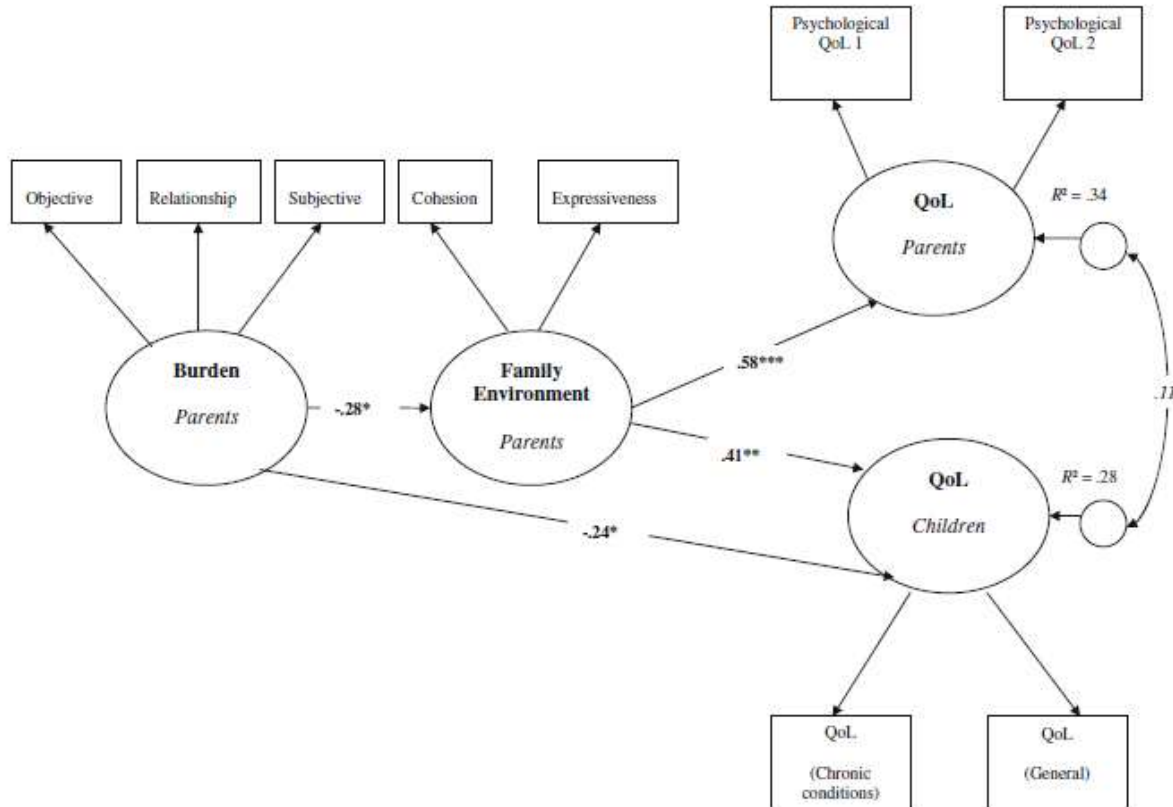


Figure 2. Structural equation model testing the indirect effects of caregiver burden on parents' and children's quality of life via family environment (parents' reports). Bold figures represent standardized coefficients; non-bold figures represent Pearson correlation coefficients. For simplicity, measurement error terms are not shown; *** $p \leq .001$; ** $p \leq .01$; * $p \leq .05$.

Discussion

In the present study, we sought to examine the role of whole family variables on the quality of life of children with asthma and their parents/main caregivers. We predicted that a family environment with higher levels of cohesion and expressiveness would be linked to better QoL of both family actors (children and their parents), a hypothesis which was supported by our empirical findings. Moreover, we also found support for the predictions that burden experienced by parents, in their role as the primary caregivers of their children, affected their perceptions about the family environment and also their own and their children's QoL. In addition, our results showed that the

negative effect of caregiver burden on the QoL of both family members could be direct (in the case of children's QoL) and indirect (in the case of children's and parents' QoL). Next, we start by discussing this study's results addressing the protective function of family environment and the negative impact of caregiver burden. We then examine some caveats and conclude by discussing the clinical implications of this study's main findings.

Family Environment and QoL in Families with Pediatric Asthma: "Just Like any other Family?"

The first set of findings from this study strengthens the growing body of literature advocating that a positive family environment is beneficial for the adaptation of children with asthma (Josie et al., 2007; Kazak, 1989; Krulik et al., 1999). The novelty of our study lies in the gathering of reports of family environment and QoL from both parents and children. This design allowed to control for the interdependence among family members and also to test mutual influences they potentially exerted on each other. We concluded that, beyond the positive impact of parents' own perceptions of how well the family was doing in their QoL, their family perceptions also had an additional impact on their children's QoL. However, the way children perceived their family environment was only linked to their QoL, but not to their parents', a finding that gives insight into the different processes by which family factors play a role in the well-being of different family members. In line with past asthma research (Annett et al., 2010), our results showed that a family that is perceived as cohesive and a safe context for sharing opinions, worries, and feelings, is a protective factor for children's and parents' development and well-being. Markson & Fiese (2000), for instance, found that in families who endorsed more meaning to family rituals, children presented lower levels of anxiety. In the absence of longitudinal data to analyze causality paths, these authors considered, on one hand, that family rituals could help stabilize the family in a context of multiple stressors and also, on the other hand, that families who were more organized might be more prepared to face the challenges of dealing with a chronic illness. Additionally, we consider that a possible avenue by which a good family environment is linked to better QoL involves social support. Cohesive and expressive families are likely to be privileged sources of support (and, in a dynamic fashion, promoters of social-support seeking strategies development), an empirically tested important resource for children with chronic health conditions (Barros, Matos & Batista-Foguet, 2008; Wallander & Varni, 1989) and their parents (Horton & Wallander, 2001).

Children with asthma, who are likely to deal with recurrent hospitalizations and emergency room visits, medical appointments, school absences, etc., will benefit from a well organized and reliable family system. This kind of system is likely to promote feelings of security about children's environment, and also, possibly, about the management of their disease ("I feel safe and my family helps me manage my disease"). In addition, a family who provides children with opportunities to

express their worries and fears about the disease and about their daily lives is an important resource to help deal with both the demands of the disease and the normative challenges of their developmental phase. Parents/caregivers of children with asthma exposed to several stressors, such as personal distress, financial burden, or parental responsibility in the areas of asthma symptoms prevention and intervention and adherence to medical regimens (Kaugars, Klinnert & Bender, 2004; Mailick, Holden & Walther, 1994), are likely to find a good family environment as a safe haven and a support source to deal with all these challenges. The finding that children's QoL is influenced by their parents' views on the family environment, but not the inverse, can be explained within a system and developmental framework. Firstly, although the family environment is a dynamic result of the interaction between all members, parents, due to their roles and position in the family, are the main people in charge of decisions, planning, and overall family organization. When parents hold more negative views about the family environment, family life is more likely to be affected (for instance, by the interruption of routines and rituals) and, consequently, exert a steadier negative influence in the well-being of everyone in the system. Secondly, factors predicting parents' and children's QoL are diverse. As adults, parents move in several contexts and, thus, the way they appraise their life might be influenced by different ecological layers, such as their economic situation, work-related issues, and the couple relationship, among others. Although the majority of children in our sample are in early adolescence, a developmental phase characterized by the exploration of new contexts in a more independent way (school, peer and community groups), family is still a major source of support and influence (Laursen & Collins, 2009). Thus, younger family members might be more influenced by what happens in the family, in comparison to their adult parents. In fact, our study showed that a significant percentage of children's QoL was explained by family environment, reinforcing its role as an important resource for family dealing with pediatric asthma. These results held when statistically controlled for asthma severity, an indication that family environment is beneficial for families in different points of the disease spectrum.

Overall, this set of results recall the similarities between families with children with asthma and other families, including healthy ones. It is widely acknowledged that being connected to one's family and having a warm supportive environment is linked to a range of positive outcomes for individuals regardless of their age and developmental phase (e.g. Laursen & Collins, 2009; Marks & Greenfield, 2008).

“Parents and caregivers”: Caregiver Burden as an Additional Challenge of Families with Children with Asthma

Literature has often suggested that the burden of caring for a person with a chronic illness has negative impact on families and individuals' adaptation. However, to date, few empirical studies have examined these links (Canning et al., 1996). The results of this study show that, when

experiencing more caregiver burden, both parents and children held less positive perceptions about family environment (although correlations were only marginally significant) and also reported poorer QoL. Providing care for a child with a chronic illness is a multifaceted chore. Besides the disease management itself, parents are confronted with the need to deal with health care systems, learn the disease jargon, face their and the child's emotional reactions throughout the disease trajectory and, often, articulate caregiving demands with their professional roles (Streisand & Tercyak, 2004). The recognition of the additional strain and specificities of the caregiving tasks has originated the term "career of caregiver" (Raina et al., 2004). Since this is an unexpected career, parents are not usually prepared for all the tasks and challenges associated with this role. These individuals, "parents and caregivers" are, thus, simultaneously dealing with the demands and responsibilities of parenting and with learning how to provide care for a child with a chronic condition with all its implications. In the specific context of asthma, due to the unpredictable nature of the disease (Streisand & Tercyak, 2004), the articulation of these roles can be particularly taxing.

Our study findings highlighted two ways by which caregiver burden affected family members' QoL. First, we verified that parents' caregiver burden had a direct link to children's QoL. Among several possible explanations for this result, we advance two. It is possible that when the individuals experience higher levels of burden, their caregiving tasks are impaired or even neglected. For instance, a caregiver under high stress might be less efficient in the task of managing the disease, namely monitoring their child's adherence to treatment or proactively engaging in symptom prevention. In addition, it is also likely that high levels of burden interfere with parenting tasks: parents in this condition might be less attentive, responsive, or warm. This is consistent with Fiese et al.'s (2008) finding that the burden of routine asthma care was associated with critical mother-child interaction patterns (mother criticism and rejection), which in turn were associated with higher anxiety and lower QoL for children. In our study, we extended Fiese and colleagues' results by testing family environment as a possible mediator of the links between burden and QoL. As predicted, we verified that caregiver burden affected both parents' and children's QoL via parents' views of family environment. When parents reported higher levels of caregiver burden, they also viewed their family as a less cohesive and expressive context, which in turn was linked to parents' and children's reports of worse QoL. We argue that the experience of caregiver burden in at least one of the parents is easily spread to the whole family environment, as the stress and negative emotional reactions (worry, anxiety, frustration, and fatigue, etc.) associated with burden (Biegel et al., 1991; cit. in Bolden & Wicks, 2009; Pinqart & Sörensen, 2003) are likely to affect the dynamics of the family, specifically, their sense of cohesion as a group and opportunities for open communications of thoughts and feelings. Interestingly, caregiver burden was not linked to disease severity and the mediation model results remained unchanged when we controlled for asthma severity reported by clinicians. These findings seem to indicate that parents can experience caregiver

burden even if asthma is milder and under control and that the negative effects of the burden on family environment and QoL take place independently of the clinical diagnosis of severity.

Limitations of the Study

This study's main limitation is the reduced sample size. Even though we controlled for this variable, due to the low frequencies of families in the groups of different levels of asthma severity, we were unable to test its moderating role on the links examined in this study. In addition, where smaller effects could be detected and the moderating role of these variables on this study's links could be examined, it is possible that a more detailed set of results would emerge in a larger study. The individual and family demands of chronic health conditions changes throughout the child's and the family's developmental trajectories (Kazak, 1989) and, unfortunately, such specificities could not be addressed in our study. Finally, correlations between caregiver burden and family environment were only marginally significant and must be interpreted with caution and followed up with further research.

Another caveat is that the cross-sectional nature of this study did not permit disentangling causality on the links between family environment, QoL, and caregiver burden. Although we have tested these links in a specific way according to literature and previous research, relationships among these variables are likely to be bidirectional. Thus, better QoL among the family members might contribute to better family environment and, also, parents who perceive better family environment are likely to experience lower levels of burden for providing care to their asthmatic child. Finally, we advance two suggestions for further research. In this study, we only assessed the primary family caregiver who was, in most cases, the mother. Further studies including other family members' reports will allow drawing a more complex picture of these families' universe. Plus, it would be valuable to further examine more closely the processes by which burden and family functioning affect QoL, namely exploring the possible mediating role of disease management behaviours on these relationships. Nevertheless, this study has several strengths, namely the inclusion of two family members' reports, the analyses of transactional influences, and insights into how specific family factors (parents' experienced burden and whole family variables) contribute to parents' and children's QoL.

Conclusions and Clinical Implications

These results, framed in the context of pediatric asthma, allow for the conclusion that family factors are key components for understanding children's and parents' QoL. Among family factors, we have identified family resources and family challenges, potentially modifiable factors which can be

included in practical interventions aimed at improving family members' QoL. Family resources were identified as the positive aspects of the family (i.e., parents and children perceiving a cohesive family environment which also facilitates open communication and expression of thoughts and feelings). Family challenges referred to the burden of the caregiver that can be experienced by parents who are also the child's primary family caregivers and to the negative impact that this variable can have on family environment and parents' and children's QoL.

How can these findings be applied to intervention in the field? We discuss two possible paths, one at the level of the intervention's content, and the other at the level of its format. In regard to the first, interventions should focus on strategies to maintain/promote a positive whole-family environment. In view of multiple stressors, perceiving that the family "still stands" as a stable and reliable context is beneficial for both children and their parents. In this sense, it is important to work on empowering families through improving the family's own identity and sense of competence. Specifically we found that fostering a sense of belonging among family members and encouraging them to both listen to other family members and to self-disclose their opinions, worries, thoughts and feelings might be a fruitful road to improve individual QoL. One of the challenges that families with pediatric asthma face in maintaining a positive family environment is the burden that can be felt by the main caregiver; particularly when the caregiver experiences heightened burden, high levels of stress, and increased negative emotional reactions are inputted into the family system. Our findings suggest that attending to burden reduction in primary caregivers (targeted specially at those who are struggling with the demands of caregiving tasks), may improve the whole family environment and increase not only their QoL but also their child's QoL.

Embedded in the transactional approach to pediatric asthma (Fiese et al., 2008), our findings highlighted the manner in which parents influenced their children's QoL. In short, the more burdened that parents reported experiencing and the less positive views they had about their families, the worse their children's QoL. Also, parents' and children's perceptions about family environment and QoL were significantly related. In terms of the interventions' format, this provides extra empirical evidence for the acknowledged need to target the family as a whole, involving all (or the available) family actors. Our results, in line with past research, suggest that interventions will be more efficient if, besides aiming at the child's views on the family, they also address parents' perceptions. A possible rewarding avenue for intervention might be increasing family awareness about the mutual influences between parents and children, motivating parents to be more attentive to their own needs as a way to protect their children. Thus, parents can be active agents in preventing the piling-up of stress which can lead to crisis (Clawson, 1996). Finally, there are also implications at more macro-contextual levels, namely the need for parents of children with chronic illness to have a balanced work-life articulation and flexible work conditions which allow attending extra demands of their informal, yet demanding, caregiving "career".

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