

# Assessment of health-related quality of life in asthmatic children and their caregivers

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## ABSTRACT

**Background:** Asthma is a common disease in Egypt that puts a serious burden on children's health-related quality of life (HRQOL) and their primary caregiver. **Objectives:** To assess HRQOL of asthmatic children and their caregivers and to identify the most important determinants that adversely affect (HRQOL) of them. **Materials and Methods:** This cross-sectional study included 112 pairs of asthmatic patients (7-17 years old) and their primary caregivers attending the outpatient pediatric and chest clinics at Benha University and chest Hospitals. Pediatric asthma QOL questionnaire (PAQLQ), pediatric asthma caregiver's QOL questionnaire (PACQLQ), asthma control questionnaire, and questionnaire of main determinants of asthma were used. **Results:** The overall PAQLQ score ranged between 1.27 and 5.73 ( $3.27 \pm 1.05$ ), and the overall PACQLQ score ranged between 1.18 and 5.85 ( $3.21 \pm 1.17$ ). There was a significant positive correlation between caregiver individual and overall QOL scores and their children (individual and overall QOL scores). Maternal educational level, social score, and asthma control score were the determinants of overall PAQLQ score for asthmatic children (95% confidence interval [CI] =  $-0.79 \pm -0.04$ ,  $0.03 \pm 0.08$ ,  $-0.33 \pm -0.004$ , respectively,  $R^2 = 0.46$ ). Social score, asthma control score of the children, and parental smoking were the predictors of overall caregiver QOL score (95% CI =  $0.003 \pm 0.06$ ,  $-0.40 \pm 0.01$ ,  $-1.09 \pm 0.04$ , respectively,  $R^2 = 0.32$ ). **Conclusion:** Childhood asthma significantly adversely affects the QOL of the affected children and their caregivers.


**KEY WORDS:** Childhood Asthma; Caregivers; Quality of Life

## INTRODUCTION

Asthma is a highly prevalent chronic respiratory disease affecting 300 million individual worldwide.<sup>[1]</sup> The prevalence is increasing in most countries especially among children and adolescents.<sup>[2]</sup> The WHO has estimated that 16 million disability-adjusted life years are lost annually due to asthma, representing 1% of the total global disease

burden. Pediatric asthma accounts for a large proportion of childhood hospitalizations; absenteeism from school and missed work days by parents.<sup>[3]</sup> Asthma is a significant burden not only in terms of health-care costs but also of lost productivity and reduced participation in family life. Annual worldwide deaths from asthma have been estimated at 250,000 deaths.<sup>[4]</sup>

Asthma is relatively common in Egypt with 7.7% prevalence among school children in the Nile Delta region,<sup>[5]</sup> particularly among children from less wealthy families.<sup>[6]</sup> Asthma imposes a significant burden not only in terms of health care costs but also of lost productivity and reduced participation in family life. It is the first cause of absence from school and the third cause of hospitalization of children under 15 years of age.<sup>[7]</sup> Mortality and morbidity are not the only important outcome

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variables to be considered when we evaluate child health interventions; a quality of life (QOL) perspective can identify sensitive child and adolescent issues that may be affected by illness or disability of treatment.<sup>[8]</sup>

Health related quality of life (HRQOL) is defined as the functional effects of an illness and its consequent therapy on a patient, as perceived by the patient.<sup>[9]</sup> KSA reported that asthma caused an interruption in daily life that influences physical, emotional and social activities of asthmatic children.<sup>[10]</sup>

In addition to evaluation of the patient, the integral assessment of asthma requires the evaluation of caregiver HRQOL since the latter is correlated to management of the disease and the presence of certain morbidity indicators: School absenteeism, reduced daily life activities, and an increased number of visits to the Emergency Service.<sup>[11]</sup>

## MATERIALS AND METHODS

This cross-sectional study conducted on asthmatic children their main caregivers (who had spent at least >75% of their time caring for their patients, mainly mothers)<sup>[12]</sup> in two outpatient clinics (Benha University Hospital and Benha Chest Hospital) from 1<sup>st</sup> January to 31<sup>st</sup> August 2015.

Inclusion criteria include all patients aged (7-17) years old with intermittent or persistent asthma and their caregivers who visited the clinic during the study period and accept to participate.

Exclusion criteria were children with other chronic illness affecting major organ systems such as cardiac, renal, and hematological.

Sample size was calculated using the formula below which is used when comparing means.<sup>[13]</sup>

$$N = 4\sigma^2 (Z_{crit} + Z_{power})^2 / D^2$$

N = Total sample size which is the sum of the sizes of both comparison groups

$\sigma$  = the standard deviation of each groups, assumed to be equal in both groups=1

Z<sub>crit</sub> = the desired significance criterion = 0.05

Z<sub>power</sub> = Desired statistical power = 80%

D = the minimum expected difference = 0.5.

So the sample size was 125 pair (asthmatic child and his caregiver).

Of those, 112 pair who completed the questionnaires; 50 pair from chest hospital and 62 pair from Benha University Hospital (50 pair from pediatric clinic and 12 pair from chest clinic).

Every 3<sup>rd</sup> clinically diagnosed asthmatic child and his caregiver, who met the inclusion criteria was taken (systemic random sample), and data were collected using pediatric asthma QOL questionnaire (PAQLQ), pediatric asthma caregiver's QOL questionnaire (PACQLQ), and asthma control questionnaire (ACQ) (obtained from QOL Technologies Ltd., after written approval from Jilly Styles [Personal Assistant to Professor Elizabeth Juniper, McMaster University Canada]).

PAQLQ measures the functional (physical, emotional, and social) problems that were most troublesome to asthmatics (23 questions in three domains [symptoms (5), activity limitation 2 generic (general), 3 patient-specific]) and emotional function (8). Children were asked to recall their experiences during the previous week and to respond to each question on a 7-point scale (7 = no impairment, 1 = severe impairment). Three of the activity questions were "patient-specific" which means that each child identified and scored three activities which were limited by his asthma.

It has been fully validated for use in both clinical practice and clinical trials. It has got both discriminative properties (reliability and cross-sectional validity) and strong evaluative properties (responsiveness and longitudinal validity).<sup>[14]</sup>

## PACQLQ

Caregivers were asked to recall their experiences during the previous week (time specification) and to score impairment on a 7-point scale (7 = no impairment, 1 = severe impairment).<sup>[15]</sup> It has 13 items in 2 domains (activity limitation [4Q] and emotional function [9Q]).

Health related QOL (HRQOL) will be considered good or bad according to the total score (7 [no impairment], 5-6.9 [mild impairment] both scores are considered good QOL. 3-4.9 [moderate impairment], 1-2.9 [sever impairment] both scores are considered bad QOL).

It is composed of: Sociodemographic factors including social score,<sup>[16]</sup> disease-related factors duration, level of control by specific ACQ-6 composed of six questions only (Night - time waking, symptoms on waking, activity limitation, shortness of breath, wheeze and rescue short-acting  $\beta_2$ -agonist use) with 7-point scale answer (0 = totally controlled, 6 = extremely poorly controlled) with a time specification of 1 week. The questionnaire is self-administered for children  $\geq 11$  years and interviewer administered for those (7-10) years.<sup>[17]</sup>

Patients' scores were then classified into three prescribed groups as having well-controlled asthma (ACQ-6 score <0.75); partially - controlled asthma (ACQ-6 score 0.75-1.5), or uncontrolled asthma (ACQ-6 score >1.5).

Furthermore, disease adverse events related to patient as school absenteeism due to asthma, hospital admission and its number, intensive care unit admission and its number, difficulty in consultation, difficulty in obtaining prescribed asthma drugs and presence of drug side effects.

Weight and height of the patients were taken to calculate body mass index (BMI).

The study design and methodology was approved by the Ethical Committee of Scientific Research, Faculty of Medicine, Benha University. An informed written consent in Arabic language was obtained from all caregivers of the participants who agreed to their child's participation in the study, and verbal assent was taken from the children.

Data were analyzed using SPSS (Statistical Package for Social Sciences) version 16. Qualitative data were presented as count and percentage while quantitative data as mean  $\pm$  standard deviation. Independent *t*-test was used to compare data between two groups and one-way ANOVA was used when more than two groups were to be compared. Correlations among QOL score and different study parameters were determined using Pearson's test. Multivariate analysis was performed by multiple linear regression to find out the significant determinants of QOL of asthmatic children and their caregivers. For all tests,  $P < 0.05$  is considered significant.

## RESULTS

### Sociodemographic Characteristics

A total of 112 pair of children aged 7-17 yEAR old (10.7) and their caregiver were included. With equal percentage of female and male patients (50%) each. Most of them (78.5%) were in primary school; more than half of the patients lived in rural areas. The majority of fathers had intermediate education/high education (51.8%). Semiprofessional work was the main paternal occupation (39.3%). All caregivers were mothers. The highest percentage of mothers had secondary education (41%), and most of them (68.8%) were housewives. The majority of patients (54.5%) belonged to middle social class. History of parental smoking included 42% of patients and 42.0% also had family history of asthma and fathers were the most common relative with asthma (38.3) (Table 1).

Table 2 demonstrates that the mean overall PAQLQ score (3.27 [1.05]) was nearly similar to the score of symptoms, emotional function, and physical domain.

### Effect of Sociodemographic Factors on QOL for the Studied Children

Table 3 reveals that symptoms domain scores were significantly higher among adolescent patients (3.59 [1.03]);

**Table 1:** Sociodemographic and personal characteristics of the studied patients and their caregivers

Variables	Number (112) (%)
Age (mean age 10.7)	
7-12 (children)	86 (76.8)
13-17 (adolescents)	26 (23.2)
Sex	
Male	56 (50)
Female	56 (50)
Residence	
Urban	48 (42.9)
Rural	64 (57.1)
Child education	
Primary	88 (78.5)
Preparatory	21 (18.8)
Secondary	3 (2.7)
Father education	
Illiterate	4 (3.6)
Read and write/basic education	14 (12.5)
Secondary education	36 (32.1)
Intermediate/high education	58 (51.8)
Father occupation	
Unemployed	2 (1.8)
Unskilled manual worker	12 (10.7)
Skilled manual worker	19 (17.0)
Trades/business	23 (20.5)
Semiprofessional/clerk	44 (39.3)
Professional	12 (10.7)
Mother education	
Illiterate	11 (9.8)
Read and write/basic education	23 (20.6)
Secondary education	46 (41.0)
Intermediate/high education	32 (28.6)
Mother occupation	
Housewife	77 (68.7)
Employed	35 (31.3)
Social class	
Low social class	40 (35.7)
Middle social class	61 (54.5)
High social class	11 (9.8)
Parental smoking	
Negative	65 (58)
Positive	47 (42)
Family history of asthma	
Negative	65 (58)
Asthmatic relative	
Mother	10 (8.9)
Father	18 (16.1)
Siblings	13 (11.6)
Others (grandparents)	6 (5.4)

emotional domain scores were significantly higher among male group (3.57 [1.18]), patients who live in rural areas had significantly higher scores in overall, symptoms and emotional domain scores (3.52, 3.47 and 3.65, respectively). Symptoms domain scores were significantly higher among patients with preparatory education (3.65) ( $P < 0.05$ ).

Mother educational level affected overall, symptoms and emotional function score of QOL with better scores among

patients with highly educated mothers (3.68, 3.6 and 3.87, respectively) ( $P < 0.05$ ). Patients with uncontrolled asthma were significantly associated with low QOL scores (Table 4).

Table 5 shows that overweight/obese patients significantly had lowest QOL scores and highest asthma control scores ( $P < 0.05$ ).

**Linear Regression for Determinants of QOL for Children with Bronchial Asthma**

Maternal education, social score, and asthma control score were the determinants of overall PAQLQ score for children

with bronchial asthma which was used as the dependent variable in this model (Table 6).

**QOL Scores for the Studied Caregivers**

Table 7 reveals that there was a significant direct correlation ( $P < 0.05$ ) between caregivers (individual scores and overall score of QOL) and their children (individual and overall score of QOL). Social score, asthma control score of children, and parental smoking were the predictors of overall caregiver QOL score which was used as the dependent variable in this model (Table 8).

**DISCUSSION**

HRQOL measures have proved to be beneficial for the patient-health professional encounter and communication.<sup>[18]</sup>

Studied patients showed impaired QOL, with mean score 3.27 (1.27-5.73). Similarly, Al-Gewely *et al.* and Perosa *et al.*<sup>[9,19]</sup> reported that participants showed impaired QOL (3.5-4.7). This was lower than Sweden<sup>[20]</sup> and Brazil.<sup>[21]</sup>

This study found that the physical domain score was the most affected QOL domains which come in accordance with<sup>[4,22]</sup>

**Table 2:** Pediatric asthma quality of life questionnaire (PAQLQ) scores

Quality of life scores (PAQLQ) (112)	Mean±SD	Range
Overall	3.27±1.05	1.27-5.73
Physical	3.20±1.07	1.20-6.00
Symptoms	3.28±1.10	1.00-6.20
Emotional	3.34±1.17	1.38-6.38

Total score is 7 (as the score increase, means better quality of life). PAQLQ: Pediatric asthma quality of life questionnaire, SD: Standard deviation

**Table 3:** Comparison between patient’s overall and domain scores of QOL regarding their age, sex, residence, education and social class

Patients QOL domains	Overall	Physical	Symptoms	Emotional
<b>Age group</b>				
Children (86)	3.18 (1.05)	3.20 (1.11)	3.09 (1.10)	3.15 (1.12)
Adolescents (26)	3.58 (1.00)	3.52 (0.94)	3.59 (1.03)	3.64 (1.30)
<i>t</i> -test	1.72	1.34	2.02	1.50
<i>P</i> value	0.08	0.1	0.04*	0.1
<b>Sex</b>				
Male (56)	3.42 (1.02)	3.31 (1.01)	3.40 (1.08)	3.57 (1.18)
Female (56)	3.13 (1.07)	3.25 (1.14)	3.01 (1.10)	3.11 (1.12)
<i>t</i> -test	1.52	0.29	1.87	2.07
<i>P</i> value	0.1	0.7	0.06	0.04*
<b>Residence</b>				
Urban (48)	3.52 (1.04)	3.45 (1.12)	3.47 (1.04)	3.65 (1.17)
Rural (64)	3.09 (1.02)	3.15 (1.03)	3.01 (1.11)	3.11 (1.12)
<i>t</i> -test	2.2	1.45	2.22	2.48
<i>P</i> value	0.03*	0.1	0.02*	0.01**
<b>Patients education</b>				
Primary (88)	3.20 (1.06)	3.20 (1.09)	3.14 (1.10)	3.26 (1.18)
Preparatory (21)	3.68 (0.91)	3.64 (0.99)	3.65 (0.99)	3.76 (1.08)
Secondary (3)	2.69 (0.91)	3.00 (0.53)	2.23 (1.16)	2.83 (1.06)
<i>F</i> -test	2.34	1.53	3.16	1.86
<i>P</i> value	0.1	0.2	0.04*	0.1
<b>Social class</b>				
Low (40)	3.17±1.08	3.11±1.09	3.16±1.14	3.23±1.15
Middle (61)	3.27±0.96	3.35±0.92	3.21±1.03	3.30±1.18
High (11)	3.84±1.09	3.96±1.28	3.47±1.24	4.07±1.07
<i>F</i> -test	1.94	3.20	0.38	2.48
<i>P</i> value	0.1	0.04*	0.6	0.08

QOL: Quality of life, \*Significance at <0.05, and \*\*Significance at <0.001

**Table 4:** Comparison between patient’s overall and domain scores of QOL regarding their mother’s educational level and asthma control level

Patients QOL domains	Overall	Physical	symptoms	Emotional
Mother education				
Illiterate (11)	2.91±0.70	2.97±0.70	2.83±0.77	2.92±0.97
Read and write/basic education (23)	3.17±1.15	3.18±1.14	3.12±1.17	3.22±1.28
Secondary/diploma (46)	3.28±0.72	3.42±0.70	3.22±0.68	3.19±0.97
Intermediate institute/faculty (32)	3.68±0.1.10	3.59±1.16	3.60±1.23	3.87±0.1.16
F-test	2.85	1.73	2.4	3.64
P value	0.04*	0.1	0.07	0.01
Asthma control level				
Controlled (7)	4.16±1.29	4.11±1.16	4.07±1.45	4.30±1.38
Partially controlled (11)	3.55±0.81	3.58±0.81	3.54±0.85	3.52±1.16
Un controlled (91)	3.16±1.1	3.18±1.06	3.08±1.05	3.23±1.09
F-test	3.70	3.08	3.49	3.22
P value	0.02*	0.05*	0.03*	0.04*

\*Significance at <0.05, QOL: Quality of life

**Table 5:** Comparison between overall PAQLQ score and asthma control score of the patients regarding their body weight

Body weight	Overall PAQLQ score (112) Mean±SD, Number	Asthma control score (109) Mean±SD, Number
Underweight	3.13±1.07, 29	4.06±0.80, 28
Normal weight	3.39±1.05, 71	2.71±1.37, 70
Overweight/obese	2.95±0.91, 12	4.79±0.99, 11
F-test	1.30	21.99
P value	0.2	0.001**

The lower asthma control score the better control (<0.75 in controlled asthma). PAQLQ: Pediatric asthma quality of life questionnaire, SD: Standard deviation, \*Significance at <0.05 and \*\*Significance at <0.001

**Table 6:** Multiple linear regression analysis for the predictors of overall PAQLQ score

Overall PAQLQ score	Beta	T	P value	95% CI
Predictors				
Residence	-0.12	-0.95	0.34	-0.78±0.28
Father education	0.04	-0.32	0.75	-0.35±0.26
Mother education	0.34	-2.24	0.02	-0.79±-0.04
Social score	0.70	4.65	0.000	0.03±0.08
Asthma control score	-0.21	-2.05	0.04	-0.33±-0.004
Duration of the disease	-0.05	-0.43	0.66	-0.07±0.05
Admission to the hospital	-0.08	-0.68	0.49	-0.17±0.08

R<sup>2</sup>= 0.46, Adjusted R<sup>2</sup>= 0.39, F= 6.59, P value=<0.001. PAQLQ: Pediatric asthma quality of life questionnaire, CI: Confidence interval

similarly activity limitation domain was the most affected domain in previous studies measuring QOL among asthmatic children in Poland<sup>[23]</sup> and Brazil.<sup>[21]</sup>

This may be inferred to that physical function such as full participation in school sports activity, running and strenuous exercise is limited by asthma. Furthermore, the nature of childhood period is involvement into different physical activities which lead to the appearance of limitation in activities.

In this study, young age group of patients adversely affected physical domain score being worse in asthmatic children than asthmatic adolescents; this study revealed that there were higher scores of overall and individual QOL domains among asthmatic adolescents than asthmatic children, both total and single domain scores improve as the age of children increases.<sup>[24,25]</sup> Adolescents are able to handle the burden of the disease than younger children owing to cognitive and emotional developmental variations in grasping the content measured.

Female sex adversely affected QOL with higher scores of all PAQLQ domains among asthmatic males. Girls are more anxious about their health, over-report their symptoms, show their deficiencies than boys and incorporate their conditions and the associated treatment regimens into their social and personal identities.<sup>[20,26,27]</sup>

On the other side, some studies found the reverse and explain their findings by high prevalence, mortality, airway resistance and wide range of activities among males than females.<sup>[9,28]</sup>

Asthmatic urban dwellers got higher scores of QOL than rural ones, persons lived in small towns may have experienced more prolonged crises due to more limited access to health services, especially emergency, with higher rates of mortality<sup>[19,29]</sup> while another study could not demonstrate a significant difference in the QOL scores between rural and urban residence.<sup>[9]</sup>

Mother educational level affected overall and emotional function score of QOL with better scores among patients

**Table 7:** Correlation between QOL domain and overall score of caregivers and their children

Overall score	Overall PAQLQ score (112) <i>r</i>	Activity limitation score (112) <i>r</i>	Symptom score (112) <i>r</i>	Emotional function score (112) <i>r</i>
Caregiver emotional score	0.68**	0.63**	0.60**	0.67**
Caregiver physical score	0.71**	0.68**	0.67**	0.68**
Caregiver overall score	0.74**	0.69**	0.67**	0.79**

\*\*Significance at <0.001. PAQLQ: Pediatric asthma quality of life questionnaire, QOL: Quality of life

**Table 8:** Multiple linear regression analysis for the predictors of caregiver overall QOL score

Overall caregiver QOL score	Beta	T	P value	95% CI
Predictors				
Patient age	0.01	0.09	0.92	-0.11±0.12
Patient sex	0.03	0.21	0.83	-0.49±0.60
Mother education	-0.16	-0.99	0.32	-0.64±0.22
Parental smoking	-0.24	-1.89	0.06	-1.09±0.04
Social score	0.37	2.18	0.03	0.003±0.06
Asthma control score	-0.23	-1.93	0.05	-0.40±0.01
Duration of the disease	0.000	0.002	0.99	-0.08±0.08
Admission to the hospital	-0.17	-1.26	0.21	-0.25±0.06

$R^2=0.32$ , Adjusted  $R^2=0.21$ ,  $F=3.10$ ,  $P\text{ value} \leq 0.01$ . QOL: Quality of life, CI: Confidence interval

with highly educated mothers. 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>[9,19]</sup>

The level of asthma control significantly affected QOL domain scores as children and adolescents with impaired asthma control were found to have more impaired HR-QOL compared with children and adolescents with controlled asthma. Similarly, researchers found that a child whose asthma symptoms are not well controlled might experience increased level of anxiety and/or depression, it is believed that emotional reaction as coping strategy influences HRQOL negatively.<sup>[27,30]</sup>

Overall PAQOL score of overweight/obese patients is insignificantly lower than normal and underweight patients while asthma control score is impaired among overweight/obese asthmatic children and adolescents. QOL in children with both excessive body weight and asthma was lower than expected on the basis of the sum of the separate effects of asthma alone or excessive body weight alone. Treatment in children should be aimed at both asthma and excessive body weight. Also, response to asthma medications is influenced by an increasing BMI.<sup>[31,32]</sup> Obesity has a significant adverse effect on asthma control.<sup>[33,34]</sup>

This study found that there was a direct correlation between caregiver QOL domain scores and QOL domain scores of their children. Obviously, the more impaired QOL in parents

as a result of their child's asthma affects all aspects of family life and it may cause psychological difficulties for his/her parents or other family members, and may affect their interpersonal relationships.<sup>[10,35-37]</sup>

In contrast to these results, results by Farnik et al. and Walker et al.<sup>[23,38]</sup> found no correlation between PAQLQ score and PACQLQ score.

### Recommendations

Regular evaluation of HRQOL is recommended to be incorporated into routine asthma care. There is a need to develop asthma management strategies for improving HRQOL.

A study limitation is related to its conduction among a sample of asthmatic children who had particular characteristics excluding those with other chronic conditions other than asthma. All of our patients were outpatients undergoing regular check-ups in general and specialized tertiary hospitals. Therefore, our patients were not representative of all asthmatics, which restrict the possibility of extrapolating our findings to the asthmatic population in general. Another limitation of our study is related to its cross-sectional design, and hence the long-term effects of asthma on QOL of asthmatic children could not be evaluated.

### CONCLUSION

This study showed that the most affected QOL domain for asthmatic children was physical limitation domain, maternal educational level, social score, and asthma control score were the main predictors of overall PAQOL score. The most affected caregiver QOL domain was emotional function domain and social score, asthma control score of the child and parental smoking.

Patient sex, residence, body weight, difficulty in consultation, and difficulty in obtaining prescribed asthma drugs were the main predictors of asthma control score.

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