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Ahmed PA
Ulonnam CC
Mohammed-Nafi'u R

Assessment of quality of life among children with bronchial asthma and their caregivers at the National Hospital Abuja, Nigeria

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Ahmed PA (✉)
Ulonnam CC, Mohammed-Nafi'u R
Department of Paediatrics,
National Hospital Abuja, Nigeria.
Email: ahmedpatience@yahoo.com

Abstract*: Background:* The global disease burden associated with bronchial asthma has continued to increase particularly among children. Asthma-related quality of life is a health related assessment of disease impact on patient and care givers.
Aim: To determine the perceived quality of life (QOL) among children with bronchial asthma and their caregivers as well as the related factors.
Subjects and methods: This was a prospective study of children diagnosed with bronchial asthma and the caregivers attending the Respiratory Clinic of the National hospital Abuja, Nigeria. Using the Paediatric Asthma Quality of Life Questionnaire (PAQLQ) and the Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) information from the various domains was obtained. The PAQLQ 23 questions assessed the child physical domain (5), emotional (8) and social behaviors (10), and the PACQLQ 13 questions assessed the caregivers' activity limitation domain (4) and emotional function (9).Mean QOL scores from each domain and overall scores were calculated based on a seven-point scale. A QOL score of 7 was reported as best with no impairment; score one as least and severest impairment; score 4 as mid point in the range from 2-6 of moderate degree impairment. Other information on the demographic biodata and clinical information from child and caregivers was also obtained.
Results: Forty-three children and 43 caregivers each were enrolled, from August to December 2014. Patients were aged 7-15years; 25(58.1%) males, 18(41.9%) females; while caregiver's were males 23(53.5%), females 20(46.5%), age range 21-48years. 25(58.1%) caregivers were of middle- lower socio-economic status; 20(46.5%) children had persistent asthma, 22(51.2%) well controlled, 21(48.8%) partly controlled. Medication use were; none, 17 (39.5%); long acting beta2 agonist/ inhaled corticosteroids (LABA/ ICS), 13(30.2%); antihistamine, 8 (18.6%); leukotriene receptor antagonist (LTRA),5(11.6%). Overall mean QOL was 4.89(4.54-5.24;95% CI) for the children and 4.6 (3.91- 4.82; 95% CI) for caregivers; correlation (R) 0.438 p=0.003.Multiple regression showed that females gender had significant impairment in mean QOL scores in the activity domain (p= 0.022), and those with poor control and severe asthma also had significant impairment in mean QOL ($p < 0.05$).
Conclusion: Asthma impacted QOL of both the asthmatic children and caregivers with female gender in the activity domain, severe and not well controlled disease as independent predictors of quality of life.

Key words: Asthma, Paediatrics, Caregivers, QOL, Assessment.

Introduction

Asthma is a chronic inflammatory disorder of the airways associated with airway hyper responsiveness that leads to recurrent episodes of wheezing, breathlessness, chest tightness, and coughing. However, in children 5 years and younger, the clinical symptoms of asthma are variable and non-specific[1]. Oguonu et al[2]

reported that bronchial asthma accounted for 27.7percent of the 8974 children admitted with respiratory diseases at the paediatric emergency unit of University of Nigeria teaching hospital (UNTH) Enugu.
Oluwole et al [3] in a report to validated the ISAAC questionnaire on 1736 Nigerian school children, aged 13-14 year, had prevalence rates of asthma to be 7.5percent (95% CI 6.0 - 9.2%) and 8.0percent (95% CI 6.0-10.4%) in the rural and urban communities respectively. While Falade et al[4] had earlier reported a cumulative prevalence of symptoms of wheezing, allergic rhinoconjunctivitis, and atopic eczema among 6- to 7-year-old Nigerians to be 7.2, 11.3 and 10.1percent, respectively. Ahmed et al, reported a prevalence rate of 6.9percent over a two year period among childhood asthma at the National hospital Abuja- Nigeria.[5]

Asthma-related quality of life refers to the perceived impact that asthma has on the patient's quality of life (QOL). Asthma symptoms are commonly used to assess the impact on patient's level of disease severity and control, which could be done using retrospective questionnaires alone or composite scores of asthma control. Quality of life measures convey an overall sense of well-being of the person concern. Having uncontrolled asthma can negatively impact quality of life, affecting the sufferer and other family members; with unscheduled trips to the doctor or emergency department, modifications to the home environment to reduce triggers, and increased caregiver responsibilities. Asthma is the most common chronic disease of childhood and in the latter part of the 20th century, reached epidemic proportions.[6] Its prevalence increased from 7.3 percent in 2001 to 8.4 percent in 2010, when 25.7 million persons had asthma for the period 2008–2010 in the United States. [7] Significant disease burden from asthma include clinical, economic and humanistic among it's sufferers and their caregivers.[8] The clinical burden is associated with the high rates of healthcare resource utilization among asthma patients during hospitalizations, emergency department (ED), physician visits, and prescription medication use. The economic burden, with financial impact nearly 56 billion dollars per year, representing lost wages, medical costs, missed work and school, and early death resulting from asthma.[9] The reported direct costs ranges from an average annual cost of $366 to $647 per patient and a total annual population-level cost ranging from ~ $46 million in British Columbia to ~ $141 million in Ontario[8]. Indirect costs are time loss from work, productivity loss, and functional impairment. The humanistic burden of asthma in studies showed a high (31 -50percent) prevalence of psychological distress and diminished quality of life (QOL) among asthma patients and relatives compared to subjects without asthma[8]. A disease-specific health-related quality of life instrument was developed by E. Juniper and colleagues for children and that of the parents/ caregivers using the Paediatric Asthma Quality of Life Questionnaire (PAQLQ) and Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQOL) 2010, respectively[10]. Some studies have reported on QOL of the paediatric asthmatic children in our environment. However, this report is to highlight on the QOL as perceived by both the paediatric patient and their primary care givers.

Aim: To assess the perceived QOL of the paediatric patient and their caregivers. To determine related factors such as socioeconomic status, medication use, asthma severity and disease control level on QOL using the PACQL and PACQLQ 2010.

Methodology

Children aged 7–16 years with established physician-diagnosed asthma, were enrolled. The paediatric patient and their primary caregivers were enrolled from the paediatrics respiratory clinic of the National Hospital Abuja, a tertiary health centre in a developing centre after due explanation and consent and assent was obtained. Patients were referred to this clinic from the emergency paediatric unit of the paediatric department, general paediatric outpatient unit of the family medicine department of the hospital and directly from other private and government hospitals within the federal capital city of Abuja- Nigeria. Asthma diagnosis was based on a combination of clinical features obtained from the history, examination finding, laboratory investigation and treatment outcome.[1] These features included history of recurrent breathlessness, recurrent cough especially at night and early mornings in younger children, wheezes, and chest tightness in older children. Others additional features were a positive family history of asthma, presence of atopy disorders like rhinitis, conjunctivitis and skin eczema in child or any one of parent or close family relatives. Examination findings were presence of fast breathing/respiratory distress, wheezes, and chest rhonchi; with or without presence of skin or eye allergies and chest deformities. Older children over 7years with peak expiratory flow rate (PEFR) or spirometry increase in PEF after 4 weeks or forced expiratory volume in one second (FEV_1)on controller medication of >12% predicted values. Drug medications given included long acting beta 2 agonist/ inhaled corticosteroids (LABA/ ICS) combination, leukotriene receptor antagonist (LTRA); nebulized salbutamol or meter dose inhaler with oral steroids for acute exaercabations. Information of children age and sex, medication use, admissions and level of severity and control were retrieved from the case folders.

The sample size was calculated for a finite population; $n = n^0/ 1+ n^0/N$; [11] Where $n^0 = z^2 p (1-p)/ d^2$; prevalence (p)at5.3,[12] z set at 1.96 at 95% confidence interval; tolerable error (d) at 0.05; N = estimated population of children with the asthma at the NHA in 2013of 62; hence $n^0 = (1.96)^2 * 0.053 * 0.947/ (0.05)^2$; = 77.13.n = 77.13/ 1+ 77.13/62 =34.4 children, attrition rate at 10%, 39 children were required. The Paediatrics Asthma Quality of Life Questionnaire 2010 (PAQLQ 2010), was applied to the child in English or interpreted in the native language as much as possible through an interpreter, while the primary caregivers completed the self-administered

Paediatrics Asthma Care Quality of Life Questionnaire (PACQLQ 2010). Children enrolled were from 7 years old to 15years. The caregiver were assisted to have a clear interpretation when they asked help by the principal investigator or and any member of the research team who had all been trained on the study protocol. The caregiver was a parent or one who lived with the child at least 75% of the time, who had accompanied the child to the clinic visit and was able to communicate directly with the interviewer. This was a one- time assessment for both child and caregiver. The PAQLQ had 23 questions that assessed the child in the domains of physical activity, emotional function and social behaviors. The physical activity limitation domain had five questions, emotional functions with eight and 10 questions in the social behavior. The child was asked to recall their experiences during the previous week and responded to each question on a seven -point scale. The mean scores in domains was calculated as the mean QOL scores for each domain, and the mean overall mean also calculated from all the domains. The PACQLQ for the caregiver had 13 questions in two domains; activity limitation with four questions and emotional function with nine questions. The mean overall quality of life scores and mean values in all the domains per child and caregivers were calculated separately. A QOL score of seven was the best score with no impairment; and score four was in the middle range; indicating moderate degree of impairment, scores between 2- 6 representing a range of impairment, and score one was least and severest impairment.Social class was assessed using Olusanya et al[13] score based on maternal educational level and father's profession; and classified as high socioeconomic classes; classess1 and 2; lower social classes 4 and 5; 3 as middle.

Asthma severity was defined based on the Global Initiative for Asthma (GINA) protocol, that defines four categories; mild intermittent, mild persistent, moderate persistent and severe persistent.[14] Asthma control was defined based on GINA classification; the three categories being; controlled, partly controlled and uncontrolled. A child was considered either well control or not according to the guidelines.[14]

Ethical clearance was obtained from the National hospital Abuja Ethics and Institutional Review board. Data was analyzed using SPSS package version 20. Pearson correlation coefficients were used to assess the relationship between the PAQOL and PACQLQ. P value of less than 0.05 was set as significant.

Results

Forty three children with asthma and 43 caregivers were enrolled from the period of August – December 2014. Children ages ranged from 7 – 15 years with a mean (SD) 10.14 (2.45) years, of which males were 25 (58.1%); females 18(41.9%); giving a ratio of 1.4:1.The caregiver's were 23(53.5%), males and 20(46.5%), females; age range 21-48years and mean (SD) 34.8 (7.04) years. Caregivers socioeconomic status (SES) were 18(41.9%) upper and lower 8(18.8%) shown in figure 1.Sixteen (37.2%) asthmatic children had a positive history of atopy and 6(14.0%) of the children were admitted for acute exacerbation of asthma in the previous six months.

Fig 1: Gender and socioeconomic distribution of 43 asthmatics and their caregivers

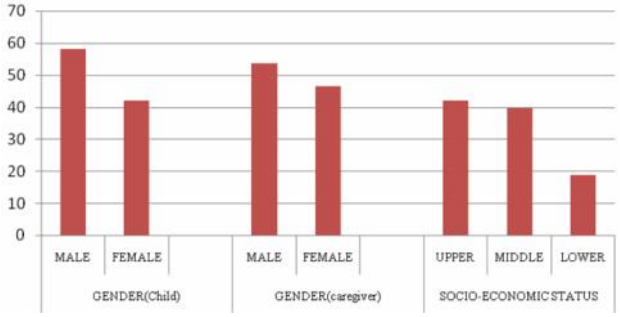

Table 1: Degree of severity and control of bronchial asthma and medication use among 43 asthmatic children

Variables	Number (%)
Asthma Severity	
Mild Intermittent	23(53.5)
Mild Persistent	15(34.9)
Moderate Persistent	5(11.6)
Severe Persistent	0(0)
Asthma Control	
Controlled	22(51.2)
Partially controlled	21(48.8)
Uncontrolled	0(0)
Drug Use	
No medication	17(39.5)
LABA/ICS	13(30.2)
Antihistamine	8(18.6)
LTRA	5(11.6)

Thirty eight (88.4%) had mild intermittent and mild persistent asthma, and 22(51.2%) well controlled. About a third (30.2%) of the asthmatic children was on LABA/ICS (table 1).

Table 2: Comparison of the mean PAQL score of children and PACQL scores of caregivers in the QOL domains

	PAQL Score		PACQL Score			
	Mean	95% CI	Mean	95% CI	R	P value
Domain						
Overall	4.89	4.54-5.24	4.6	3.91-4.82	0.438	0.003*
Activity limitation	5.1	4.77-5.43	3.77	3.47-4.29	0.238	0.124
Symptoms	4.73	4.31-5.15	-	-	-	-
Emotional functions	4.98	4.59-5.36	4.86	4.24-4.99	0.368	0.015*

*p value significant

The mean QOL was impaired for asthmatic child and caregiver using the PAQLQ, and PACQLQ respectively, with a significant positive correlation (R) 0.438, p value 0.003.Emotional domain was more significantly impaired in the asthmatic subjects and caregivers, p value 0.015 (table 2).

Table 3: Mean QOL Scores Of Children On The PAQLQ With Socio-Demographic Variables

Social Demography	Activity Limitation			Symptoms			Emotional Function			Overall Scores		
Age (years)	Mean	MD	P value	Mean	MD	P value	Mean	MD	P value	Mean	MD	P value
7-9	4.83	0.5	0.13	4.59	0.27	0.53	4.64	0.63	0.1	4.66	0.45	0.2
10-15	5.33			4.85			5.27			5.1		
Sex												
Male	5.38	0.67	0.04	4.68	0.11	0.81	4.92	0.15	0.71	4.91	0.05	0.89
Female	4.71			4.79			5.06			4.87		
Socioeconomic class												
Lower	5.18		0.19	4.69		0.99	4.7		0.62	4.8		0.82
Middle	4.74			4.77			4.88			4.8		
Upper	5.4			4.71			5.19			5.03		

MD- mean deviation
Mean QOL was significantly lower among the females in the activity domain (table 3)

Table 4: Mean QOL scores of care givers using the PACQLQ with the socio-demographic variables of the asthmatic children

Social Demography	Activity Limitation			Emotional Function			Overall Score		
Age (years)	Mean	MD	P value	Mean	MD	P value	Mean	MD	P value
7-9	3.64	0.46	0.263	4.08	0.53	0.103	3.95	0.5	0.093
10-15	4.1			4.61			4.45		
Sex									
Male	4.09	0.49	0.236	4.2	0.04	0.385	4.2	0.04	0.88
Female	3.6			4.24			4.24		
Socioeconomic class									
lower	3.63		0.799	3.83		0.282	3.77		0.37
middle	4.01			4.43			4.31		
upper	3.88			4.53			4.33		

MD- mean deviation
Mean QOL was lower among the pre-adolescent groups (7-9years) in the activity domain and lower socioeconomic class though not significant (table 4).

Table 5: QOL scores with the PAQLQ in the children according to presence of Atopy, Asthma severity and control

	Activity Limitation			Symptoms			Emotional Function			Overall Score		
Atopy	Mean	MD	P value	Mean	MD	P value	Mean	MD	P value	Mean	MD	P value
yes	4.94	0.26	0.46	4.58	0.23	0.6	4.91	0.1	0.81	4.78	0.19	0.6
no	5.19			4.82			5.01			4.97		
Asthma severity												
mild intermittent	5.48		0.09	5.2		0.04	5.35		0.09	5.28		0.06
mild persistent	5.33			4.33			4.44			4.43		
moderate persistent	4.61			3.78			4.88			4.53		
Asthma control	5.18		0.19	4.69			4.7		0.62			0.82
controlled	5.26	0.34	0.31	5.17	0.9	0.03	5.37	0.8	0.03	5.26	0.75	0.03
partly controlled	4.92			4.27			4.57			4.51		

MD- mean deviation
With the PAQLQ, children with atopy had lower mean QOL scores though not significant; those with moderate persistent asthma had significant symptoms; and those with partly controlled asthma had significant symptoms and emotional impairment (table 5).

Table 6: PACQLQ Scores of caregivers among the children with asthma according to presence of atopy, asthma severity and control

	Activity Limitation			Emotional Function			Overall Score		
Atopy	Mean	MD	p value	Mean	MD	p value	Mean	MD	p value
yes	3.84	0.07	0.882	4.26	0.28	0.383	4.15	0.18	0.56
no	3.91			4.54			4.33		
Asthma severity									
mild intermittent	5.48			5.35		0.09	4.45		0.04
mild persistent	5.33			4.44			3.72		
moderate persistent	4.61			4.88			4.62		
Asthma control									
controlled	4.34	0.98	0.019	5.37	0.8	0.03	4.6	0.78	0.008
partly controlled	3.4			4.57			3.82		

MD- mean deviation

The caregivers reported a lower mean QOL in the partly controlled children to be significant in the activity domain, and overall scores p<0.05; (table 6).

Table7: Multiple regression study variable showing independent determinant of QOL in the subjects

	Activity Limitation	Symptoms	Emotional Function	Overall Score
Age group	NS	NS	NS	NS
Gender	p=0.022	NS	NS	NS
Socio-economic status	NS	NS	NS	NS
Atopic history	NS	NS	NS	NS
Asthma severity	NS	p=0.005	p=0.018	p=0.009
Asthma control	NS	p=0.015	p=0.017	p=0.015

NS not significant

Multiple regression showed that gender (female) in the activity domain, asthma severity and control were significant independent variables of QOL; p values <0.05 (table 7).

Discussion

The mean QOL of the asthmatic children and caregivers from this report was 4.89 (4.54- 5.24, 95%CI) and 4.6 (3.91-4.82, 95% CI) respectively. This mean overall QOL score is lower than the Ayuk et al,[12]with a mean QOL score 5.3 (4.9 - 5.5, 95% CI,) among Nigerian children from Enugu. Childhood asthmatics were more in males and children with history of atopy. Fadele et al[4] earlier highlighted atopy as risk factor in the ISAAC phase three report in children aged 6-7 years, with prevalence rates of 11.3 and 10.1percent of rhinoconjuctivites and atopic eczema among Nigerian asthmatic children. It is important to stress the need to educate caregivers and the community of avoiding early exposure of infants to allergic stimulating agents and encouraging protective habits such as exclusive breastfeeding for six months and avoidance of cow's milk and other allergens.[15] The role of atopy in asthma is well established.[15]

The aim of all treatment in childhood asthmatic is to achieve well control. Most of the study population of children had mild disease (intermittent and persistent), with well controlled in about half. Subjects with well control asthma will have no daytime or night symptoms, no limitation in daily activities, no use of reliever medications, no exacerbations and normal/ near normal lung functions as defined by the Global Initiative for Asthma (GINA) protocol. Subjects with well control will require less use of medications and have less frequent need for hospital visit for emergency care that burden the family finances, hence impart on quality of life. When asthma is well control both the child and family or caregiver would be expected to have less impairment of well being. In the care of asthmatic children, caregivers may have to give up jobs, leisure time, and social activities to take care and meet the needs of their loved ones with chronic illnesses as reported by Martins et al.[16]An Australian survey, in the 2011–12 showed that asthma was the fourth highest chronic condition requiring sufferers to take time off work, school or study in the previous 12 months (18.4percent); after mental or behavioral conditions (31.2percent), cancer (30.9percent), and kidney disease (19.3percent)[17]. Also the proportion of people who required time off work, school or study due to asthma was highest among 0- 14year old, accounting for 42.4percent compared to 21.8percent among the 15–25 years old[17]. In the same report among school aged children approximately 30percent had documented one or more days of school absenteeism due to asthma and activity limitations in the previous 12 months[17].

Emotional domain was more significantly impaired in the asthmatic subjects and caregivers, p value 0.015 which was least affected in the Ayuk et al report[12]. There was a significant positive relation in the emotional domain QOL scores among the asthmatic children and the adult caregivers (R) 0.368, p=0.015. It can be inferred that asthma impacts on the families well being. This brings to the fore the importance of having long-term comprehensive management plan that include family education for both the asthmatic children and their primary caregivers. The report by Williams et al,[18] also demonstrated the negative impact of childhood asthma on the caregivers.

Young asthmatics (7-9years) and males were found to have lower mean QOL scores. The young children may not fully understand what asthma means and not understand its relation to well being of an individual. This response must be interpreted with caution, however it was not significant. However, the adult caregivers tend to show greater concern when younger children are diagnosed with asthma, with even family denial and sometimes exaggerated response from this. This may be interpreted to mean that caretakers' quality of life is directly related by the child's asthma age and disease severity. The report by Halterman et al[19] concluded that caretaker's quality of life, as assessed by the PACQLQ, is directly influenced by the child's asthma severity as well as other family factors among a group of young urban children with significant asthma.

This report shows that females had greater impairment in the activity domain compared to their male counterpart. The explanation of this observed lower mean values in the female asthmatic child may be due to their more involvement in activity like cleaning of the house and sweeping the floor; which exposes her more to risk factors such as dust mite and cockroach dust that are well established risks factors for asthma.Female gender was a significant independent predictor of QOL from this report. Asthmatic children and caregivers from lower and middle social classes had lower QOL scores. Asthma has been found to affect all social classes for various reasons, in both developed and developing countries. A likely explanation of the effect of social classes on illnesses such as asthma is the mediation through pathways that include environmental exposures, access to healthcare, stress, and psychological/cultural factors[20].

Asthma severity and poor control were found to be independent predictors of quality of life. Children with moderate persistent asthma had significant impaired QOL indicating poor control. This worsen state of disease in moderate persistent disease impacted on the caregivers QOL as shown with the positive correlation between the asthmatic children and the caregivers responses seen in the emotional domain. Asthma has being shown to have diverse impacts on the child, caregiver and society to varying degrees. Some miss school, not being able to participate in certain activities or work due to their asthma or in order to care for a child with asthma. Such impairment on the sufferer or career may be a physical, psychological or social wellbeing, and tend to be more pronounced when the sufferer has severe or poorly controlled asthma.

Conclusion

The female gender was a significant predictor of QOL. Children with severe disease presented with poor control and significant impairment in QOL in the emotional domains which correlated with the caregivers' responses using both PAQOL and PACQOL questionnaires.

Authors' contributions
PAA: Study concept and design,
PAA, CCU, RMN: Acquisition of data,
PAA, CCU: Analysis and interpretation of data and Statistical analysis
PAA: Drafting of the manuscript and Critical revision of the manuscript for important intellectual content
All authors read and approved the final version of the manuscript.
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Limitation

The study only observed caregiver responses over a one-time period. A longitudinal observational study of caregivers' information would have been more adequate; along with the asthmatic children clinical score over a longer period.

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