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Quality of life of children with bronchial asthma and their caregivers: A hospital-based study

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ABSTRACT

Objectives: This study aims to describe the health-related quality of life (QOL) and their associated factors in children with bronchial asthma as well as their caregivers in Mansoura, Egypt.

Methods: This cross-section hospital-based study included 171 dyad of children with physician diagnosed asthma and their caregivers attending the outpatients' clinics of three hospitals. Data were collected using the Arabic versions of the pediatric asthma quality of life questionnaire (PAQLQ) and the pediatric asthma caregiver's quality of life questionnaire (PACQLQ). Asthma severity was assessed using Global Initiative for Asthma guidelines.

Results: The overall mean scores of the PAQLQ and its activity, emotion, and symptom domains were 4.7, 4.3, 4.9, and 4.7; respectively. The overall mean scores of the total PACQLQ and its activity and emotion domains were 4.2, 5.4, and 4.0; respectively. Children with low socioeconomic status (SES) had a significantly lower total, activity and emotion domains of PAQLQ scores. Low and very low SES of the family, uncontrolled, and severe asthma are associated with low QOL of both asthmatic child and his caregivers.

Conclusions: Early control of severe asthma will contribute to a better QOL of affected children and their caregivers.

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KEYWORDS

Caregivers; quality of life; pediatrics asthma

Introduction

Bronchial asthma (BA) is a heterogeneous chronic inflammatory disease, characterized by recurrent episodes of wheezing, dyspnea, chest tightness, and cough. It is very common in children and adolescents [1]. It is a public health problem in all countries regardless of the level of development [2]. It is common in Egypt, and probably underdiagnosed and undertreated, particularly among children from less wealthy families [3]. The burden of asthma to governments, healthcare systems, families, and patients is increasing worldwide [4].

The quality of life (QOL) is defined as the perception that individuals have of their position in life, in the context of the culture and system of values in which they live, and relation to their objectives, expectations, standards, and concerns. QOL can change according to the environment and the experiences, as well as in response to certain diseases [5,6]. Chronic diseases, such as asthma, can impair QOL in its various bio-psychosocial domains and can affect the daily lives of the affected population [7,8]. Asthma-specific QOL questionnaires have been developed to quantify, in a formal and standardized way, the effects of asthma on the patient's daily life and wellbeing, and the extent to which a given treatment reduces these effects [9,10].

Measuring the QOL of caregivers is important for interventions designed for young children with asthma [11]. Few studies were done in other regions of Egypt but none was done in our locality on QOL of these children and their caregivers;

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so, the objectives of this study are to describe the health-related QOL of children with asthma and their caregivers and their associated factors.

Subjects and Methods

This cross-sectional study was carried out at the Pediatric Allergy and Immunology Unit, Mansoura University (90 patients), the Outpatient Clinic at Talkha Central Hospital (56 patients) and Chest Department, Mansoura University (25 patients). Patients were recruited consequently during their routine visits to outpatients' clinics of the selected hospitals. The inclusion criteria were children aged 7–17 years with physician-diagnosed asthma for at least 1 year duration, not suffering from other chronic diseases.

The study protocol was approved by the Local Institutional Review Board, Faculty of Medicine, Mansoura University. Consent was obtained from the child's caregiver. The study objectives, tools, and the confidentiality of data were explained to the children and their caregivers.

Sample size was calculated online (https://www.dssresearch.com/Knowledge Center/toolkitcalculators/samplesizecalculators.asp). The mean QOL score in Egyptian asthmatic children was found to be 4.1 with standard deviation (SD) of 1.0 [12], with precision of 2%, alpha error of 5% (i.e., 95% confidence level) and beta error of 20% (i.e., study power of 80%) then, the sample size should be at least 155. Ten percent was added to compensate for non-response; thus, the final sample is at least 171. Data were collected through an interview administered questionnaire containing:

1. Child age and sex, socio-demographic characteristics of the family using the socioeconomic status (SES) scale of El-Gilany et al. [13]. This scale contains seven domains (Parents' education & occupation, family possession, home sanitation, economic, and healthcare domains) with a total score of 84. Socioeconomic level was classified into very low, low, middle, and high levels depending on the quartiles of the score calculated.
2. Clinical data, e.g., duration and severity of asthma, treatment given, and the level of control. Severity of asthma was assessed retrospectively from the level of treatment required to control symptoms and exacerbations. Mild asthma can be controlled by step 1 or 2 treatment. While severe asthma requires step 4 or 5 treatment to maintain symptom control [10]. Asthma control was classified into controlled and uncontrolled according to childhood asthma control test. The score ranges from 0 (poorest asthma control) to 27 (optimal asthma control). A cut-off point ≤19 indicates uncontrolled asthma [14].
3. Weight and height measurements with the calculation of body mass index (BMI). Classification of patient's BMI into underweight, normal, overweight, and obese was done according to the Egyptian Growth Charts for boys and girls [15].
4. The Arabic version of the interviewer administrated pediatric asthma quality of life questionnaire (PAQLQ). It measures the functional (physical, emotional, occupational, and social) problems that are most troublesome to children (7–17 years) with asthma [16]. PAQLQ has 23 questions in three domains (symptoms, activity limitation, and emotional function). The PAQLQ has a time specification of 1 week [17,18]. The patient had to respond to each question on a seven-point scale (seven = no impairment, one = severe impairment). Individual questions were equally weighted. The overall PAQLQ score was the mean of the responses to each of the 23 questions. The resultant overall and each domain score would be between one and seven with high score indicating better QOL. The domains were analyzed in exactly the same way (the domain scores were also the mean values for the items in each domain). The Arabic version of the pediatric asthma caregiver's quality of life questionnaires (PACQLQ) was used to measure QOL of caregivers [16]. It includes 13 items (four concern activity limitations and nine concern emotional functions). Responses to each item of the PACQLQ are given on a seven-point scale, ranging from 1 to 7, with the higher scores indicating less impairment. The result was expressed as a mean score per item for each of the domains, as well as for the overall QOL [16].

Data were analyzed using SPSS statistical program version 20 (SPSS Inc., Chicago, IL). Qualitative variables were presented as number and percent. Quantitative variables were tested for normality distribution and found to be normally distributed. They were presented as mean ± SD. Independent *t*-test was used for two groups comparison and analysis of variance (*F*) test was used for more than two groups comparison with Bonferroni post-hoc multiple comparisons. Spearman's

correlation coefficient was used to calculate correlation between child and parents scores of QOL and quantitative variables. Variables with significant correlations were entered into a linear regression model to detect the independent predictors of QOL. $P \leq 0.05$ was considered to be statistically significant.

Results

The overall mean scores of the PAQLQ and its activity, emotion, and symptom domains were 4.7, 4.3, 4.9, and 4.7, respectively. Children with low and very low SES had a significantly lower total, activity and emotions domains of PAQLQ scores compared to those with higher SES. Patients with controlled asthma had significantly better total and the three domains asthma scores. Also, patients with severe asthma had significantly worse total and categorical PAQLQ score (Table 1).

The overall mean scores of the total PACQLQ and its activity and emotion domains were 4.2, 5.4, and

Table 1. Scores of total PAQLQ and its domains and their variations with child characteristics.

Child characteristics	Total	PAQLQ score			
		Total Mean ± SD	Activity Mean ± SD	Emotions Mean ± SD	Symptoms Mean ± SD
Overall	171	4.7 ± 1.6	4.3 ± 1.3	4.9 ± 1.8	4.7 ± 1.8
Child age (years)					
7–11	92	4.7 ± 1.6	4.3 ± 1.3	4.7 ± 1.8	5.0 ± 1.7
12–17	79	4.6 ± 1.7	4.2 ± 1.3	4.7 ± 1.9	4.7 ± 1.9
Significance test		t =0.6, P = 0.6	t = 0.02, P = 0.9	t = 0.2, P = 0.9	t = 1.3, P = 0.2
Sex					
Male	87	4.7 ± 1.7	4.2 ± 1.4	4.8 ± 1.9	4.9 ± 1.9
Female	84	4.6 ± 1.5	4.3 ± 1.2	4.6 ± 1.7	4.9 ± 1.7
Significance test		t = 0.3, P = 0.8	t = 0.9, P = 0.4	t = 0.8, P = 0.4	t = 0.2, P = 0.8
BMI					
Normal	90	4.4 ± 1.7	4.3 ± 1.3	4.7 ± 1.8	5.0 ± 1.8
Under weight	52	4.7 ± 1.6	3.9 ± 1.4	4.1 ± 1.9	4.8 ± 1.8
Overweight/obese	29	4.9 ± 1.5	4.6 ± 1.2	5.0 ± 1.7	4.9 ± 1.8
Significance test		F = 0.9, P = 0.4	F = 2.6, P = 0.08	F = 1.3, P = 0.3	F = 0.3, P = 0.8
Residence					
Urban	89	4.6 ± 1.7	4.3 ± 1.4	4.6 ± 1.9	4.9 ± 1.9
Rural	82	4.7 ± 1.5	4.2 ± 1.3	4.8 ± 1.7	5.0 ± 1.7
Significance test		t = 0.6, P = 0.6	t = 0.5, P = 0.7	t = 1.0, P = 0.3	t = 0.5, P = 0.7
SES					
Very low	31	4.2 ± 1.4[A]	3.6 ± 0.9[A]	4.4 ± 1.6[A]	4.5 ± 1.8
Low	44	4.3 ± 1.9[B]	4.1 ± 1.6[B]	4.2 ± 2.1[B]	4.6 ± 1.9
Middle/high	96	5.0 ± 1.5[A,B]	4.6 ± 1.2[A,B]	5.0 ± 1.7[A,B]	5.2 ± 1.7
Significance test		F = 3.8, P = 0.024	F = 7.6, $P \leq 0.001$	F = 3.6, P = 0.03	F = 2.6, P = 0.1
Asthma control					
Controlled	93	6.1 ± 0.7	5.3 ± 0.9	6.3 ± 0.7	6.4 ± 0.9
Uncontrolled	78	3.5 ± 1.1	3.4 ± 0.9	3.4 ± 1.3	3.7 ± 1.3
Significance test		t = 17.7, $P \leq 0.001$	t = 13.1, $P \leq 0.001$	t = 17.4, $P \leq 0.001$	t = 15.8, $P \leq 0.001$
Asthma severity					
Mild	78	5.9 ± 1.0[A,B]	5.1 ± 1.1[A,B]	6.0 ± 1.1[A,B]	6.2 ± 1.0[A,B]
Moderate	81	3.8 ± 1.3[A,C]	3.6 ± 1.0[A,C]	3.8 ± 1.5[A,C]	4.0 ± 1.5[A,C]
Severe	12	2.5 ± 1.0[B,C]	3.0 ± 0.9[B,C]	2.3 ± 1.2[B,C]	2.5 ± 1.1[B.C]
Significance test		F = 86.6, $P \leq 0.001$	F = 53.9, $P \leq 0.001$	F = 76.4, $P \leq 0.001$	F = 84.0, $P \leq 0.001$
Number of inhaler#					
None	22	4.3 ± 2.0	4.0 ± 1.4	4.3 ± 2.2	4.5 ± 2.2
1	123	4.8 ± 1.7	4.3 ± 1.4	4.8 ± 1.9	5.0 ± 1.8
2	19	4.2 ± 0.9	3.7 ± 0.8	4.4 ± 1.0	4.3 ± 1.2
3	7	5.5 ± 0.8	4.9 ± 0.8	5.0 ± 0.7	5.9 ± 1.1
Significance test		F = 1.6, P = 0.2	F = 2.0, P = 0.1	F = 1.3, P = 0.3	F = 1.9, P = 0.1
Duration of inhaler use*					
<3 years	61	5.1 ± 1.8	4.6 ± 1.6	5.1 ± 2.0	5.4 ± 1.8
≥3 years	88	4.5 ± 1.4	4.0 ± 1.0	4..5 ± 1.5	4.7 ± 1.6
Significance test		t = 2.5, P = 0.013	F = 2.7, P = 0.007	t = 2.0, P = 0.042	t = 2.7, P = 0.008

A, B, & C significant difference between the corresponding groups by Bonferroni's post-hoc multiple comparison.
#Salbutamol, terbutalin, inhaled corticosteroids (ICS), combined long-acting beta agonists and ICS.
*Among inhaler users (149).

4.0, respectively. The total PACQLQ and its emotion mean scores were significantly higher in children of middle/high SES, the controlled asthma, in mild asthma, and short duration of use of inhalers. Parents of older children had significantly better QOL when compared with younger children (Table 2).

Table 3 shows that both PAQLQ and PACQLQ have positive significant correlation with age, socioeconomic score, and asthma control level. However, they are negatively correlated with both asthma severity and duration of inhalers use. Asthma control level and asthma severity are the independent predictors of PAQLQ. The independent predictors of PACQLQ are socioeconomic score, asthma control level, and PAQLQ.

Discussion

Measures of QOL indicate how much asthma interferes with daily life and how the child adapts to illness. Clinicians and researchers routinely use QOL

Table 2. Scores of total PACQLQ and its domains and their variations with child characteristics.

Child characteristics	Total	PACQLQ score		
		Total Mean ± SD	Activity Mean ± SD	Emotions Mean ± SD
Overall	171	4.2 ± 1.8	5.4 ± 1.1	4.0 ± 1.9
Child age (years)				
7–11	92	4.2 ± 1.8	5.5 ± 1.0	4.0 ± 1.9
12–17	79	4.1 ± 1.8	5.3 ± 1.1	3.9 ± 1.9
Significance test		t = 0.4, P = 0.7	t = 1.1, P = 0.3	t = 0.3, P = 0.8
Sex				
Male	87	4.1 ± 1.9	5.2 ± 1.2	3.9 ± 1.9
Female	84	4.3 ± 1.7	5.7 ± 0.8	4.0 ± 1.8
Significance test		t = 0.7, P = 0.5	t = 3.2, P = 0.002	t = 0.6, P = 0.5
BMI				
Normal	90	4.2 ± 1.8	5.4 ± 1.0	4.0 ± 1.8
Under weight	52	4.0 ± 1.8	5.4 ± 1.2	3.7 ± 1.9
Overweight/obese	29	4.4 ± 1.8	5.3 ± 1.0	4.2 ± 1.9
Significance test		F = 0.7, P = 0.5	F = 0.3, P = 0.8	F = 0.9, P = 0.4
Residence				
Urban	89	4.2 ± 1.7	5.3 ± 1.2	4.0 ± 1.8
Rural	82	4.2 ± 1.9	5.5 ± 0.9	3.9 ± 1.9
Significance test		t = 0.03, P = 0.98	t = 1.2, P = 0.2	t = 0.2, P = 0.8
SES				
Very low	31	4.1 ± 1.4	5.4 ± 0.8	3.8 ± 1.4
Low	44	3.6 ± 2.2[A]	5.6 ± 0.9	3.4 ± 2..3[A]
Middle/high	96	4.5 ± 1.6 [A]	5.33 ± 1.2	4.2 ± 1.7[A]
Significance test		F = 3.4, P = 0.04	F = 1.6, P = 0.2	F = 3.2, P = 0.04
Asthma control				
Controlled	93	5.8 ± 0.9	5.4 ± 1.1	5.6 ± 1.0
Uncontrolled	78	2.8 ± 1.1	5.4 ± 1.1	2.5 ± 1.1
Significance test		t = 19.0, $P \leq 0.001$	t = 0.01, P = 0.99	t = 19.1, $P \leq 0.001$
Asthma severity				
Mild	78	5.5 ± 1.3[A,B]	5.6 ± 1.1	5.4 ± 1.3[A,B]
Moderate	81	3.2 ± 1.4[A,C]	5.3 ± 1.1	2.9 ± 1.4[A,C]
Severe	12	2.3 ± 0.8[B,C]	5.1 ± 0.8	2.0 ± 0.8[B,C]
Significance test		F = 81.0, $P \leq 0.001$	F = 2.6, P = 0.08	F = 834, $P \leq 0.001$
Number of inhaler[#]				
None	22	4.4 ± 1.9	5.6 ± 1.0[A]	4.2 ± 2.1
1	123	4.3 ± 1.9	5.5 ± 1.0[B,C]	4.0 ± 1.9
2	19	3.3 ± 1.3	4.8 ± 1.0[B]	3.1 ± 1.3
3	7	4.2 ± 0.1	4.3 ± 2.1[A,C]	4.3 ± 0.4
Significance test		F = 1.6, P = 0.2	F = 6.3, $P \leq 0.001$	F = 1.6, P = 0.2
Duration of inhaler use*				
<3 years	61	4.6 ± 2.1	5.4 ± 1.0	4.4 ± 2.1
≥3 years	88	3.8 ± 1.5	5.4 ± 1.2	3.6 ± 1.6
Significance test		t = 2.7, P = 0.009	t = 0.004, P = 1.0	t = 2.9, P = 0.005

A, B, & C significant difference between the corresponding groups by Bonferroni's post-hoc multiple comparisons.
#Salbutamol, terbutalin, Inhaled corticosteroids (ICS), combined long-acting beta agonists and ICS.
*Among inhaler users (149).

Table 3. Correlation coefficient (r) linear regression between different quantitative parameters and total scores of PAQLQ and PACQLQ.

	PAQLQ			PACQLQ		
	r	Linear regression		*r*	Linear regression	
		β	*P*		*β*	*P*
Age (years)	0.18*			0.2*		
BMI	0.03			0.04		
Socioeconomic score	0.35***			0.26***	0.23	0.04
Asthma control level	0.9***	5.6	≤0.001	0.9***	1.6	≤0.001
Asthma severity	−0.7***	−15.2	≤0.001	−0.7***		
Number of inhalers	0.01			−0.14		
Duration of inhalers	−0.23**			−0.19*		
PAQLQ		Not applicable		0.93***	0.43	≤0.001
Constant		31.2			−11.7	
Significance		$F = 302.9$; $P \leq 0.001$			$F = 371.8$; $P \leq 0.001$	
R^2		0.81			0.88	

*, **, & *** significant correlation at $P \leq 0.05$, $P \leq 0.01$, & $P \leq 0.001$; respectively.

as an indicator of successful management of childhood asthma. Poorly controlled asthma impairs the QOL of children [19,20].

In this study, the overall mean scores of the total PAQLQ and its activity, emotion and symptom domains were 4.7, 4.3, 4.5, and 4.7; respectively, these are far away from the ideal score of seven for the total and each of the three domains. However, these are slightly higher than the corresponding mean scores reported by previous studies in other regions of Egypt [12,21,22]. The corresponding mean scores were much lower in Jordanian asthmatic children [23].

The overall mean scores of the total PACQLQ and its activity and emotion domains were 4.2, 5.4, and 4.0; respectively. Also, these are far away from the ideal score of seven for the total and the two domains. However, these are slightly higher than the corresponding mean scores reported by El-Gendi et al. [22] and El-shazly et al. [24] in other regions of Egypt.

We found significant positive correlations between PAQLQ and the total and all domains of PACQLQ (*r* ranges from 0.32 to 0.93). Previous studies in Egypt found that the caregiver's and children's health-related QOL were significantly associated with each other [22,24]. Obviously, the more impaired QOL in parents as a result of their child's asthma affects in 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 [25–28]. In contrast to these results, other studies in other countries found no correlation between PAQLQ and PACQLQ scores [29,30].

A previous study indicated that parents might not perceive accurately their child's asthma symptoms and they get their impression of their child's symptoms from watching especially the more severe symptoms. Also, parents can report symptoms when their child tells about the symptoms [31]. It was recommended that questionnaires measuring QOL of children should include children's self-report to reflect their beliefs and perspectives [32]. Therefore, obtaining QOL data in a straightforward way from the children is preferred.

The present study revealed a non-significant difference for the total and all domains of both PAQLQ and PACQLQ scores in different patients' age groups. This is in contrary to a previous study in Cairo, Egypt which found a significant negative correlation between age of patients and the total, activity and emotion domains of PAQLQ scores, but not with the symptoms score [12]. Also, a study in Jordan found that older patients' age was associated with better QOL [23]. Adolescents are able to better handle the burden of the disease than younger children owing to cognitive and emotional developmental variations in grasping the content measured [33].

Studies showed conflicting results about the QOL of children with asthma in relation to gender. The present study revealed a non-significant variation of the total and all domains of both PAQLQ and PACQLQ scores between males and females, apart from the activity domain of PACQLQ. This agrees with previous findings [21,34]. The lower score of activity domain of PACQLQ reflects a discrimination against girls. Parents may be more anxious about the limited activity of boys. In the conservative culture, boys are supposed to be more active outside

home than girls. A previous study in Cairo, Egypt found that male sex adversely affected the activity score [12]. Girls integrate the disease and the associate health regimen into their public, reflecting on the fact that asthma is part of their identity, whereas boys choose to treat their asthma in private, indicating a stigma that asthma affected the masculine identity [35]. On the other hand, a Jordanian study showed that the overall and the three domains scores of PAQLQ were lower in females than males [23]. Rydstrom et al. [36] showed that girls are limited in their activities and influenced emotionally by their asthma compared with boys.

The present study revealed a non-significant variation of the total and all domains of both PAQLQ and PACQLQ scores with different BMI categories of asthmatic children. A previous study showed a significant difference in QOL between obese asthmatic children (but not overweight) compared to the normal weight ones [37]. The authors attributed to possibility of the presence of other factors that influence QOL of these children rather than body weight.

There is a common suggestion that QOL would be lower in rural than urban asthmatic patients due to physical inaccessibility of health care services [38]. In the contrary to these suggestions, this study couldn't reveal significant difference in QOL score between rural and urban asthmatic children and their caregivers. This agrees with Al-Gewely et al. [12]. This could be attributed to equal health awareness and accessibility of means of transportation to the nearby hospitals.

The current study revealed that children and their caregiver from low and very low SES have lower scores of QOL. This reflects the lack of awareness of affordability of health care. Moreover, high SES is a reassurance to the family members and contributes to their psychological wellbeing [39]. This finding agrees with previous studies in Egypt [22,24] and other countries [40,41].

Studies have demonstrated that there was association between treatment of asthma symptoms and improvement of children's QOL physically, emotionally, socially, and spiritually [19,42,43]. In this study, the uncontrolled asthma is associated with low scores of QOL of both the children and their caregivers. Poor asthma control is associated with frequent symptoms, limitation of activities, and worry about asthma attacks. This is in agreement with previous findings in Egypt and other countries [22,24,26,44].

In the present study, severe asthma has a negative association with the QOL of both children and their caregivers. This agrees with previous studies in different countries [11,21,45–51]. A study on Dutch adolescents revealed that symptoms severity affected overall and positive QOL, both directly and indirectly, via coping. The lifestyle restricted by coping strategies and worrying about asthma were associated with poorer overall QOL. The use of the coping strategies––restricted lifestyle, positive reappraisal, and information seeking was related to increased scores of the positive QOL domain; whereas hiding asthma was related to lower scores [52].

In this study, the prolonged use of inhalers had adverse effects on QOL of both children and their caregivers. This finding may reflect the impact of disease chronicity and the need for daily maintenance medications. A previous study concluded that the use of daily maintenance medications predicted worse parental QOL scores [11]. Usually, good maintained therapy should indicate better asthma control and better QOL, it seems to be rather the effect of remodeling due to the lack of therapy.

In conclusion, asthmatic children and their caregivers have impaired QOL. These impairments are mainly associated with uncontrolled asthma, severe asthma, and longer duration of inhalers use. Early control of severe asthma will contribute to a better QOL of the affected children and their caregivers. Healthcare provider should consider QOL in the management plan with more attention to children from low socioeconomic standards. A community-based study will give the full-picture of QOL of asthmatic children and their caregivers.

Study Limitations

Being a hospital-based study with relatively small sample size, its results cannot be generalized to asthmatic children in the community, especially those not receiving care. Also, the cross-sectional nature of the study does not show the changes in QOL with time and the seasonal variation. Recall bias of children and their caregivers is another limitation.

Implications and Contribution of the Study

This study included a neglected aspect of management of childhood BA that is QOL of asthmatic children and their caregivers. Assessment of QOL should be a routine for these children and their caregivers, especially those with severe uncontrolled asthma with low SES.

Conflict of Interest

None.

Funding

None.

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