

# A Clinical Study on Quality of Life Instrument Used In Assessing Adolescents with Chronic Bronchial Asthma

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## ABSTRACT

**Aim of the Study:** The aim of the study was to study the quality of life (QOL) using an instrument “Pediatrics QOL questionnaire” in adolescents with bronchial asthma.

**Materials and Methods:** A total of 76 adolescents undergoing treatment for bronchial asthma were assessed of their QOL. A similar number of normal adolescents were used as control group. All the data were collected using “Pediatrics QOL questionnaire” from the children and their parents/guardians who had taken care of the child for at least 6 months using standard prescribed treatment by physicians.

**Results and Discussion:** A total of 152 children including 76 asthmatics and 76 normal children were included in the study. All the children were assessed using QOL instrument on four domains of QOL: Physical, emotional, social, and educational. The children with asthma had a more compromised QOL in the physical domain.

**Conclusions:** Children with chronic diseases have a relatively compromised QOL and focusing simply on control of primary illness may not address the full range of child’s emotional and behavioral difficulties. Multidisciplinary team management is essential in achieving an improved QOL and patient satisfaction.

**Key words:** Adolescents, Bronchial asthma, Instruments for quality of life, Quality of life

## INTRODUCTION

The term “quality of life” (QOL) is used to refer the individuals’ subjective satisfaction with important aspects of life, physical and mental well-being, social relationships, social and individual activities, individual satisfaction, and health maintenance.<sup>[1]</sup> One of the QOL-related components is the health-related QOL (HRQOL). It is based on the definition provided by the World Health Organization (WHO). The constitution of the WHO (1946) states that: “Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”<sup>[2]</sup> Recent studies showed the relationship between

the specific effects of the pediatric chronic disease in children and QOL. Children and adolescents with chronic disease will often have a lower QOL as seen in Duchenne Muscular Dystrophy,<sup>[3]</sup> asthma,<sup>[4]</sup> and heart disease.<sup>[5-7]</sup> Bronchial asthma is the most common respiratory crisis encountered in pediatric clinical practice. Children and adolescents with asthma are troubled not only by symptoms such as shortness of breath, cough and wheeze but also by the physical, social, educational, and emotional impairments that they experience as a result of having asthma.<sup>[8]</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. It is a public health problem not just for high-income countries; it occurs in all countries regardless of the level of development.<sup>[9]</sup> Pediatric asthma accounts for a large proportion of childhood hospitalizations, health-care visits, absenteeism from daycare/school and missed work days by parents.<sup>[10]</sup> Chronic Illnesses cause stigma, a loss of self-esteem and family strain. Various studies have shown that asthma caused adolescents and children to feel self-pity,

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**Month of Submission :** 12-2017  
**Month of Peer Review :** 01-2018  
**Month of Acceptance :** 01-2018  
**Month of Publishing :** 02-2018

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poor self-opinion, poor peer relations, and social isolation. It also leads to anxiety and strain in caregivers of asthma patients.<sup>[11]</sup> Thus, direct assessment of QOL is necessary to understand the impact of the disease on patient's well-being as well the effect of treatment undertaken. It cannot be assumed that similar relationships to QOL seen in adults with asthma will hold true for adolescents.<sup>[12]</sup> In asthma, there are several reasons to examine adolescents as a unique group distinct from young children and adults.<sup>[13]</sup> There are very few studies which have focused on adolescents. The present study is an attempt to understand the impact of bronchial asthma on the QOL of adolescents based on a clinical study in a tertiary teaching hospital of Kerala.

### Type of the Study

This was a prospective, cross-sectional comparative clinical study.

### Institute of Study

This study was conducted at KMCT Medical College Teaching Hospital.

### Period of Study

This study was from February 2014 to January 2017.

## MATERIALS AND METHODS

The study was conducted in a tertiary teaching hospital of Kerala among the adolescent children attending the pediatric outpatient department (OPD) with complaints of chronic bronchial asthma. An Ethical Committee Clearance was obtained before the commencement of the study. An Ethical Committee approved consent letter was used during the study. 76 adolescent children were clinically assessed using the answers to the QOL questionnaires filled up by the parents and/or guardians.

### Inclusion Criteria

1. Adolescent children suffering from chronic bronchial asthma for more than 6 months duration were included.
2. Adolescents who are under treatment for chronic bronchial asthma were included.
3. Parents and or guardians who are taking care of the adolescents were included in giving the answers to the QOL questionnaire.

### Exclusion Criteria

1. Coexisting other chronic or severe acute diseases.
2. Parents who are unable to understand and answer the pediatric QOL questionnaires.
3. Adolescents with developmental retardation.
4. Adolescents hospitalized for acute attacks of bronchial asthma in the last 1 month affecting adversely QOL index.

76 adolescent children who were attending the pediatric OPD for minor illnesses were included as a control group. The socioeconomic status was graded using the Modified Kuppaswamy scale, modified for the current cost inflation index. The population was composed of two groups: Group A – Adolescents aged 9–18 years of age, known bronchial asthmatics on treatment. Group B – Normal adolescents aged 8–18 years having no chronic disease served as controls.

### Instrument Used

Pediatric QOL inventory, version 4.0 was used for the study.<sup>[6]</sup> It is based on a modular approach to measure HRQOL in children and teenagers over a wide age range. The instrument was translated into vernacular by a linguistic expert. The instrument had two parts: (1) Parent form and (2) child form: Each consisting of 23 questions. It was a generic instrument that included a broad spectrum of child and family-focused health areas divided into four domains. These were physical, emotional, social, and educational domains, each having further subdivisions. The standard recall period was past 1 month. The responses were measured on a 5-point rating score from never to almost always. The items of the four scales were grouped together on the actual questionnaire for ease of creating scale scores. To create scale scores, the mean was computed as the sum of the items over the number of the items answered. If more than 50% of the items in the scale were missing, the scale score was not computed. The total score was computed as the sum of all the items over the number of items answered on all the scales. All the data were analyzed using standard statistical methods.

## OBSERVATIONS AND RESULTS

Among the 76 adolescent children in Group A, there were 49 (64.47%) males and 27 (35.52%) were females with a male to female ratio of 1.81:1. In Group B the males were 50 (68.42%) and females were 26 (31.57%) with a male to female ratio of 1.92. In Group A children aged 8–12 were 43 (56.57%) and aged 13 to 18 were 33 (43.42%). In Group B children aged 8 to 12 were 45 (9.21%) and aged 13 to 18 were 31 (40.78%). In Group A the mean age was  $9.18 \pm 2.6$  and in Group B the mean age was  $9.34 \pm 2.3$ . In Group A the children belonging to urban residential areas 53 (69.73%) and rural areas were 23 (30.26%). In Group B the children belonging to urban residential areas 51 (66.10%) and rural areas were 25 (32.89%). In Group A children belonging to upper socioeconomic class were 21 (27.63%), middle group were 27 (35.2%), and lower group were 28 (36.84%). In Group B children belonging to upper socioeconomic class were 25 (32.89%), middle group were 26 (34.21%), and lower group were 25 (32.89%). The demographic data of bronchial asthma

and control group were matching and significant statistically with  $P < 0.05$  ( $P$  taken as significant at  $<0.05$ ) in variables related to gender incidence in females, rural incidence and socioeconomic groups [Table 1].

The mean parent and child scores for bronchial asthma and normal children were calculated and tabulated in Table 2. Asthmatic children experienced a poor QOL in all four domains with maximum affect on physical and emotional domains. Parents of asthmatic children had also reported significantly lower scores in all domains especially physical, emotional, and educational domain as well as parent total score. The scores were relatively lower in children aged 13–18 years when compared to 8–12 years age group. QOL of children as reported by parents was significantly impaired with higher daytime or nighttime frequency especially in the physical domain. Each domain had a significant contribution to total parent and child score [Table 3]. In bronchial asthma, physical domain had greatest contribution to total score in the parent as well as child scores. There was no significant correlation between age at onset, duration of illness or family history with QOL in any domain except for the negative impact of family history on parent score in social and educational domains in bronchial asthma children. Although the mode of treatment, i.e., inhaled bronchodilator or steroids or oral medication had no significant difference in asthma children and the control group.

Each domain had a significant contribution to total parent and child score [Table 3]. In asthma, physical domain had greatest contribution to total score in parent as well as child scores when compared to the control group.

## DISCUSSION

HRQOL was introduced to modern medicine to assess and evaluate the QOL in patients following treatment to various diseases. Spirits of life and therapy are not separate from physical health. A QOL perspective can identify sensitive child and adolescent issues that may be affected by illness or disability of treatment.<sup>[14,15]</sup> Various studies have confirmed that chronic morbidities are high-risk factors for poor psychosocial outcomes; low self-esteem, behavioral problems, and academic difficulties.<sup>[16,17]</sup> Among the many indices developed for measurements of QOL are all in adults; those for children are still in developing stage. As the present study is a small, no new instrument of measurement of QOL was introduced in this paper but an instrument bused by Marino *et al.*<sup>[6]</sup> was used. In the present study, the QOL in children with bronchial asthma was studied and compared with a normal control group of adolescents. The two groups were compared on

four dimensions of QOL: Physical, emotional, social, and educational. It was observed that in this study asthmatic children had significantly lower scores in all the domains as well as total child score. Parents of asthmatics also reported a poor QOL in all the domains, especially physical, emotional, and educational domains. Varni *et al.*<sup>[18]</sup> in their study showed low scores in the physical, emotional, and educational domains, while having relatively better scores in social domain in adolescents with asthma. When compared to normal children also they found the significantly lower score in all domains. Fuhlbrigge *et al.*<sup>[19]</sup> observed that bronchial asthma has potential interference with society in terms of QOL. Okelo *et al.*<sup>[12]</sup> showed in their study more of emotional problems faced by adolescent asthmatics than other variables. Asthmatic children had a poor QOL in comparison to normal children in all the domains, with physical, emotional, and

**Table 1: The demographic data (Group A and B; n=76)**

Variables	Age groups	B. asthma (%)	Controls (%)	P
Age (years)	8–12	43	45	0.321
	13–18	33	31	0.368
	Mean±SD	9.18±2.6	9.34±2.3	
Gender	Male	49 (64.47)	50 (68.42)	0.641
	Female	29 (35.52)	26 (31.57)	0.029
Residence	Urban	53 (69.73)	51 (66.10)	0.186
	Rural	23 (39.73)	25 (32.89)	0.047
Socioeconomic groups	Upper class	21 (27.63)	25 (32.89)	0.024
	Middle class	27 (35.2)	26 (34.21)	0.041
	Lower class	28 (36.84)	25 (32.89)	0.031

SD: Standard deviation, B. asthma: Bronchial asthma

**Table 2: The mean parent and child score for bronchial asthma and normal children**

Variable	Asthma group		Normal group	
	Parent domain	Child domain	Parent domain	Child domain
Physical	64.2–15.2	68.0–11.3	83.2–11.4	89.1–9.4
Emotional	63.1–15.7	70.2–13.1	81.6–12.5	87.3–10.9
Social	79.2–19.2	84.3–13.6	88.2–12.4	90.8–10.4
Education	66.5–17.1	72.0–12.8	79.4–13.5	81.4–11.8
Total score	68.6–13.7	71.4–10.5	85.1–9.2	86.5–9.4

**Table 3: The contribution of parent and child domain scores to total score**

Quality of life domain	Control group		Asthma group	
	Parent domain	Child domain	Parent domain	Child domain
Physical	0.453	0.416	0.448	0.466
Emotional	0.282	0.319	0.276	0.290
Social	0.253	0.233	0.280	0.293
Education	0.341	0.337	0.250	0.285

educational domain affected more than social. Rydstrom *et al.*<sup>[20]</sup> identified that asthmatic children have significant impairment in physical and emotional domains. Austin *et al.*<sup>[21]</sup> observed that adolescents with asthma had a more compromised QOL in the physical domain. When compared to gender predilection to affection of QOL in diseases, it was reported that females were more disturbed than males in adults. But studies to compare the gender predilection in children are not readily available.<sup>[22]</sup> The present study was found to be in concurrence with the study by Felder-Puig *et al.*<sup>[22]</sup> In a similar study by Zandieh *et al.*<sup>[23]</sup> they found HRQOL in boys were more disturbed than girls and also in caregivers of male asthmatic patients than caregivers of female asthmatic patients. Socioeconomic class had significantly affected parent physical score in asthma children. It could be due to lack of resources for regular treatment, financial stress or lack of awareness to utilize health-care services. The increased frequency of symptoms (daytime or nighttime) had significantly lowered QOL especially in parent physical domain, child physical, emotional, and education domain score as well as child total score. The daytime frequency had an inverse correlation with child physical domain and parent emotional domain score. However, duration of current episode had no significant correlation with child outcome of QOL. Mode of treatment (inhaled steroid, bronchodilator, or oral medication) had no significant impact on parent and child score in asthmatic group in any domain. This can be due to double impact of severity of disease requiring multidrug therapy and the side effects of the drugs. It remains a challenge to the pediatrician treating children with chronic disorders to improve the QOL and not his disorder. It remains difficult to assess the QOL of the using the pediatric instruments available. Even extensive interviews and physical examination and additional clinical tests may not be sufficient to assess the impact a chronic disorder results in affecting the child's well-being. A multi-disciplinary approach only can assist in the holistic care and assessment of the child and its family. A change of attitude from pediatricians is always required, toward measurement of functional status and subjective perception of illness, as well as to evaluate the HRQOL.

## CONCLUSIONS

To optimize the health care in the management of childhood chronic disorders, instruments of quality of health should be used by the pediatricians to evaluate the impact of chronic disorder on all aspects of a child's functioning in daily life. The assessment should also assess the limitations which are relevant to the child as these interfere in his daily life. Regular counseling sessions and encouragement should be undertaken during their follow-up visits. Recognizing the high risks of chronic diseases

and an approach of multidisciplinary team management of children will result in significant improvement in the quality of life and ultimately patient satisfaction.

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**How to cite this article:** Bijumon AV, Ahammed KN. A Clinical Study on Quality of Life Instrument Used In Assessing Adolescents with Chronic Bronchial Asthma. *Int J Sci Stud* 2018;5(11):86-90.

**Source of Support:** Nil, **Conflict of Interest:** None declared.