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A Prospective Study to Assess the Quality of Life in Children with Newly Diagnosed Asthma and Their Caregivers using the Pediatric Asthma Quality of Life Questionnaire

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Abstract

Objectives: The study aims to assess the quality of life (QOL) in newly diagnosed asthmatic children and their caregivers before and after treatment using mini pediatric asthma quality of life questionnaire (PAQLQ) and pediatric asthma caregivers quality of life questionnaire (PACQLQ) and to compare their quality of life with ACS (asthma clinical severity score).

Materials and Methods: This prospective study was done among 99 children and their caregivers, who were interviewed using mini PAQLQ and PACQLQ on 2 occasions: at the time of inclusion and 4 weeks after treatment. During their clinic visit, asthma clinical severity scoring was done, and children were treated according to GINA (Global Initiative for Asthma).

Results: After 4 weeks of treatment, there was a significant change in all domains of mini PAQLQ ($P < .001$) and PACQLQ ($P < .001$). In children, the change in the emotional domain after treatment was minimal when compared to other domains. When ACS was compared with mini PAQLQ and PACQLQ, children with well-controlled asthma had a better quality of life than partially-controlled asthmatic children ($P < .001$) and there wasn't a significant change in the quality of life of the caregivers after treatment ($P = .321$)

Conclusion: During treatment, QOL of newly diagnosed asthmatic children and their caregivers showed significant improvement but children lagged in their emotional domain. Despite medical intervention, these children also require psychological support and counseling. Also, caregivers didn't perceive a change in their QOL when compared with ACS and it indicates that parent's and child health-related quality of life should be taken as independent dimensions.

Keywords

quality of life, newly diagnosed asthma, children, caregivers, asthma clinical severity

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Introduction

Asthma is the most common chronic inflammatory disorder of the lower respiratory tract in children and it is the foremost reason for emergency department visits, as well as a cause for significant disability, morbidity, and sporadic mortality at all ages. According to published literature, the prevalence of bronchial asthma in children ranged from 2% to 23% in India.[1] It is one of the common chronic illnesses in children causing school absenteeism, it affects children's educational potential and adversely affects a child's quality of life (QOL). Asthma is a disease that can result in varying degrees of restriction in the physical, emotional and social spheres of a patient's life.[2]

QOL in asthmatic children has been described as the measure of asthma severity/symptoms, emotions, activity limitations, school absenteeism, and emergency visits. Several studies in asthmatic children had stated that there is a difference in the QOL results of children and their

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parents. Irrespective of the delineation of QOL and variation in definitions between urban and rural families, most studies specify that there was a significant impairment in QOL in children with asthma and their families.[3] There is an assumption that poor QOL scores are observed in children with very severe asthma than children with mild asthma. However existing literature had revealed that QOL is not related to asthma control and is a separate entity determining overall asthma health status.[4-7] It is important that all asthmatic children should lead a healthier lifestyle with good QOL. In India, there is a scarcity of data on risk factors for pediatric asthma, QOL and the severity of asthma in newly diagnosed children and their caregivers, warranting the need for an evaluation of QOL. This study was carried out to assess the pre and post-treatment QOL in children with newly diagnosed asthma, to identify the coping mechanisms used by the caregivers and to compare the QOL of children and their care givers with the Asthma Clinical Severity score at pre and post-treatment stages.

Materials and Methods

This prospective cohort study was carried out among children newly diagnosed with bronchial asthma at pediatric asthma clinic of the tertiary teaching institution for a period of 2 years between 2017 and 2019. The inclusion criteria comprised of children in the age group of 7 to 17 years, newly diagnosed asthma according to Global Initiative for Asthma (GINA) guidelines,[5] and children/parents who could read and respond to the questionnaire in English. The exclusion criteria consisted of children on oral steroids anytime in the 2 weeks prior to data collection, children diagnosed as asthma and on preventer therapy, children with recurrent chest infections requiring treatment with multiple antibiotics, children with intellectual disability and those refusing to participate in the study.

Based on the available literature, a lowest prevalence of 2% was taken for calculation of sample size. At 95% confidence limits and 3% absolute precision, the sample size was calculated as 84. Accounting 10% for refusals, the sample size was further increased to 92 and rounded off to 100. The participants for the study were selected by purposive sampling. Approval was obtained from the Institutional Ethics Committee prior to the commencement of the study. Each participant and caregiver were explained in detail about the study and informed consent was obtained prior to the data collection. A primary caregiver usually a parent, who accompanies the child to every clinic visit.

Data was collected at 2 points in the study. The first point of data collection was upon diagnosis of bronchial asthma. At this stage the data recorded included a structured interview schedule to obtain data regarding demographics, family and socioeconomic history and history of allergies, clinical examination by the principal investigator, assessment of nutritional status by measuring weight and height using standardized scales. Body mass index (BMI) was calculated by plotting the weight for height in the World Health Organization (WHO) BMI charts, interviewer administered mini PAQLQ and PACQLQ to obtain data regarding QOL among the participants and care givers. These scales were developed by Juniper et al.[5,8-12] The PAQLQ assessed the QOL under 3 domains (symptoms, activity limitation and emotional function). The PACQLQ assessed the QOL among caregivers under 2 domains (activity limitation and emotional function). Appropriate permissions were obtained from the authors for the perusal of the scales. Asthma Clinical Severity (ACS) was measured using the ACS scoring developed by Juniper et al. It includes awakened by symptoms at night, daytime symptoms, Sputum expectoration, Limitation of activities, Beta agonist use more than 2 times per day and FEV1 less than 80% of the predicted value.[8] For each question, scores range from 0-6(higher is worse). Patients recall their experiences during the previous week and respond to the 6 questions on a 7-point scale. The items are equally weighted, and the ACS score is the mean of the 6 items. Patients are classified as well-controlled 0.0 to 0.75, Partially-controlled 0.76 to 1.5 and Poorly-controlled >1.5. FEV1 is measured by spirometry manufactured by Spirolab model no TUK-MIR045, Italy.

The participants were treated for bronchial asthma according to GINA guidelines. The treatment of this children included preventers (inhaled steroids or inhaled steroids plus long acting beta 2 agonists) and relievers (inhaled short acting beta2 agonists). After 4 weeks, the participants were reviewed and data obtained included clinical examination by the principal investigator, assessment of nutritional status by measuring weight and height using standardized scales. Body mass index (BMI) was calculated by plotting the weight for height in the World Health Organization (WHO) BMI charts. An interviewer administered mini PAQLQ and PACQLQ to obtain data regarding QOL among the participants and care givers. Asthma Clinical Severity (ACS) was also measured.

Data was entered and analyzed using SPSS ver.17 software. The demographic particulars were expressed as percentages. QOL was presented as mean scores and comparison of QOL with ACS was carried out using Independent sample t test. Comparison of parameters before and after the treatment was carried out using Paired sample t test. A P-value $<.05$ was considered statistically significant.

Results

Initially, 120 children were enrolled as newly diagnosed asthma. 21 children were lost to follow up. The results of 99 children are presented below.

Table 1. Background Characteristics.

S. No	Characteristics	Frequency (n = 99)	%
1	Age (in years)		
	7-11	50	51
	12-17	49	49
2	Sex		
	Males	63	64
	Females	36	36
3	Body mass index		
	Severely thin	1	1.0
	Thin	12	12.2
	Normal	84	84.8
	Overweight	0	0
	Obese	2	2.0
4	Exposure to allergies*		
	Allergic rhinitis	17	17.2
	Exposure to pets	8	8.1
	Atopic dermatitis	0	0
	Allergic conjunctivitis	0	0
	Family history of bronchial asthma	17	17.2

*The percentage will not total to 100.

The majority of the participants, 63 (64%) were found to be male. Children were divided into 2 age groups 7 to 11 years (young children) and 12 to 17 years (adolescence) and there was an equal distribution of asthma among both the age groups (49% and 51%) respectively. We split the children into these groups as children more than 11 years were found to have a better understanding of their symptoms. Though obesity is associated with an increased risk of asthma, 84% of children with asthma in our study were found to have normal BMI. Among the risk factors for asthma, Allergic rhinitis and a family history of bronchial asthma constituted 17% of the study group. Cooking gas was the most common type of cooking fuel used in our study population.8% of the asthmatic children gave a history of exposure to pets. Atopic dermatitis and allergic conjunctivitis were not present in the children diagnosed with asthma; 89% of the children who participated in the study belonged to lower middle class in the socio- economic strata as per Kuppusamyclassification.[13] About 95% of the children in our study population lived in urban areas (Table 1).

According to GINA guidelines, children with asthma were categorized into various types of asthma. 59.6% of children had moderate persistent asthma and among them 64% and 53% were males and females, respectively. Most of the children in both the age groups were found to have moderate persistent asthma (7-11 years-57% and 12-17 years-62%) (Figure 1).

Based on the asthma clinical severity scores (ACS), the children were classified as well-controlled, partially-controlled and poorly-controlled at each visit separately. As per the ACS score, assessed before and after treatment, there is a decrease in the severity of asthma post treatment, which is well demonstrated by the increase in the number of children in the well-controlled group and a decrease in the number of children in the partially-controlled and poorly-controlled group. The mean ACS scores showed a statistically significant change ($P < .001$) after 4 weeks of treatment indicating an objective improvement in the clinical status of the child with treatment (Table 2).

Statistically significant increase is seen in activity limitation, symptom and emotional domains of mini PAQLQ after treatment ($P < .0001$). There was also a significant change in the mean total scores showing an overall improvement in the child's condition with medical intervention. On the statistical analysis of the QOL from the caregiver's point of view, a significant change ($P < .0001$) was noted in the mean scores of both the activity and emotion domains of PACQLQ with treatment. The Mean of the grand mean total of PAQLQ and PACQLQ also showed a significant statistical change (Table 3).

In pre-treatment and post treatment categories, children with well-controlled asthma had a significantly better quality of life ($P < .001$) than partially-controlled children (Table 4).

Caregivers of children with well-controlled asthma showed notable differences compared to the quality of life of the caregivers of children with partially-controlled asthma and this is statistically significant. Post treatment, there was no significant change in the quality of life of the caregivers in both the groups indicating that despite improvement in the quality of the life of the child, the caregiver didn't perceive a significant change (Table 5).

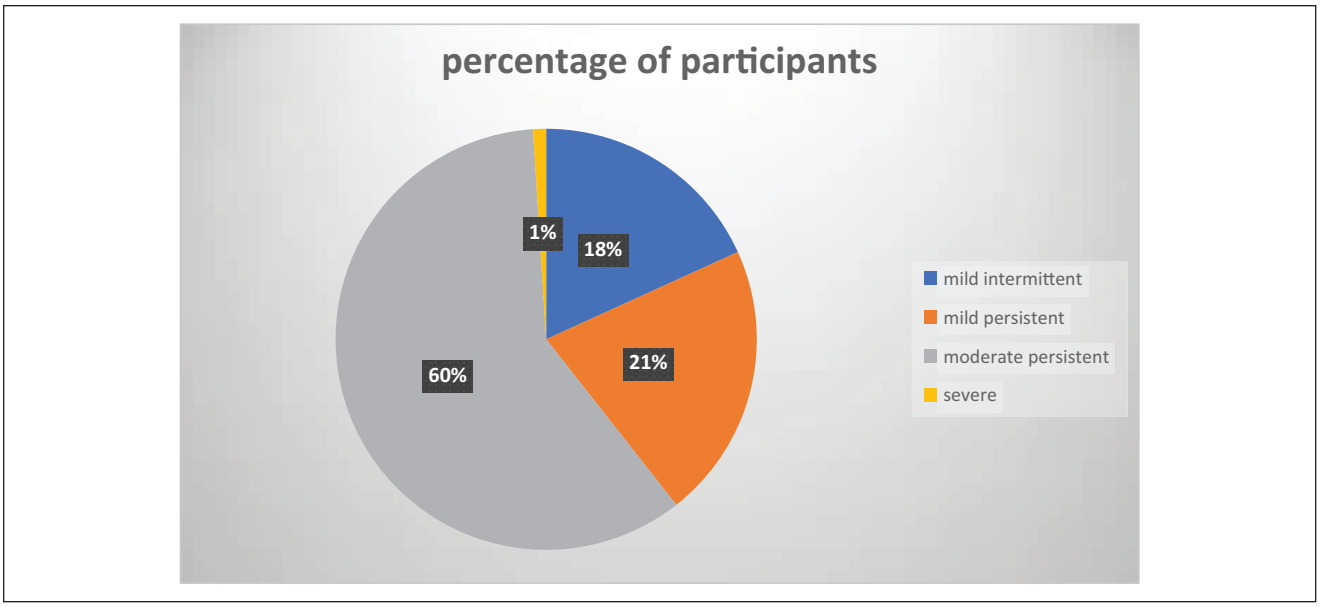

Figure 1. Grading of asthma at the time of diagnosis.

Table 2. Asthma Control as per Asthma Clinical Severity Score (ACS).

Status	Pre treatment N (%)		Post treatment N (%)
Well-controlled	13 (13%)		25 (25%)
Partially-controlled	85 (86%)		74 (75%)
Poorly-controlled	1 (1%)		0 (0)
Mean	1.076		0.88
SD	0.29		0.29
P-value		<.0001*	

*Statistically significant.

Table 3. Analysis of the Mean Mini PAQLQ and the PACQLQ Scores Pre-treatment and Post-Treatment.

	Pre-treatment		Post-treatment				
QOL domain	Mean	SD	Mean	SD	Mean difference	*T* value	*P*-value
PAQLQ (No. of items)							
Activity (3)	4.642	0.4760	6.114	0.2373	−0.92	−43.43	<.0001
Symptom (6)	4.722	0.4550	6.164	0.2529			
Emotion (4)	5.123	0.3681	4.990	0.3705			
Grand total (13)	4.829	0.4100	5.756	0.2378			
PACQLQ (No. of items)							
Activity (4)	4.610	0.1366	5.892	0.1608	−0.98	−67.8	<.0001
Emotion (9)	4.354	0.1072	5.052	0.1758			
Grand total (13)	4.482	0.0882	5.472	0.1258			

The present study also observed a statistically significant correlation between ACS and PAQLQ in the post treatment. It was observed that with every increase in the ACS score, there was a significant reduction in the PAQLQ, thereby indicating that QOL was significantly dependent on reducing the severity of asthma (Table 6).

Discussion

Quality of life in children with asthma is measured not only clinically, but also on perception of symptoms, activity limitation and emotional factors. It is important to understand that primary caregivers equally feel the burden of the

Table 4. Comparison of ACS versus PAQLQ Score Pre-Treatment and Post-Treatment.

	Well-controlled		Partially-controlled		
Level of control	Mean	SD	Mean	SD	*P*-value
PAQLQ pre-treatment	5.290	0.2889	4.753	0.3767	<.001
PAQLQ post-treatment	5.981	0.1697	5.680	0.2078	<.001

Table 5. Comparison of ACS versus PACQLQ Score Pre-treatment and Post-Treatment.

	Well-controlled		Partially-controlled		
Control of asthma	Mean	SD	Mean	SD	*P*-value
PACQLQ pre-treatment	4.491	0.0873	4.425	0.0727	.009
PACQLQ post treatment	5.479	0.1255	5.450	0.1267	.321

Table 6. Correlation between ACS (post treatment) and QOL (post treatment).

S. No	Domain	Correlation coefficient	*P*-value
1	PAQLQ-activity limitation	−0.631	.0001*
2	PAQLQ-symptom domain	−0.321	.0001*
3	PAQLQ-emotional function	−0.547	.0001*
4	PACQLQ-activity limitation	0.188	.063
5	PACQLQ-emotional function	−0.017	.865

*Statistically significant.

disease. In the present study, 64% of the study population were boys which in concordance with studies done by Nair et al and La Scala et al.[6,14] The incidence and prevalence of asthma is higher in boys up to the age of 14 years. During puberty, there is a paradoxical change in asthma with girls being more commonly affected than boys. The girls tend to have more severe asthma with less remission compared to boys, this is due to the decline in lung function influenced by estrogen and progesterone during menarche.[15] Many studies have observed that a higher prevalence of asthma in the younger age groups was consistent with the widely believed concept of "children outgrow their allergies".[16] This has been witnessed in the present study.

Based on the GINA guidelines, 59.6% of the participants had moderate persistent asthma, with 57% among 7 to 11 years. The findings were akin to studies done by La Scala et al, Singh et al and Gomes de Souza.[14,17,18] In the adolescent age group, 62% of children had moderate persistent asthma, similar to the findings of a Brazilian study and Qureshi et al.[19,20] Increased prevalence of moderate persistent asthma in the present study could be attributed to the environmental, predisposing factors, seasonal, and living conditions of the children. In this study, there was a high prevalence of allergic rhinitis (17%) when compared to other risk factors for asthma. Literature findings suggest allergic rhinitis accounts for 10 to 25% of the world population and our findings emphasize the conception of "united airways".[21] Positive family history (17%) and exposure to pets (8%) were found in the present study. Ratageri et al and other studies reported that exposure to pets and family predisposition play a significant role in the onset of asthma.[22,23] In this study, 89% of the study population belonged to the lower middle class and 11% belonged to the upper lower class. Similar findings were supported by Lal et al.[24] In this study, 95% of the participants were living in urban areas. Chakravarthy et al in his study observed that urban children in the age group of 6 to 12 years experienced more episodes of breathing difficulty and nocturnal cough than their rural counterpart.[25]

In this study, there is a significant improvement in all the 3 domains of the PAQLQ after treatment. But the improvement in the emotional domain was not found to be as high as it was found to be in the other domains. This could be because of shorter duration of follow up (4 weeks) as compared to 9 weeks in the study by Juniper et al.[8] However, similar findings as the present study was observed in study done by Nair et al.[7] Furthermore, the role of educator in the pediatric asthma clinic is likely to influence the emotional management of the disease. However, there are no studies to justify this finding. There is also a significant increase in caregivers QOL in both the domains (activity and emotional) following the treatment of the child, which in concordance with study done by Nair et al.[7]

In this study, when Asthma clinical severity scores was compared with mini PAQLQ and PACQLQ, children with well-controlled asthma had a better quality of life than partially-controlled asthmatic children; however there wasn't a significant change in the quality of life of the caregivers after treatment. The findings were similar to the findings of Farnik et al, and Guyatt et al.[26,27] Both children and caregiver perception are vital in planning and implementation of care policies. Children are being guided by their caregivers and a decrease in caregiver distress could benefit the child's family life and help in amalgamation within the society.[26]

Strengths

The present study is one of the few studies carried out in India among children with newly diagnosed asthma. This study has also identified the scope for counseling services which may be complemented to routine outpatient care for children with asthma.

Limitations

As this is a hospital-based study, the results cannot be applied to the general population. In our study, we had used a mini PAQLQ with a shorter duration of follow up post treatment. Hence there is a need to use the original PAQLQ with longer duration of follow up post treatment for the better assessment of quality of life in children with newly diagnosed asthma.

Conclusion

The present study has emphasized that QOL of newly diagnosed asthmatic children and their caregivers showed significant improvement with treatment using GINA guidelines. However, immense efforts are required to alleviate the emotional problems of these children. It may therefore be concluded that there is a need for a psychological support and counseling of these children with asthma as well as their caregivers at various stages of their treatment. Also, Post treatment, there was no significant change in the quality of life of the caregivers indicating that parent and child health-related quality of life should be taken as independent dimensions.

Authors' Note

Presentations at a meeting: none.

Author Contributions

Dr. B. Monika made a substantial contribution to the design of the work and analysis and interpretation of data. Dr. A. Preethi made a substantial contribution to the design of the work and analysis and interpretation of data. Dr. P. N. Vinoth drafted the article and revised it critically for important intellectual content and also approved the version to be published.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethical Approval

This study was approved by Institutional Ethics Research Committee of Sri Ramachandra Institute of Higher Education and Research (Deemed to be University) Ref: **CSP-MED18/JAN/41/01**

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