

## Quality of life of asthmatic children and adolescents: relation to maternal coping

*Qualidade de vida de crianças e adolescentes asmáticos: sua relação com estratégias de enfrentamento materno*

*Calidad de vida de niños y adolescentes asmáticos: su relación con estrategias de enfrentamiento materno*

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### ABSTRACT

**Objective:** To evaluate the quality of life of asthmatic children and adolescents, its relation with sociodemographic and clinical variables, and maternal coping strategies.

**Methods:** Cross-sectional study in which children and adolescents with asthma answered a quality of life questionnaire, and their mothers did the same with a coping scale.

**Results:** Out of the 42 children and adolescents investigated, 74% were classified as having mild/severe persistent asthma; 19%, mild persistent asthma; and 7%, intermittent asthma. A total of 69% of the participants showed impaired quality of life with mean scores ranging between 4.7 and 3.5, with greater harm in the domain of symptoms (score=3.6). There was a significant association between maternal schooling and the general index of quality of life, whereas maternal coping strategies were not associated with the severity of asthma. A large number of strategies used by mothers to cope with their children's crises were related to the management of stressors or to religious practices, and the latter presented negative correlation with the children's quality of life general index, showing that mothers whose children had worse quality of life used more religious coping.

**Conclusions:** Asthmatic children, particularly those with moderate/severe persistent asthma, showed significant alterations as to quality of life. The high percentage of mothers

using religious strategies, particularly in face of more severe clinical conditions, seem to indicate that they feel powerless to act, thus requiring concrete and useful orientation to low income families.

**Key-words:** quality of life; asthma; coping; child; adolescent.

### RESUMO

**Objetivo:** Avaliar a qualidade de vida de crianças e adolescentes asmáticos, sua relação com variáveis sociodemográficas e clínicas e estratégias de enfrentamento materno.

**Métodos:** Estudo transversal no qual crianças e adolescentes com asma responderam a um questionário de qualidade de vida, e suas mães a uma escala de enfrentamento.

**Resultados:** Foram estudadas 42 crianças e adolescentes com idades entre 7 e 15 anos, sendo 74% classificados como tendo um quadro de asma persistente moderada/grave, 19% como persistente leve e 7% asma intermitente; 69% dos entrevistados apresentaram prejuízo na qualidade de vida, com escores médios variando de 4,7 a 3,5 e maior prejuízo no domínio sintomas (escore=3,6). Houve associação significativa entre escolaridade materna e índice geral de qualidade de vida, mas não entre gravidade da asma e tipo de enfrentamento materno. Grande parte das estratégias

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utilizadas pelas mães para enfrentar as crises do filho estava direcionada ao manejo de estressores ou práticas religiosas, estas com correlação negativa com o índice geral de qualidade de vida da criança, sinalizando que mães cujos filhos tinham pior qualidade de vida usavam mais enfrentamentos religiosos.

**Conclusões:** Crianças asmáticas, especialmente com asma persistente moderada/grave, apresentaram alterações significativas em sua qualidade de vida. A alta porcentagem de uso de estratégias religiosas por parte das mães, especialmente frente a quadros mais graves, parece indicar que elas se sentem impotentes para atuar, necessitando de orientações concretas e factíveis para uma população de baixa renda.

**Palavras-chave:** qualidade de vida; asma; enfrentamento; criança; adolescente.

## RESUMEN

**Objetivo:** Evaluar la calidad de vida de niños y adolescentes asmáticos, su relación con variables sociodemográficas, clínicas y estratégicas de enfrentamiento materno.

**Métodos:** Estudio transversal en el que niños y adolescentes con asma contestaron un cuestionario de calidad de vida (PAQLQ-A) y sus madres a una escala de enfrentamiento (EMEP).

**Resultados:** Se estudiaron 42 niños y adolescentes con edad de 7-15 años y, entre ellos, el 74% fueron clasificados como teniendo un cuadro de asma persistente moderada/grave, el 19% como persistente y el 7% asma intermitente; el 69% de los entrevistados presentaron perjuicio en la calidad de vida, con escores medianos variando de 4,7 a 3,5 y mayor perjuicio en el dominio de síntomas (escore=3,6). Hubo asociación significativa entre escolaridad materna e índice general de calidad de vida, pero no hubo asociación entre gravedad del asma y tipo de enfrentamiento materno. Gran parte de las estrategias utilizadas por las madres para enfrentar las crisis de los hijos estaba dirigida al manejo de estresores o prácticas religiosas. Estas últimas con correlación negativa con el índice general de calidad de vida del niño, señalizando que madres cuyos hijos tenían peor calidad de vida usaban más enfrentamientos religiosos. **Conclusiones:** Niños asmáticos, especialmente con asma persistente moderada/grave, presentaron alteraciones significativas en su calidad de vida. El alto porcentaje de uso de estrategias religiosas por parte de las madres, especialmente frente a cuadros más

graves, parece indicar que ellas se sienten impotentes para actuar, necesitando de orientaciones concretas y factibles para una población de bajos ingresos.

**Palabras clave:** calidad de vida; asma; adaptación psicológica; niño; adolescente.

## Introduction

The prevalence of asthma has increased in recent decades and is today one of the leading chronic diseases in the world, affecting children of all ages, social classes, and ethnic groups<sup>(1,2)</sup>. Asthma is a public health problem; therefore, appropriate actions for its control need to be planned<sup>(3)</sup>.

The consequence of asthma is not only physical, represented by breathing difficulties, but it also causes a strong emotional impact, associated with school absenteeism, social constraints, stress, affective disorders, depression, insomnia, and negative social perceptions, which end up changing the quality of life of children and their families<sup>(2,4)</sup>. The disease, if untreated, besides imposing limits on physical activity, can make the child insecure due to the unpredictability of exacerbations, which is worsened by the little information they have about the disease<sup>(5)</sup>. When mothers explain to children the stressful events related to asthma, children cope better with crises, have fewer behavioral disorders and better quality of life<sup>(6,7)</sup>.

Asthma, like other chronic diseases, is a stressful condition not only for the child but also for parents. The family's way of coping influences the child's adherence to treatment<sup>(8,9)</sup> and has a critical role in the quality of life of the child. The skills of the family to adapt to the multiple demands of a child with a chronic illness do not only depend on the severity of the condition, but on the mother's ability to assess and react to stressors<sup>(7)</sup>. Sales *et al*<sup>(4)</sup>, after adjustment for severity of asthma and recent family stressors, showed that mothers who used more active ways of coping to solve problems, had children with lower anxiety and better quality of life than those who used avoidance strategies.

Quality of life (QOL) in healthcare represents the patient's perception regarding their disease, symptoms, and functional, psychological, and social status. It is an essential component in the assessment of the patients' health status, his response to treatment, and progression of the condition<sup>(10)</sup>. The first attempts to assess QOL of children were taken from parents' perception, by considering the child unable to assess their gains and losses. Later studies showed

that children are able to understand the disease process<sup>(11)</sup> and that parents and children do not always share the same views on the impact of the disease in the child's life<sup>(10,12)</sup>. Thus, the current trend is to use instruments answered by the children in order to get their own perception about the disease, as well as involve them in decisions about their treatment and care<sup>(12,13)</sup>.

In this perspective, Juniper *et al*<sup>(14)</sup> developed a questionnaire for children over 7 years, the Pediatric Asthma Quality of Life Questionnaire (PAQLQ), from their experience with the Asthma Quality of Life Questionnaire (AQLQ) for adults. The PAQLQ was validated for the English language and subsequently published in 20 other languages. Some of its advantages are: it is applicable even when the condition is stable, it is able to capture small changes and includes fundamental functions to children's lives<sup>(14)</sup>. The first version for Portuguese was performed by La Scala *et al*<sup>(15)</sup>. In 2010, Sarria *et al*<sup>(15)</sup> showed a new version and determined the psychometric properties of the Portuguese official version with good psychometric performance and suitability of the instrument to the Brazilian context.

The aim of this study was to evaluate quality of life directly with asthmatic children and adolescents and investigate the relationship of quality of life with some sociodemographic and clinical variables, and with maternal coping strategies. Starting from the hypothesis that children and adolescents with more severe conditions have worse quality of life, there is an association between the severity of asthma and the ways of maternal coping, and between the latter and the quality of life of children and adolescents.

## Method

Cross-sectional study involving children with asthma at an Outpatient Pediatric Pulmonology Clinic at a University Hospital in the countryside of the state of São Paulo, in the period from February to June 2009. The study was approved by the Research Ethics Committee of the institution and all participants and parents signed the Informed Consent Form.

Patients were selected on the day of the medical appointment at the Outpatient Clinic and those who met the following inclusion criteria were included: age  $\geq 7$  years without respiratory comorbidities such as cystic fibrosis or bronchopulmonary dysplasia, and who were not using systemic corticosteroids within 2 weeks prior to study entry. Among children who met the inclusion criteria, each day three patients were randomly selected, as this

is the maximum number to enable the assessment on the same day of the visit. The children who failed to answer the questionnaire due to the difficulty of understanding or clinic indisposition, were excluded from the assessment of QOL, but their mothers were kept in the study for evaluation of ways of coping. The evaluation of mothers and children occurred in an environment of privacy, with an average duration of 50 minutes.

The classification of asthma severity was performed by the medical staff, as proposed by the IV Brazilian Guidelines for the Management of Asthma – 2006<sup>(16)</sup>, taking into account the following criteria: presence of diurnal and nocturnal symptoms, limitation of physical activity; need for rescue medication, lung function, and frequency of exacerbations. According to these criteria, patients were classified as having mild intermittent asthma, mild persistent asthma, and moderate/severe persistent asthma.

Permission to use the instrument of quality of life was requested directly to the authors<sup>(14)</sup>, who sent the material translated into Portuguese by La Scala *et al*<sup>(13)</sup>.

The PAQLQ is a specific instrument to assess QOL in individuals with asthma, aged between 7 and 17 years. It consists of 23 items divided into three domains: activity limitations (5 items), symptoms (10 items) and emotional function (8 items). All PAQLQ items are answered on a 7-point Likert scale, ranging from 1 (severely affected) to 7 (unaffected). The items are then added, and their means represent scores (total and by domain).

The Ways of Coping Checklist (WCCL) was validated for the Brazilian population by Seidl *et al*<sup>(17)</sup>. It consists of 45 items, distributed into four factors: (a) problem-centered coping ( $\alpha=0.84$ ), (b) emotion-focused coping ( $\alpha=0.81$ ), (c) search for religious practices/wishful thinking ( $\alpha=0.74$ ), (d) seeking social support ( $\alpha=0.70$ ). The answers are given on a Likert scale of 5 points. Higher scores are indicative of greater use of a determined coping strategy.

The demographic information of children and their families, including maternal age, education level and occupation, and age of child were obtained from medical records. The outcome of interest was the quality of life of children and adolescents with asthma.

The database was structured in Excel 2000 and statistical analyses performed by SAS for Windows, version 9.2. The Shapiro Wilk test was applied to test for normality of the variables. As the quality of life scores were normally distributed, the comparison of the means of the different domains

was performed by ANOVA for repeated measures, followed by the multiple comparison test of Tukey. To compare coping strategies, as the scores were not normally distributed, a Gamma generalized linear model and log link function were used, considering repeated measures (Generalized Estimation Equation). Then we applied a test of multiple comparisons (LSMeans test) with  $p < 0.05$ , comparing the medians 2x2. To evaluate possible predictors of the overall index of quality of life among the sociodemographic and clinical variables, univariate logistic regression was calculated. The association between maternal ways of coping and the child's quality of life was investigated by Pearson's correlation. In all analyzes the significance level was 5%.

## Results

Of the total of 58 subjects randomly selected, eight mothers refused to participate for fear of missing public transportation. Five children were unable to answer the questionnaire and 3 evaluations were suspended for clinical problems. In total, 42 children answered the quality of life questionnaire and 50 mothers responded to the ways of coping.

The mean age of children was 9.5 years, ranging from 7 to 15 years, with a predominance of girls ( $n=25$ ; 59%). The majority ( $n=31$ ; 74%) was classified as having moderate/severe persistent asthma, 8 (19%) patients had mild persistent asthma, and a few children had intermittent asthma ( $n=3$ ; 7%).

The mean age of mothers was 34 years, 22 (44%) were between 18 and 30 years and three mothers were older than 50 years. Regarding education, 24 (48%) had incomplete elementary school and 19 (38%), complete high school. Only four mothers (8%) had complete elementary school or higher education. Most mothers had a steady partner ( $n=41$ ; 82%) and 25 (50.0%) were housewives.

Regarding the quality of life of children, the mean overall index and of different domains ranged from 4.7 to 3.5, with significant impairment in the symptoms domain when compared to limitation of activities and emotional function (Table 1).

Among the socio-demographic and clinical variables only maternal education was found to be a protective factor, children of mothers with higher education level were 56% more likely to have good general index of quality of life (Table 2).

When comparing maternal ways of coping it was found that the emotional coping was significantly less used when compared to the following ways of coping: problem-centered,

religious and social support (Table 3). By correlating the types of coping, there was a significant correlation only between religious and emotional coping (0.007%).

There was no association between asthma severity and maternal ways of coping (Table 4), but there was a negative correlation between the mean scores of religious coping with the overall quality of life and the symptoms domain (Table 5).

## Discussion

In this study, there was a predominance of children/adolescents with moderate/severe conditions, which is expected in the sample of a tertiary care center, with a higher percentage of severe cases in relation to the recorded in population studies, where intermittent or mild persistent scenarios predominate<sup>(1)</sup>.

**Table 1** - Mean and standard deviation of scores of overall quality of life and of the domains: activities, symptoms, and emotions of 42 children with asthma subjected to the PAQLQ-A

| Domains                   | Mean  | SD   |
|---------------------------|-------|------|
| General index             | 4.12  | 1.27 |
| Limitations in activities | 4.64  | 1.48 |
| Symptoms                  | 3.58* | 1.69 |
| Emotional function        | 4.49  | 1.59 |

\*Significant difference between symptoms and other domains (Anova;  $p < 0.05$  and Tuckey;  $p < 0.05$ ; SD: standard deviation).

**Table 2** - Univariate logistic regression model to assess predictors of quality of life index of children with asthma

| Variables           | p    | OR   | 95%CI       |
|---------------------|------|------|-------------|
| Maternal Occupation | 0.85 | 1.05 | (0.66–1.66) |
| Maternal Age        | 0.43 | 0.83 | (0.53–1.32) |
| Maternal education  | 0.02 | 0.56 | (0.34–0.90) |
| Marital Status      | 0.54 | 1.2  | (0.66–2.20) |
| Disease Severity    | 0.51 | 1.19 | (0.70–2.00) |

$n=42$ ; OR: Odds Ratio; 95%CI: 95% confidence interval

**Table 3** - Median, 75th percentile and 25th percentile of ways of coping of 50 mothers of asthmatic children

| Ways of coping   | Med.  | P25  | P75  |
|------------------|-------|------|------|
| Problem-Centered | 3.55  | 3.30 | 4.00 |
| Religious        | 3.70  | 2.75 | 4.40 |
| Social support   | 3.30  | 2.60 | 4.20 |
| Emotion-focused  | 1.80* | 1.40 | 2.58 |

\*Significant difference between emotional coping and other ways of coping (Generalized Estimation Equation, followed by the multiple comparison test;  $p < 0.05$ ); Med.: median.

**Table 4** - Comparison between ways of coping of mothers of children with moderate/severe asthma and intermittent/mild persistent asthma

| Ways of coping   | Mothers of children with moderate/severe asthma |       |       | Mothers of children with intermittent/mild persistent asthma |       |       | p     |
|------------------|---|-------|-------|--|-------|-------|-------|
|                  | Med.  | P25   | P75   | Med.   | P25   | P75   |       |
| Problem-Centered | 3,550   | 3,300 | 4,000 | 3,500  | 2,800 | 4,400 | 0.556 |
| Religious        | 3,650   | 2,200 | 4,400 | 3,700  | 3,100 | 4,000 | 0.747 |
| Social support   | 3,300   | 2,600 | 4,200 | 2,600  | 2,000 | 3,400 | 0.135 |
| Emotional        | 1,800   | 1,300 | 2,500 | 1,700  | 1,600 | 2,500 | 0.979 |

n=50; Generalized Estimation Equation to find the differences between ways of coping:  $p < 0.05$ ; Med.: median.

**Table 5** - Correlation between maternal ways of coping and the overall index scores and the three domains of quality of life (n=42)

| Ways of coping   | Values | Quality of Life |                           |          |                    |
|------------------|--------|-----------------|---------------------------|----------|--------------------|
|                  |        | General Index   | Limitations of activities | Symptoms | Emotional function |
| Problem-Centered | r      | -0.129          | -0.259                    | 0.160    | 0.043              |
|                  | p      | 0.412           | 0.096                     | 0.310    | 0.782              |
| Religious        | r      | -0.538          | -0.002                    | -0.375   | -0.232             |
|                  | p      | <0.001          | 0.988                     | 0.014    | 0.138              |
| Social support   | r      | 0.026           | 0.034                     | 0.026    | -0.003             |
|                  | p      | 0.869           | 0.828                     | 0.868    | 0.982              |
| Emotional        | r      | -0.231          | 0.095                     | -0.176   | -0.198             |
|                  | p      | 0.139           | 0.549                     | 0.264    | 0.208              |

r: Pearson correlation coefficient; p: statistical significance

Most children showed a change in quality of life, with overall mean rate of 4.0 and mean values between 3 and 4 in different domains of PAQLQ. Patients with intermittent asthma had higher scores (score=5.6), i.e., better quality of life, compared to patients with mild persistent asthma (score=4.0) and moderate/severe persistent asthma (score=3.8). According to Vidal *et al*<sup>(9)</sup>, a score below 5.0 reflects significant changes in quality of life. These authors evaluated Chilean children with persistent asthma at different levels of severity with the PAQLQ, and obtained a score lower than 5.0 in 40% of them. A similar result, with mean general index of 4.6 was obtained by Levy *et al*<sup>(18)</sup> in children and adolescents aged from 4 to 17 years.

In Brazil, children evaluated in tertiary services, with the same instrument, showed a better perception of their quality of life, with mean scores around 5.0 and 6.0<sup>(13,15)</sup>. Some hypotheses can be raised to explain the different results. Firstly, this research included several children with controlled scenarios of severe persistent asthma, possibly with worse quality of life, excluded in the study by Sarria *et al*<sup>(15)</sup> and uncommon (only 2 children) in the study by La Scala *et al*<sup>(13)</sup>.

One should also consider that, although the subjects of the three studies were patients treated in tertiary services,

there are differences in the clientele of the three centers. Two centers are located in capital cities and this study was developed in an institution located in a midsize city, which serves patients from a wide region made up of medium-sized cities, and small rural communities. It is documented that patients with asthma who live in rural communities have more limited access to health services, especially emergency, with higher rates of mortality<sup>(19,20)</sup>. In this research, the subjects living in small towns may have experienced more prolonged crises due to lack of resources near their homes, causing a more negative perception of their quality of life.

Children considered the symptoms domain what most affected their quality of life. The same was observed in a study with children with mild and moderate persistent asthma<sup>(21)</sup>. In adult patients with moderate/severe asthma, before starting treatment, shortness of breath, wheezing and coughing were strong predictors of poor quality of life<sup>(22)</sup>.

Regarding the emotional domain, differently from adults<sup>(22)</sup>, it was perceived by children as the least affected, similar to what was found in other studies that had children as subjects<sup>(9,13,18)</sup>. The results regarding the emotional impact of chronic illness in children are controversial. Studies in children showed fear, anxiety and even depression, while in others there was no emotional damage, especially in

younger children or those with greater time living with the disease<sup>(23)</sup>. For some authors, the low levels of anxiety and depression, especially in severe cases, may signal a highly defensive profile, repressive adaptive style, as if the child, to fit the crisis, underestimates or hides the symptoms and anxiety, which will ultimately impact negatively on their health, with signs of tension, headaches, allergies, ulcers, and hypertension<sup>(24)</sup>.

Among socio-demographic factors, only education of the caregiver proved to be a predictor of children's better quality of life. In another study with Italian children, low parental education was the variable with the greatest predictive power on the prevalence of asthma, especially severe asthma and hospitalizations<sup>(19)</sup>.

High maternal education has been associated with the ability to care properly, greater appreciation of scientific knowledge, and ability to articulate resources for the needs of the child<sup>(25)</sup>. Perhaps mothers with higher education have more knowledge about asthma and its evolution, what to do when symptoms appear, and how to prevent crises, minimizing the damage to the quality of life of the child. Reinforcing this hypothesis, in the research by Stephan and Costa<sup>(26)</sup>, the poorest mothers, those with low education, and those who were younger had less knowledge about the proper management of crises, recognition of worsening wheezing episodes and triggers. The lack of knowledge possibly delays recognition of milder forms of the disease and the mothers only seek medical services on the face of severe cases, often requiring hospitalization<sup>(19)</sup>.

The level of education has also been used as an indicator of socioeconomic status<sup>(27)</sup>. The role of socioeconomic status on the quality of life of children with asthma is still controversial. There was significant association in some studies<sup>(19,27)</sup>, but not in others<sup>(15,28)</sup>. Belonging to lower social classes is often indicative of the subject's exposure to various etiologic risk factors, such as houses with mold and damp environments, the presence of various allergens, being a passive smoker and having a greater chance of exposure to external pollution, which can trigger asthma events. The lack of financial resources can also hamper access to health services and the purchase of medications needed to control exacerbations<sup>(18)</sup>. However, we must emphasize that, although a low socioeconomic level is a potential risk factor, when the community had an adequate structure of health care, this variable had little influence on the incidence and severity of disease<sup>(15)</sup>.

With regard to coping strategies, there was no association between severity and maternal ways of coping, contradicting the initial hypothesis of the study. Both mothers of children with moderate/severe asthma as those of children with intermittent/mild asthma used predominantly religious practices, followed by problem-oriented strategies. The emotion-focused coping was significantly less used by all mothers.

The finding that caregivers resorted very frequently to strategies directed at managing the problem and to few strategies focused on emotion confirms data from other studies with adult patients<sup>(29)</sup>, family members of children with chronic illnesses<sup>(30)</sup> and even mothers of children with asthma<sup>(4,31)</sup> who identified the use of active strategies, associated with the child's low anxiety and better quality of life.

Regarding the use of religious coping, previous researches had already signaled for the wide use of it by users of health services. A review study showed that in Brazilian culture, most patients reported religious beliefs and believed that religion could help deal with their illnesses<sup>(32)</sup>. It is considered as a standard positive coping pattern when religious practices are accompanied by actions centered on the problem, meaning that the individual, in addition to concrete actions to alleviate symptoms, prays to avoid greater stress. However, this association was not observed in this study. Religious coping was associated with emotional coping and worse quality of life of the child.

Religious coping and emotion-centered coping are used by patients in advanced stages of the disease<sup>(32)</sup>, which may mean that in the face of more severe events mothers were aware of the lack of control towards the problem, so they expected miracles and, thereby, relieved the distress. If, in the short-term these ways of coping help preserve maternal psychological balance, their effects in long-term, are worrying because they can jeopardize treatment adherence<sup>(4)</sup>.

Some limitations of the study need to be pointed out. The study did not investigate other biological characteristics, except for asthma severity. Regarding the assessment of the severity of the conditions, it was obtained indirectly from medical records, upon arrival at the service. Although physicians had long experience in diagnostics and had used the same reference to classify the severity, it was not possible to calculate the degree of reliability between different raters.

The sample was small, but obtained randomly by draw, with a limit of three children per query to avoid the need to return to the health service for participation in the study. Regarding the composition of the sample, due to

characteristics of the health service, a sample with prevalence of moderate/severe persistent asthma was obtained. However, with the analyzed sample it was possible to answer the questions that motivated the investigation.

In conclusion, children with asthma, particularly with moderate/severe persistent asthma, showed changes in their quality of life. Maternal education proved to be a protective factor, while the severity of the disease did not influence the quality of life, nor was associated to maternal coping strategies. Religious coping was correlated with the overall index of quality of life and the symptoms of the child, indicating

that mothers who used more religious coping had children with worse symptoms and worse overall quality of life.

The high percentage of exclusive use of religious strategies by mothers of children with more severe symptomatology suggests that they feel powerless to act and would benefit from concrete and realistic guidelines for a low-income population. In the impossibility to control the events, mothers should seek care at the nearest emergency room. Immediate interventions help reduce the duration of exacerbations and the damage to the child, which will impact on the quality of life of the child and the family.

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