

Original Article**Quality of Life of Children with Asthma and Their Caregivers: A Study at a Single Tertiary Care Centre in Northern Sri Lanka**¹Umasankar N, ¹Sathees T, ¹Sathiadas MG¹Faculty of Medicine, University of Jaffna**Abstract**

Asthma is the most prevalent chronic disease among children, representing a leading cause of paediatric morbidity and healthcare utilisation. It profoundly impacts various aspects of children's quality of life and the quality of life of their caregivers. This study aims to assess the quality of life experienced by children with asthma and their caregivers and to determine the association between asthma control and quality of life.

The children aged 6 to 16 years with asthma under the care of paediatric clinics at Teaching Hospital Jaffna and their caregivers were recruited. Data were collected through an interviewer-administered questionnaire. Pearson correlation coefficient was used to assess the correlations between asthma score and quality of life, and a linear regression was done to identify whether the asthma score can predict the child's quality of life.

Ninety-nine children and their caregivers participated in the study. Asthma was more prevalent among boys (54.5%). The mean age of children was 115.5 ± 31.6 months. The mean score on the childhood asthma control test was 19 ± 4.05 . The child-reported mean quality of life score was 74.47 ± 10.05 . Overall quality of life score was significantly diminished in children with uncontrolled asthma ($p=0.003$). There was a weak, positive correlation between the child's total quality of life score and the asthma score. ($r=0.25$, $p=0.006$)

In conclusion, this study highlights that asthma exerts a significant impact on children's quality of life, particularly when the condition remains uncontrolled. The weak, positive correlation between the child's asthma control score and total QoL score indicates that while asthma severity affects QoL, it is not the sole determinant

Keywords

Asthma, Quality of life, Children, PedsQL, Caregivers

Introduction

Asthma is a chronic, heterogeneous, complex inflammatory disease of the respiratory system, characterized by recurrent symptoms such as cough, wheezing, chest tightness, and difficulty in breathing. It is the most common chronic disease of childhood and adolescence.

Asthma affected an estimated 262 million people and caused 455 000 deaths in 2019 [1] Globally, according to the Phase III International Study of Asthma and Allergies in Childhood, the prevalence of current asthma in the 13-14-year age group and the 6-7-year age group was 14.1% and 11.7%, respectively. [2] In Sri Lankan children, the prevalence of current wheeze in the age group of 13-14 years is 17.5%, and in the 6-7-year age group, it is 18.1%. [3] A recent report by the World Health Organization (WHO) indicates that one in 10 children has asthma symptoms [4]

Quality of life (QOL), defined by the World Health Organization, is "an individual's perception of their position in life in the context of the culture and value systems in which they live and to their goals, expectations, standards, and concerns." [5] Measuring the quality of life of children with chronic diseases such as asthma is essential because it provides a comprehensive view of a person's overall well-being rather than just their disease status. The importance of understanding the impact of disease and treatment on the Quality of Life of children is now recognized.

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Asthma significantly affects many aspects of children's quality of life. Recurrent symptoms like coughing, wheezing, and breathlessness limit physical activity, disrupt sleep, and impair academic performance, all of which impact overall well-being. Additionally, the psychosocial effects of living with a chronic condition—including anxiety, social isolation, and stigma—add further challenges for children with asthma.

Asthma can affect children's and caregivers' Quality of Life (QOL).[6] Care for a child with asthma is a difficult and complex task. This involves monitoring of symptoms, medication supplementation, and visits to healthcare facilities for follow-up and in emergencies. Due to the chronicity of asthma, caregivers could suffer from long-term stressors that affect their decision-making, work responsibilities and productivity[7] Moreover, caregivers frequently suffer from poor quality sleep because they need to be vigilant to observe any child's symptoms, especially at midnight. They easily get stressed and wake many times to check on the child and provide care if needed[8]

Health-related quality of life (HRQoL) is a complex, multidimensional concept that includes social, emotional, and physical functioning or well-being and is related to the patient's health state [9]. This increased recognition has increased the use of child self-report and proxy-report instruments in paediatric clinical practice.

There are several well-documented and validated generic HRQoL questionnaires available for use with children and proxies, such as the Paediatric Quality of Life Inventory (PedsQL) [10], the Child Health Questionnaire (CHQ) [11], or the Quality-of-Life Scale for Children (QOL-C) [12].

The asthma caregivers' quality of life is commonly assessed using the Paediatric asthma caregiver's quality of life questionnaire (PACQLQ), which is a validated questionnaire available in multiple languages.[13]

This research aimed to explore the quality of life of children with asthma and their caregivers and to determine the correlation between asthma control and quality of life.

Methodology

Study design and setting

An institution-based cross-sectional descriptive study was conducted at the pediatric clinics of Teaching Hospital Jaffna. This tertiary care hospital, located in the Northern Province of Sri Lanka, serves a population of 1.3 million across an area of 8,890.07 square kilometres, approximately 13.5% of Sri Lanka's total land area. The hospital operates five pediatric clinics each week, with an attendance of 50 to 60 children per clinic.

Study population

Children and their caregivers were recruited when the children fulfilled the following criteria: Diagnosed with asthma by a consultant paediatrician, aged between 6-16 years, on long-term inhaled corticosteroids for at least 3 months, and attending the paediatric clinics at Teaching Hospital Jaffna. Children who had other comorbidities like congenital heart disease, chronic kidney diseases, liver diseases, or bronchiectasis were excluded from the study.

Sample size

The sample size was calculated using the formula; $n = Z^2 \sigma^2/d^2$ (σ pooled standard deviation 11.05 [14] The acceptable margin of error is considered as 2.5 thus, the total sample required is 75. Considering the 15% non-response, the needed sample is 99.

Study instrument

The study instrument was an interviewer-administered questionnaire that included details regarding baseline characteristics of the study participants such as child age, sex residence and other sociodemographic factors, family history of asthma, asthma control, and quality of life of the child and the caregiver.

Asthma control

Asthma control was evaluated using the Childhood Asthma Control Test (C-ACT), a validated tool for assessing asthma control [15]. The test consists of two sections: questions 1-4 are answered by the child, while questions 5-7 are completed by the caregiver. The

C-ACT score ranges from 0 to 27, with scores above 20 indicating well-controlled asthma, scores between 12 and 19 indicating partially controlled asthma, and scores below 12 indicating poorly controlled asthma.

Quality of Life Assessment

The child's quality of life was assessed using the Pediatric Quality of Life Questionnaire (PedsQL Tamil version for India 4.0). This modular instrument measures health-related quality of life in children and adolescents aged 2 to 18 years. The PedsQL 4.0 Generic Core Scales include multidimensional child self-report and parent proxy-report scales, with 23 items relevant to healthy school and community populations, as well as pediatric populations with acute and chronic health conditions. This is a validated tool to assess the quality of life in children [16] was chosen considering both language and cultural adaptability.

The quality of life of the child was assessed separately by the child and the caregivers using both child-reported and caregiver-reported versions. A 5-point Likert response scale (0–4) was used for scoring responses from study participants. All items were reverse-scored and linearly transformed to a 0–100 scale (0=100, 1=75, 2=50, 3=25, 4=0) for better interpretation. The maximum possible score is 100 and the minimum possible score is zero. Higher scores indicate a better quality of life.

The quality of life of the caregivers was assessed using the Paediatric Asthma Caregivers Quality of Life Questionnaire (PACQLQ) Tamil version for India. This is a validated tool to assess the quality of life of the caregivers [13] it has 13 items. (activity limitation four items and emotional function nine items) A 7-point Likert response scale with 1 indicating severe impairment and 7 indicating no impairment was used to score the responses from study participants. Higher scores indicate a better quality of life.

Data collection

The investigators and data collectors collected data. Data collectors are pre-intern medical officers attached to the paediatric department, and the investigators

trained them before commencing the data collection. Data was collected from June 2022 to April 2023 by consecutive sampling methods from all the eligible study populations after obtaining informed written consent. The repetition was prevented by placing the sticker on the clinic book.

Data analysis

The data obtained from the study was analysed using IBM SPSS statistics Version 22. Univariate analysis of the socio-demographic characteristics (age, sex), family history of asthma, and asthma control was carried out and basic summary statistics were produced for each variable.

Quantitative variables such as scores for asthma control and quality of life were described using means and standard deviation. The mean quality of life scores of each domain as well as the overall quality of life scores, were calculated and presented as mean scores and standard deviation. Analysis of variance (ANOVA) was used to identify the relationship between the different age groups and sex on asthma control.

An Independent t-test was used to determine the association between quality of life and sex, family history of asthma, and asthma control. Pearson's correlation coefficient was used to assess the correlations between child-reported and caregiver-reported quality of life, asthma score, and quality of life. A linear regression was done to identify whether the asthma score can predict the quality of life of the child.

The Ethical Clearance was obtained from the Ethical Review Committee Faculty of Medicine University of Jaffna, and the administrative approval was obtained from the Director of Teaching Hospital Jaffna. Permission was obtained to use the tools C-ACT, PedsQL Tamil version for India, and PACQLQ Tamil version for India.

Results:

A total of 99 children (6-16 years old) and their caregivers, fulfilled the eligibility criteria and completed the study. Table 1 demonstrates the socio-demographic characteristics of the study participants.

Table 1 : Socio-demographic characteristics of the study participants

Sociodemographic characteristics	Number	Percentage
Age group of the child		
72- 96 months	36	36.4
97 – 120 months	23	23.2
121- 168 months	34	34.3
>168months	6	6.1
Sex of the child		
Males	54	54.5
Females	45	45.5
Main respondent		
Mother	82	82.8
Father	9	9.1
Siblings	3	3
Other relatives	4	4
Guardian	1	1
Family history of asthma		
Presence of family history of asthma	73	73.7
Absence of family history of asthma	26	26.3

The mean age of asthmatic children was 115.5 (SD 31.6) months, with a male-to-female ratio of 1.2 : 1. The main respondents are the parents (92%). About three-fourths (73.7%) of the asthmatic children had a family history of asthma.

The mean score for the childhood asthma control test was 19 with a standard deviation of 4.05. The minimum score recorded was 4 and the maximum was 27. Table 2 demonstrates the asthma control according to the childhood asthma control test.

Table 2: Asthma control depends on Childhood asthma control test

Asthma control	Males	Females	Total
Well controlled asthma (score >20)	26	25	51 (51.5%)
Partially controlled asthma (score between 19-12)	23	19	42 (42.4%)
Poorly controlled asthma (score <12)	5	1	6 (6.1%)

Asthma scores were higher for female children (M=19.53 SD3.23) when compared with male children (M18.56 SD4.59). There was a significant effect of sex on asthma score (t (97) F=4.509, p=0.036.) There was

no significant effect of family history (t (97) F=0.499 p=0.482) despite children with a positive family history (M=19.36, SD=4.13) attaining higher scores than those without a family history of asthma (M= 18 SD=3.69). A one-way ANOVA revealed that there was no statistically significant difference in the asthma scores and age groups (F (3,95) =0.219 p=0.883).

The mean child-reported total quality of life score was 74.47 ± 10.05 and the caregiver-reported total quality of life score was 70.87± 12.56. The child-reported and caregiver-reported total quality of life scores were strongly positively correlated (r = 724, p<0.001). There was a significant average difference between the child-reported and caregiver-reported total quality of life scores (t (196)=2.48, p=0.014). Figure 1 demonstrates different domains of the children’s quality of life by child-reported and caregiver-reported scores

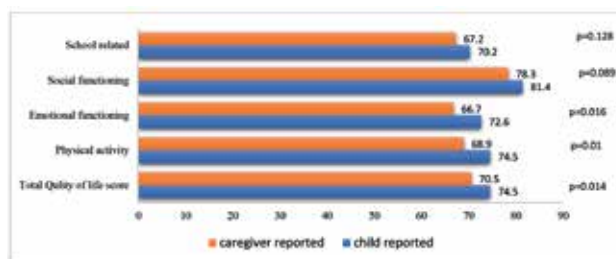


Figure 1: Child-reported and caregiver reported Quality of life scores for total and different domains

Table 3: Factors affecting the quality of life of asthmatic children

Variable	Quality of life domains				
	Physical function	Emo-tional function	Social function	School activity	Quality of life total score
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Controlled asthma	76.76 (13.06)	79.31 (13.86)	81.25 (12.73)	72.84 (11.32)	77.38 (9.83)
Uncontrolled asthma	72.07 (14.90)	65.52 (16.28)	81.46 (12.46)	67.29 (11.48)	71.37 (9.43)
Student t-test P value	0.09	0.000	0.936	0.017	0.003
Male	75.04 (14.09)	75.74 (16.06)	81 (12.72)	70.65 (12.48)	75.42 (9.9)
Female	73.82 (14.26)	68.89 (16.48)	81.78 (12.44)	69.56 (16.77)	73.33 (10.22)
Student t- test P value	0.67	0.039	0.76	0.65	0.30

Asthma control plays a significant role in the quality of life of children. Overall quality of life scores were low in children with uncontrolled asthma when compared with controlled asthma and the difference is statistically significant ($p= 0.003$) The scores were higher for children with controlled asthma on emotional components and school components when compared to uncontrolled asthma. Gender did not affect the total quality of life score but the emotional function is influenced by gender. The girls scored less for the emotional component when compared with boys and the difference is statistically significant ($p= 0.039$). (Table 3)

Table 4 demonstrates the quality of life of the caregivers. Physical activity component scores were slightly lower when compared with psychosocial scores. Pearson correlation analysis reveals a weak negative correlation between the quality of life of the caregivers and the duration of asthma ($r -0.22, p=0.033$) and income ($r -0.24, p=0.021$). Caregivers whose child with long duration of asthma and high income has a better quality of life.

Table 4: Quality of life of the caregivers with different components

Quality of life Domain	Minimum score	Maximum score	Mean score	Standard deviation
Physical activity	1.50	7.0	5.28	1.45
Psychosocial	2.22	7.0	5.58	1.07
Total quality of life of the caregivers	2.0	7.0	5.50	1.14

A statistical analysis was conducted to examine the relationship between the quality-of-life score of the child and the asthma score among 99 participants. The mean score for the total quality of the child was 74.47 (SD = 10.05), while the mean for asthma score was 19.00 (SD = 4.05). A Pearson correlation analysis revealed a weak, positive correlation between the child's total quality of life score and the asthma score, $r=0.25, p=0.006$, suggesting a slight association between higher asthma scores and higher child total scores. A simple linear regression was conducted with the child's total quality of life score as the dependent variable and the asthma

score as the predictor. The model was statistically significant, $F(1,97)=6.67, p=.011$, explaining 6.4% of the variance in the total quality of life score of the child ($R^2=.06$). The unstandardized coefficient for asthma score was $B=0.63, SE=0.24, p=.011$, indicating that each one-point increase in asthma score is associated with a 0.63-point increase in the total quality of life score of the child.

In summary, although the asthma score was a statistically significant predictor of the child's total quality of life score, it explained only a small portion of the variance, suggesting additional factors likely contributed to the child's total quality of life score.

Discussion:

This study contributes to a growing body of literature on asthma in children, focusing on the associations between asthma control, socio-demographic characteristics, and quality of life (QoL) in children with asthma and their caregivers.

The results show that asthma control status and gender significantly influence children's QoL, although the asthma score is a relatively modest predictor, accounting for only 6.4% of the variance in QoL. These findings emphasise that while asthma severity impacts children's QoL, other factors may have considerable effects, warranting a holistic approach to managing children with asthma.

The findings indicate that asthma control plays a crucial role in the QoL of children with asthma. Children with well-controlled asthma report better QoL scores across most domains, especially in emotional and school functioning. These results align with prior research, consistently showing that improved asthma management is associated with enhanced QoL and reduced functional impairment in children [17]. Emotional and school functioning are likely to be compromised in children with poor asthma control due to limitations in physical activity, increased absenteeism, and psychosocial stress. Thus, achieving optimal asthma control through adherence to treatment regimens and lifestyle modifications remains essential to improving the QoL in children with asthma.

Our study found that gender differences significantly impacted the emotional domain of QoL, with females scoring lower than males. This finding is consistent with other studies that have documented that female children have a worse perception of asthma, feel it as more symptomatic, and suffer a greater impact on their QoL, even though having similar baseline severity and obtain similar levels of control. [18] The reasons for these differences may be multifaceted, including potential variations in coping mechanisms, social support systems, and societal expectations for emotional expression. Emotional support and tailored interventions for girls with asthma may, therefore, be essential to mitigate these disparities.

Notably, caregiver QoL in our study exhibited a weak but significant negative correlation with income and asthma duration, suggesting that caregivers with higher income and children with a longer duration of asthma might have adapted better or have greater resources to manage the condition effectively. This insight aligns with recent evidence indicating that Children with chronic diseases from lower socioeconomic backgrounds experience reduced QoL compared with their wealthier counterparts. [19]

The differences observed between child-reported and caregiver-reported QoL scores are notable, with caregivers typically rating the child's QoL slightly lower. This discrepancy is in contrast with a study done in America in children with sleep disorder where the child reported scores are low. [20] In our study, the caregivers may perceive the child's QoL more conservatively, potentially due to anxiety about the disease condition's impact or its long-term management implications. This difference highlights the importance of integrating child and caregiver perspectives in clinical assessments to comprehensively understand the child's QoL and its influencing factors. Future studies could examine the mechanisms underlying these differences, particularly the role of caregiver anxiety and its impact on reporting.

The weak, positive correlation between the child's asthma control score and total QoL score indicates

that while asthma severity affects QoL, it is not the sole determinant. The asthma score explained only a small proportion (6.4%) of the variance in QoL scores, suggesting that other factors likely play more significant roles in determining QoL outcomes. For instance, psychosocial factors, environmental influences, and mental health status might contribute to the broader QoL landscape in asthmatic children [21]. This limited predictive value emphasises the need for a comprehensive approach that incorporates both clinical management of asthma symptoms and support for psychological and social well-being.

The findings emphasise the need for healthcare providers to consider asthma control alongside socio-demographic and psychosocial factors when addressing QoL in children with asthma. Interventions should focus on personalised asthma education, psychosocial support, and school-based interventions to address the emotional and academic challenges faced by children with poorly controlled asthma. Additionally, caregiver support programs may prove beneficial, particularly for those with lower income or limited resources, as these individuals may experience added stress related to the child's condition.

Further research is warranted to explore the broader determinants of QoL in children with asthma, particularly longitudinal studies that investigate the interplay between clinical, socio-environmental, and psychological factors. Such studies could help to identify modifiable risk factors and inform the development of multi-faceted interventions aimed at enhancing QoL among asthmatic children and their families.

In conclusion, this study highlights the significant impact of asthma control on QoL in children with asthma while also revealing important differences related to gender and caregiver perspectives. These insights point to a holistic model of care that integrates clinical management with family-centred and psychosocial support to address the complex needs of children with asthma and their caregivers.

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