

Assessment of Quality of Life of Primary Caregivers of Egyptian Asthmatic Children and Adolescents

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Abstract

Background: Asthma as a serious public health problem worldwide exerts a serious load on children's health-related quality of life (HRQOL) and their families. **Objective:** We assess the HRQOL of the primary caregivers of Egyptian asthmatic children and adolescents and its relation to HRQOL of their children and asthma severity. **Materials and Methods:** A cross-sectional study was conducted on 128 pairs of asthmatic children (7–16 years) and their primary caregivers. Pediatric asthma quality of life (QOL) questionnaire, pediatric asthma caregiver's QOL questionnaire, and asthma control questionnaire were used. **Results:** Uncontrolled asthmatic patients had statistically significantly lower mean caregiver score compared to controlled asthmatic ($P < 0.005$). There was a statistically significant positive correlation between caregiver's individual and overall QOL scores and their children (individual and overall QOL scores) ($P < 0.05$). A statistically significant negative correlation between asthma severity and QOL scores of the caregivers of asthmatic children and adolescents was found ($P < 0.05$). **Conclusion:** The QOL of the primary caregivers of asthmatic children is significantly adversely affected by their children's illness severity.

Keywords: Asthma, caregivers, children and adolescents, quality of life

INTRODUCTION

Asthma is a common, chronic, noncommunicable respiratory disease affecting millions of children worldwide.^[1] The incidence of asthma, its complications, and related morbidity and mortality are increasing worldwide. In Egypt, asthma is comparatively common with 6.5% prevalence among primary school children in Menoufiya governorate, mostly among children from less wealthy families.^[2] Asthma symptoms vary in severity and frequency in affected individuals and can occur several times a day or week. Asthma symptoms may be mild, moderate, or severe. Exacerbations of asthma symptoms result in school and work absence, activity intolerance, and emergency hospital visits for asthma. Nocturnal asthma exacerbations commonly cause sleeplessness. Therefore, asthma symptoms can interfere and interrupt the activities of daily life and can have an adverse impact on the quality of life (QOL) for people with the disease, including children and their caregivers.^[1]

Caregiver refers to the primary person who takes care of a child with asthma. Studies that are conducted in recent years

indicate that it is the mothers who are the main people engaged in the care process.^[3]

An essential indicator of the impact of health conditions on patients and their families is QOL and is accordingly a main outcome measure in research and clinical interventions of chronic disease. The term "QOL" is used to refer to individuals' subjective satisfaction with significant features of their life, physical, mental well-being, social relationships, individual satisfaction, and health maintenance.^[4] One of the QOL-related components is the health-related QOL (HRQOL). HRQOL is defined as the functional effects of an illness and its consequent therapy on a patient, as perceived by the patient.^[5]

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Caregiver QOL is suggested to affect health self-management behaviors for instance, treatment adherence, and decisions about seeking health-care services that could have a considerable impact on asthma control.^[6] The chronic nature of asthma negatively affect the family function and engage the family with a lot of tasks as regards the child's health-care needs, educational and medical services, costs of disease, too many absence from work and physical and emotional problems.^[7] Therefore, the fundamental evaluation of the health state of a child with asthma involves both usual clinical indices and HRQOL of both the child and the caregiver.^[8]

Although there are several questionnaires that assess parental/caregiver's HRQOL, not directly related to asthma,^[6] there is only one tool which examines the particular effect of childhood asthma on parental/caregiver functioning which is the pediatric asthma caregiver's QOL questionnaire (PACQLQ).^[9]

The aim of this article is to assess the HRQOL of the primary caregivers of Egyptian asthmatic children and adolescents and its relation to HRQOL of their children and asthma severity.

MATERIALS AND METHODS

This cross-sectional study was conducted on 128 asthmatic children and adolescents and their primary caregivers (who had spent at least >75% of their time caring for their patients, mainly mothers) according to Rehm in 2013.^[3] They were recruited from the primary and preparatory schools from Giza during the period from September 2016 to April 2018, as a part of research project, funded by the National Research Center 11th research plan, entitled "effectiveness of health education program on pulmonary functions and QOL in Egyptian asthmatic children." The present study was following the rules and regulations of the Medical Ethical Committee of the National Research Centre. Approval number was 16/381. Written informed consent was obtained from all caregivers of the participants, and verbal assent was obtained from the children. The participants were classified to children if their ages <10 years and adolescents if their ages ≥10 years according to the World Health Organization criteria.^[10] The included participants were diagnosed with asthma, and asthma severity was classified according to the guidelines of the global initiative for asthma.^[11] The inclusion criteria include patients aged 7–16 years old of both sexes diagnosed with intermittent or persistent asthma as defined by the Global Initiative for Asthma guidelines^[11] and their caregivers. The exclusion criteria were children with a history of congenital heart disease, documented immunodeficiency, cystic fibrosis or any other chronic illness, and children with any mental disease or neurological disability. The participants were followed up in the pediatric pulmonary function testing clinic at the Medical Center of Excellency, National Research Centre.

All asthmatic participants were subjected to

1. Full history taking, including age, sex, consanguinity, educational level of the child, residence, father's and mother's education, father's and mother's occupation, exposure to smoking, type of feeding, age of weaning, number of family members, history of allergy, respiratory symptoms as cough and its timing, duration of asthma, age of onset of asthma, and type of drugs used and its side effects
2. Anthropometric measurements in the form of:
 - Height was measured using Harpenden stadiometer to the nearest 0.1 cm.^[12] Weight was measured by Tanita Scale to the nearest 0.1 kg^[12]
 - Body mass index (BMI) was calculated according to the following equation: BMI = weight (kg)/height (m)²^[12]
3. Asthma Control Questionnaire: It is used to evaluate the adequacy of asthma control in individual patients. It's composed of six questions (night – time waking, symptoms on waking, activity limitation, shortness of breath, wheeze and rescue short-acting β_2 agonist use) with 7-point scale answer (0 = totally controlled and 6 = extremely poorly controlled) with a time specification of 1 week. The score of ≥1.5 was considered poor asthma control and the score <1.5 was considered well-asthma control^[13]
4. Pediatric Asthma QOL Questionnaire (PAQLQ) (the Validated Arabic version) was used to determine the influence of asthma on the child's QOL. It measures the functional problems (physical, emotional, and social) that are most common in children with asthma. The children respond to each question on a 7-point scale (7 = no impairment and 1 = severe impairment). The overall PAQLQ score was the mean score of all items and not from the mean of the domain.^[14] The children were asked to recall their experiences during the previous week as it was found that 1 week is the period for which children are believed to provide the most reliable information
5. PACQLQ (the Validated Arabic version) was used to assess the QOL of the parents/caregivers of the children with asthma. It is a self-administered instrument which includes 13 items in two domains: the "activity limitations" that explore the extent to which the child's asthma negatively impacts the caregiver's sleep, work, and family experiences and "emotional function" during the previous week. Responses to each item of the PACQLQ are given on a 7-point scale, ranging from 1 to 7, with the higher scores indicating less impairment.^[9]

The three questionnaires were obtained from QOL technologies Ltd, after written approval from Jilly styles (Personal assistant to Professor Elizabeth Juniper, McMaster University, Canada). The approval was sent through e-mail.

Statistical analysis

Collected data were coded, tabulated, and statistically analyzed using the Statistical Package for the Social Sciences Software, (SPSS) version 24 (SPSS INC, Pittsburgh, Pennsylvania, USA). Descriptive statistics were performed for quantitative parametric data as mean ± standard deviation,

Table 1: Comparison between controlled asthmatic patients (n=74) and uncontrolled ones (n=54) as regards the anthropometric measurements and quality of life scores of their caregivers

	Controlled asthmatic children	Uncontrolled asthmatic children	<i>t</i>	<i>P</i>
Age in years	10.3±3.7	10.5±3.6	-0.170	0.865
Weight in kilograms	39.7±15.4	40.7±14.6	-0.204	0.840
Height in centimeters	141.04±20.25	141.79±18.53	-0.123	0.903
Body Mass Index (BMI)	18.64±3.7	19.92±4.2	-0.904	0.373
Mean caregiver score	2.67±1.17	1.38±1.11	-3.830	0.000
Activity limitation score	5.70±1.829	4.75±1.753	1.115	0.281
Emotional effect score	5.30±1.703	3.88±1.885	1.683	0.112
Total caregiver score	5.50±1.716	4.25±1.669	1.554	0.140

P<0.05: significant, *P*<0.005 highly significant

Table 2: Comparison between children (n=58) and adolescents (n=70) as regards quality of life scores of their caregivers

	Mean±SD		<i>t</i>	<i>P</i>
	Children	Adolescents		
Activity limitation score	5.11±1.69	6.18±1.47	-1.515	0.147
Emotional effect score	4.56±1.94	5.82±1.47	-1.655	0.115
Overall caregiver scores	4.78±1.85	5.82±1.47	-1.400	0.178
Mean caregiver scores	1.34±1.25	1.85±1.34	-1.339	0.187

SD: Standard deviation

whereas they were performed for qualitative data as number and percentage. Independent sample *t*-test was used to compare the two means. Pearson's correlation was used to correlate the variables. The level of statistical significance for all tests was set at *P* < 0.05, otherwise, the tests were considered insignificant. Linear regression and multiple stepwise regression analysis were performed.

RESULTS

A total of 128 pairs of asthmatic children aged 7–16 years old, with a mean age of 10.14 years and their caregivers were included. Among the studied patients, 58 (45.3%) were male and 70 (54.7%) were female. All caregivers were mothers. Nearly 58.6% of the included participants had family number of <5, 31.2% had 5 to 7 members, and 10.2% had 8 or more members. About 82.8% of the participants were passively exposed to smoke. The study showed that 57.8% of the participants have controlled asthma and 42.2% have uncontrolled asthma. No significant correlations could be detected between caregiver QOL scores and neither age, sex of the child, household size, BMI, nor environmental tobacco smoke exposure (*P* > 0.05).

Uncontrolled asthmatics showed significantly lower mean caregiver score compared to controlled ones. A significant direct correlation between caregivers, QOL scores and those of their children. A significant negative correlation between asthma severity and QOL scores of the caregivers. Caregiver's emotional effect score was significantly more affected than caregiver's activity limitation score. [Tables 1-5].

Logistic regression analysis showed that the asthma severity score is the main predictor of total caregivers QOL score which was used as the dependent variable in this model (*P* = 0.003).

DISCUSSION

Asthma disease can result in various degrees of restrictions in a patient's life, recognized generally as a lower QOL that includes physical, emotional, and social aspects. However, the impact of asthma in children expands their caregivers and families, who face the load of care and effect on life style.^[15]

This study showed that the uncontrolled asthmatic patients had significantly lower mean caregiver score (1.36 ± 1.11) in comparison to controlled asthmatic patients (2.67 ± 1.17) (*P* < 0.05).

This is in agreement with the results of other studies,^[16,17] which also reported that poorer asthma control was an important predictor of lower caregiver QOL. Uncontrolled asthma exerts a larger toll on the caregiver and families. Additionally to the effects of uncontrolled asthma on the social and emotional facets of the caregiver, the caregivers of children who have poorly controlled asthma state have more missed work comparative to the caregivers of children with controlled asthma (31% vs. 16%),^[16] reduced work production, throughout their child's asthma episode, and higher recognized economic trouble than caregivers of children with well-controlled asthma.^[15] On the other hand, no statistically significant differences between the uncontrolled asthmatic patients and the controlled ones could be found in this study as regards age of the patients, weight, height, BMI, the score of individual domain (activity and emotional) of their caregivers, and the total caregiver's score.

Similarly, Dean *et al.*^[15] stated that the age of children with asthma did not differ statistically between controlled asthmatics and uncontrolled ones. Rodríguez-Martínez *et al.*^[17] revealed a statistically significant difference of PACQLQ scores between the patients with controlled asthma and those with uncontrolled asthma when comparing each domain separately.

The present study showed that the adolescents had nonstatistically significant higher QOL scores of their caregivers (individual and overall score of QOL) compared

Table 3: Correlation between quality of life domain and overall score of caregivers and their children (n=128)

	Overall PAQLQ score (n=128)		Activity limitation score (n=128)		Symptom score (n=128)		Emotional function score (n=128)	
	r	P	r	P	r	P	r	P
Caregiver emotional score	0.749	0.000	0.650	0.003	0.793	0.000	0.725	0.000
Caregiver activity score	0.773	0.000	0.590	0.008	0.814	0.000	0.756	0.000
Caregiver overall score	0.801	0.000	0.660	0.002	0.819	0.000	0.777	0.000

Table 4: Correlation between asthma severity and quality of life scores of the caregivers of asthmatic children and adolescents (n=128)

Asthma severity	Caregiver activity limitation score	Caregiver emotional effect score	Caregiver total score
Pearson correlation	-0.414	-0.408	-0.414
Significance (two-tailed)	0.003	0.003	0.003

Table 5: Comparison between caregiver's emotional effect score and caregiver's activity limitation score (n=128)

Activity limitation caregivers score	Mean	SD	SEM	t	df	Significant (two-tailed)
Emotional effect caregivers score	0.577	0.758	0.149	3.883	25	0.001

SD: Standard deviation, SEM: Standard error of the mean

to those of children ($P > 0.05$). Similarly, El-Gilany *et al.*^[18] found that parents of older children had better QOL when compared with younger children. Furthermore, El-Gendi *et al.*,^[8] revealed that older patients were associated with better QOL. Adolescents are recognized with their ability to handle the load of disease better than younger children due to their cognitive and emotional development.

This study found that there was a significant negative correlation between asthma severity and QOL scores (individual scores and overall score of QOL) of the caregivers of the included asthmatic patients. This finding is in accordance with the results of other studies which stated that higher asthma severity resulted in a negative effect on QOL of the caregivers of asthmatic patients and negative feelings related to their children's asthma as a consequence of decreased caregiver emotional functioning.^[19]

We found a significant positive correlation between caregivers (individual scores and overall score of QOL) and those of their children. This finding was consistent with previous studies.^[8,20] The caregiver's and child's HROOL are significantly associated with each other as the parent score was influenced by the child score.^[20] The more impairment of QOL of parents as a result of their child's asthma can affect all facets of family life, and it could result in psychological difficulties for his/her parents or other family members.^[21] In contrast to these results, Farnik *et al.*^[22] found no correlation between PAQLQ score and PACQLQ score.

This study found that the caregiver's emotional score was significantly more affected than caregiver's activity limitation score. This is consistent with other studies. El-Gendi *et al.*^[8] also found that emotional domain of caregivers of asthmatic children is more affected. In contrast,

Elshazly *et al.*^[20] stated that the caregiver's activity domain was the most affected.

In this study, no significant correlations could be detected between caregiver QOL scores (individual scores and overall score of QOL) and neither age nor sex of the child, household size, BMI, nor environmental tobacco smoke exposure.

This is in agreement with the results of other studies, i.e. Levy *et al.*^[23] and El-Gendi *et al.*^[8] also found that neither age nor sex of the child was related to PACQLQ scores. In contrast, Zandieh *et al.*^[24] reported that QOL is more bothered in caregivers of male patients than female patients ($P < 0.001$). They attributed this finding to two factors which are more disturbance of QOL in male patients and more emotional bond between mothers (the usual caregiver) and sons than daughters in Iranian families.^[24] Other studies showed that QOL of girls with asthma are more adversely affected than boys.^[8] Girls are known to be more worried about their health, over-expressing their symptoms than boys, and integrate their conditions into their social and personal characteristics.^[25]

Similarly, Levy *et al.*^[23] reported that neither BMI nor environmental tobacco smoke exposure was significantly related to caregiver QOL. Furthermore, El-Gilany *et al.*^[18] found a nonsignificant difference of the total and both domains of PACQLQ scores with different BMI categories of asthmatic children. This is might be due to the presence of other factors that could affect the QOL of these children. On the contrary, Levy *et al.* showed a statistically significant negative association between household sizes and caregiver QOL scores pointing to the effect of indoor air quality or respiratory infection related to unit crowd.^[23]

CONCLUSION

Caregivers of children with asthma face many confronts and can be intensely affected by their child's illness. Uncontrolled asthma impairs QOL of caregivers of asthmatic children. Age, sex, BMI, and household size revealed no significant difference.

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Conflicts of interest

There are no conflicts of interest.

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