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Assessing the Quality of Life in Pediatric Asthma Patients and Their Caregiver at Qassim Region, Saudi Arabia

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ABSTRACT

Due to the pathophysiology of asthma, it interrupts with the daily activities of the patients and affect the patients

psychologically. Studies show that affected children with asthma and their parents have an altered quality of life, while such studies are not done in Qassim region.

Methods: A cross-sectional study was carried among pediatric asthma patients and their caregivers. The participants are the asthmatic children at the age of 5 to 15 who visited the Respiratory Clinics and Emergency with their caregiver from January to March 2020. A sample size of 251 asthmatic children with caregivers was used. Both descriptive and inferential statistics were used in the analysis.

Results: There was a significant relationship between the caregiver gender and emotional disturbance (p=0.008) and activity limitation (p=0.000). There was no relation between the presence of another child with asthma and emotional disturbance (p =0.565) nor activity limitation (p=0.748). There was a significant relationship between asthma control status and the children symptoms (p=0.001), asthma treatment (p=0.007), worries (p=0.007) and communication (p=0.001) domains.

Conclusion: Asthma control accounts a lot on the state of both the patient and the caregiver. Effective and timely control status measures is required to ensure low levels of anxiety with caregivers and reduced symptoms with the asthmatic children. This study recommends collaboration between doctors and caregivers, where doctors will be able to train the caregivers on how best to manage children with asthma.

Key words: Care-giver, Asthma, Control-status, Quality-of-life

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INTRODUCTION

Asthma is the Greek word of gasping or panting. It is a chronic pulmonary disease that affects respiratory airways in a form of repeated attacks. Asthmatic patient suffers from multiple episodes of chest tightness, sudden breathlessness, wheezing and coughing. In rare cases asphyxiation leads to death. Asthma symptoms and complications are controlled with appropriate treatment regimen [1].

Asthma is one of the most common causes of

pulmonary diseases in children in almost all industrialized countries [2]. According to recent data from center of disease control in 2016, 6132 children younger than 18 years old, which counted with 8.3% from the target population, were diagnosed with asthma in US. Meanwhile, the prevalence of asthma in the children of Saudi Arabia have been increasing in the last three decades, which has been found to range from 8% to 25% [3]. The latest study on prevalence of pediatric asthma in Saudi Arabia conducted in 2007 among 5663 students from deferent regions; the study demonstrates that Qassim region ranked in the fourth position with sup positive prevalence of 16% [4].

The world health organization defined "health "not only an absence of disease but also being physically, mentally and socially well. For this purpose, the evaluation of health-related quality of life has been established in 1948 [5]. Pediatric asthma accounts for significant percentage of childhood hospitalization, pulmonary outpatient visits and school absenteeism, which is obviously interfere with health-related quality of life of affected children [6].

Asthmatic child commonly faces episodic events of worry, fear and panic attack regarding difficulty of breath on not having their medications as needed, in addition to frustration and sadness [7-9]. These irritable emotions lead them to have negative coping management, like avoidance of physical activities [7]. As the asthma symptoms are severe the quality of life of the affected child will be low and vice versa, a study conducted in Italy among 127 asthmatic children showed that the children with higher quality of life have a fewer asthma exacerbations and they reported higher mean value of ⟦FEV⟧_1 [10].

To reduce the current gap between the physician's knowledge about asthma physical symptoms and the individual's burden of asthma, health related quality of life assessments has an important role to fill this gap [5]. One of health-related quality of life assessments which implicated in pediatric asthma patients is PedsQL™ 3.0, that was created to merge generic core scales with disease specific module into a single and comprehensive survey [10]. PedsQL™ asthma module assesses the health-related quality of life associated with pediatric asthma in three main domains: physically, emotionally and socially.

In pediatric asthma, the child's family particularly the child's caregiver may carry a substantial burden. Some studies show no association between the caregiver's healths related quality of life and the child's asthma symptoms [11], pretreatment asthma severity [12]. On the other hand, some studies find out a considerable association between the child's and the caregiver's health related quality of life, where the caregivers of children with uncontrolled asthma show higher work absenteeism than those of children with controlled asthma [13]. Pediatric asthma caregiver's questionnaire is one method to measure the quality of life in caregivers. It designed in 1995, consist of 13 questions which aimed to measure the areas of function of caregivers with asthmatic children that includes both physical and emotional impairment [14].

RESEARCH METHODOLOGY

Research design

A cross-sectional study carried among pediatric asthma patients and their caregivers. Depending on the General authority for statistical reports in Saudi Arabia, the general population of Al-Qassim is about (1219184), pediatric age group from 0-14 years are around (313777) accounting 25.7% of general population [15]. The participants are the asthmatic children at the age of 5 to 15 who visited the Respiratory Clinics and Emergency department with their caregiver from January 2020 to March 2020. The exclusion criteria are having a psychological disorder, heart disease, tuberculosis, terminal illness, renal disease, and physical limitations. The sample size includes 255 asthmatic children and their caregivers, only 251 responders who completed the questionnaire. The study involve four secondary health care centers in four cities in Qassim region; Buraidah (Children and Maternity Hospital), Unaizah (King Saud Hospital), AlRass (AlRass General Hospital), AlBadaiea (AlBadaiea General Hospital).

Participants, sample size and selection

The participants are chosen from their medical records, the proxy of chosen participants informed of the study after being seen by the doctor. Written consent obtained from all the

involved parties. The study efficiently explained to them before taking any step into the study. Sociodemographic data including age, caregiver's educational status, and socioeconomic status will be collected from caregivers. The asthma control status of the child will be obtained from the caregiver and approved by the responsible doctor.

Data collection methods

The data of pediatric quality of life collected by using the Arabic version of both PedsQL™ 3.0 child self-report and PedsQL™ 3.0 parents report. It consists of 26 items categorized into 4 dimensions: physical functioning (11 items), treatment (9 items), worries (3 items), communication (3 items). It was designed for children and adolescents ages 2-18 years and is available in a self-report version for children/ adolescents aged 5-18 years, and a proxy-report version for parents. A 5-point response scale is utilized in both the self-report for children aged 8-18 years and the parent proxy-report (0=never a problem, 1=almost never a problem, 2=sometimes a problem, 3=often a problem, 4=almost always a problem). To further increase the ease of use, the young child self-report version (ages 5-7 years) has a simplified, 3-point response scale (0=not at all a problem, 2=sometimes a problem, 3=often a problem), with each response choice anchored to happy/ sad faces. Items were reverse-scored and linearly transformed to a 0-100 scale (0=100, 1=75, 2= 50, 3= 25, 4=0). Therefore, a higher score indicated a better QoL. Scale scores were computed as the sum of the items divided by the number of items answered [16].

For caregiver's quality of life the data will be collected by Pediatric Asthma Caregiver's Quality Of Life Questionnaire (PACQLQ), The questionnaire composed of 13 items which represent the emotional function (1,3,5,7,9,10-13) and activity limitation (2,4,6,8). The answers on each item scaled from 1 (all of the time) to 7 (none of the time) [17]. Both questionnaires have good validity and reliability [18].

Data analysis plan

The data analyzed by SPSS windows program, chi-square and Pearson correlation used to find out the relation between the asthma control status and the health-related quality of life of asthmatic child, and to find the relation between the socioeconomic status of the caregivers with their health-related quality of life. Both pediatric and caregiver health related quality of life correlation will be obtained in the bases of emotional functioning impairment and activity limitation.

Ethical consideration

A pilot study was done among 58 asthmatic patients in the secondary hospital in Unaizah (king Saud hospital) to check the validity. The study was approved by the IRB from National Committee of Bioethics- Ministry of Health-Qassim before its implementation. Written informed consent was obtained from the Caregivers as their representatives for the children participants. The authors declare that they have no conflict of interest.

FINDINGS

Out of the 251 children, 61.8% were male while 38.2% were female (Figure 1). For the caregivers, 23.5% were male and 76.5% were female (Figure 2). Responders from the cities of Qassim region Arras, Buraidah, Unaizah and Badaiea (33.5%, 23.9%, 23.55% and 19.1%) respectively. The majority of caregivers had attained a Bachelor degree accounting for 63.3%. This was followed by those who had attained secondary education

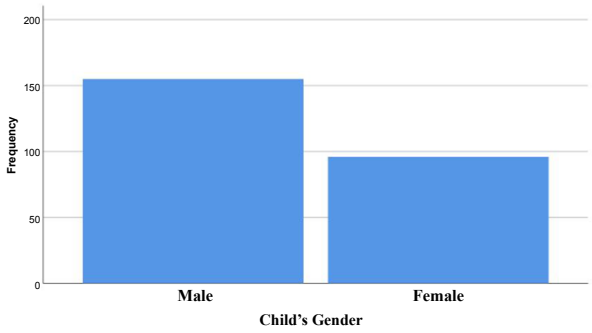

Figure 1: Children gender.

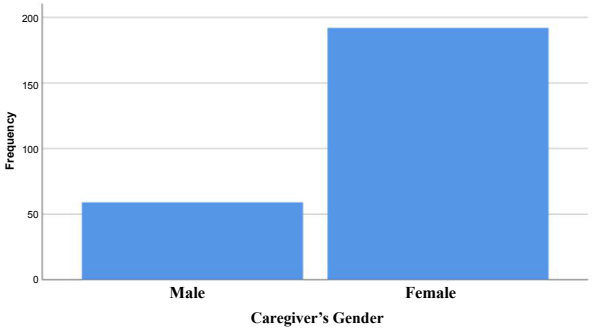

Figure 2: Caregiver gender.

accounting for 15.1%. There were 44.6% of caregivers having other children with asthma and 55.4% don't have other child with asthma (Table 1). Children aged 5 years accounted for 35%, 1 year accounted for 29%, 2 years accounted for 28% and 8 years accounted for 22%.

There was a significant relationship. Between the caregiver gender and emotional disturbance domain in PACQoL (p=0.008, significant at p<0.05). Also there was a significant relationship between the caregiver gender and activity limitation domain in PACQoL (p=0.000 significant at p<0.05). (Table 2).

There was no significant relationship between the presence of another child with asthma and caregiver emotional disturbance (p=0.0565, >0.05). There was also no significant relationship between presence of another child with asthma and activity limitation (p=0.748, > 0.05) (Table 2).

The null hypothesis of the medians of symptoms aspect of PAQoL are the same across categories of asthma control status was reject (p=0.11) hence concluding that the medians of symptoms differed across the different categories of asthma categories. The null hypothesis of same distribution of symptoms aspect of PAQoL across the different categories of asthma control status was rejected (p=0.001) hence concluding that the distributions were different. The null hypothesis of same medians of treatment aspect of PAQoL across categories of asthma control status was rejected (p=0.008) hence concluding that the medians were significantly different. The null hypothesis of same distribution of treatment aspect of PAQoL was rejected (p=0.007) thus concluding that distribution across the different categories were different (Table 3).

The null hypothesis of the medians of worries aspect of PAQoL are the same across categories of asthma control status was rejected (p=0.002)

Table 1: Demographic characteristics.

Variable		Frequency (%)
Children Gender	Male	155(61.8%)
	Female	96(38.2%)
Caregiver Gender	Male	59(23.5%)
	Female	192(76.5%)
Responders	Buraidah	60(23.9%)
	Unaizah	59(23.5%)
	Aarras	84(33.5%)
	Badaiea	48(19.1%)
Caregiver Education	Non	13 (5.2%)
	Primary	24(9.6%)
	Intermediate	7(2.8%)
	Secondary	38(15.1%)
	Bachelor Degree	159(63.3%)
	Master Degree	4(1.6%)
	Doctorate Degree	5(2.0%)
Presence of Another child with Asthma	Yes	112(44.6%)
	No	139(55.4%)

Table 2: Correlational significance of presence of another child with asthma, caregiver gender and emotional disturbance and activity limitation.

	Variable	Sig
Presence of another child with asthma	Emotional Disturbance	0.566
	Activity Limitation	0.748
Care giver Gender	Emotional Disturbance	0.008
	Activity Limitation	0

Table 3: Symptoms and treatment hypothesis testing.

Null hypotheis	Sig	Result
The medians of symptoms aspect of PAQoL are the same across categories of asthma control status	0.011	Reject Null
The distribution of symptoms aspect of PAQoL is the same across categories of asthma control status	0.001	Reject Null
The medians of treatment aspect of PAQoL is the same across categories of asthma control status	0.008	Reject Null
The distribution of treatment aspect of PAQoL is the same across categories of asthma control status	0.007	Reject Null

Table 4: Worries and communication aspects hypothesis testing.

Null hypotheis	Sig	Result
The medians of worries aspect of PAQoL is the same across categories of asthma control status	0.002	Reject Null
The distribution of worries aspect of PAQoL is the same across categories of asthma control status	0.007	Reject Null
The medians of communication aspect of PAQoL is the same across categories of asthma control status	0.01	Reject Null
The distribution of communication aspect of PAQoL is the same across categories of asthma control status	0.001	Reject Null

hence concluding that the medians of worries was different across the different categories of asthma categories. The null hypothesis of same distribution of worries aspect of PAQoL across the different categories of asthma control status was rejected (p=0.007) thus the distributions were different. The null hypothesis of same medians of communications aspect of PAQoL across categories of asthma control status was rejected (p=0.010) hence concluding that the medians of communication aspect were significantly different. The null hypothesis of same distribution of communication aspect of PAQoL was rejected (p=0.001) thus concluding that distribution of communication aspect across the different categories of asthma control status were different (Table 4).

Correlation between pediatric asthma quality of life results and pediatric asthma caregivers quality of life results is -.387 and it is significant .000 at p-value of 0.01.

DISCUSSION

With an aim to understand the quality of life of Asthma patients as well as the caregivers, a cross-sectional study has been conducted where we seek to discuss the findings in relation to past and similar studies. The study has been able to establish a relationship between the caregiver and emotional disturbance as well as activity limitation. These findings are compatible with a study on school aged children who have asthma where the researchers that caregivers with asthmatic children demonstrated disturbingly increased rates of depression and anxiety as compared to caregiver without asthmatic children [19]. The study also reported increased negative impacts on the asthmatic children where they reported increased panic attacks, missed school days and behavioral problems. In a different study [20], researchers found that caregivers with asthmatic children were more likely to experience depression which often led to a communication breakdown with the patients. This study did not establish relationship between the caregiver's emotional disturbance and activity limitation when they did not have direct contact with the child with asthma. In other hand this finding agrees with a study on the stress of caring for children with asthma where the negative experiences and the unpredictability of the disease outcomes were found to impair the ability of the caregivers to provide effective caregiving roles [21]. This study established significant relationship between asthma control status and the children symptoms and treatment. The findings are in tune with a study conducted on status of asthma control and asthma prescribing practices in the United States [22]. Researchers found that prescribing practices increased with uncontrolled asthma from 60% to 81%. In addition, the use of inhaled corticosteroids containing medication among patients with uncontrolled asthma increased by 52%. Respect to symptoms, our study agrees with a study conducted on relationship between asthma control status and urgent health care in Asia, where each symptom from uncontrolled Asthma was found to be significantly associated with urgent health-care utilization [23]. This study also established significant relationship between asthma control status and caregiver worries and communication. This finding agrees with a study conducted on association of youth and caregiver anxiety where a strong curvilinear relationship was established between caregiver anxiety level and symptom prevention [24]. The study further established a linear relationship between adolescent asthma related anxiety to adolescent symptom prevention.

The study has some limitations. Due to time limit and minimum resources, the responses were self-reported and the study noted complexity of understanding of the items and especially among the children. This could have limited the accuracy of data collected. For future research, the study proposes use of a researcher to help with the responses.

CONCLUSION

In general, this study concludes that caregiver

emotional status is key to the success of asthma management among patients. In addition, control status also accounts a lot on the state of both the patient as well as the care giver. Effective and timely control status is required to ensure low levels of anxiety with caregivers. This study recommends collaboration between nurses and caregivers where nurses will be able to train the caregivers on how best to manage children with asthma.

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