Doi: 10.32677/IJCH.2015.v02.i02.006

Original Article

Evaluating the quality of life in asthmatic children less than 5 years in an urban setting in Mumbai: A pilot study

Asha Pherwani

From Consultant Pediatrician and Allergy Specialist, P.D. Hinduja National Hospital, Veer Savarkar, Marg, Mahim, Mumbai, Maharashtra, India

Correspondence to: Dr. Asha Pherwani, 303, Samudral Mahal, Dr. A.B. Road, Worli, Mumbai - 400 016, Maharashtra, India. Phone: +91-9821141636, E-mail: ashadr42@hotmail.com

Received - 22 August 2014 Initial Review - 27 October 2014 Published Online - 30 May 2015

Abstract

Introduction: Quality of life questionnaires (QOLQs) are an important part of the clinical assessment. There are few studies in India evaluating QOL in children with childhood asthma. **Objectives:** The objective was to construct a parent answered QOLQ for asthmatic children under 5 years of age and to compare QOLQ with symptoms. **Materials and Methods:** Exploratory/pilot study conducted between January and December 2011 in asthma clinic of an urban teaching hospital. Asthmatic children below 5 years of age, who had at least three asthma attacks in the past year, were included in the study. A QOLQ was constructed having 18 items, distributed under four domains (symptoms, environment, physical activity, and behavior). Validity of QOLQ was checked and was presented to parents in a simple language, and they were taught to score them from 1 to 7. **Results:** Study consists of 41 asthmatic children (mean age = 3.7±1.1 years) with 26 (63.8%) male and 15 (36.5%) females. 15 age-matched (mean age 4±1.2 years) normal controls were also taken. The mean score was significantly higher ($p \leq 0.05$) for the domain of symptoms (4.2±2), than the domains of environment (3.6±1.8), and behavior (3.6±1.6), and these were higher than those of physical activity (3.2±2.65, $p \leq 0.05$). The mean domains of asthmatics were significantly higher (30-34%) than the controls, suggesting that the QOLQ was measuring what it was supposed to measure. Scores of the QOLQ correlated with the severity of symptoms. **Conclusion:** It is possible to determine the QOL of children below 5 years of age with parents acting as a proxy. However, larger data is needed to confirm its clinical usefulness and application.

Key words: *Childhood asthma, Children under 5, Caretakers, Parents, Proxy, Quality of life, Questionnaire*

Quality of life questionnaires (QOLQs) have become an integral part of clinical assessment, as they reveal the impact of a disease on day-to-day life of an individual, which may not be captured by clinical history, providing an essential yardstick for health assessments [1-5]. This is especially important for chronic disorders like asthma, the management of which largely depends on long-term symptoms and their control. There are constraints in designing QOLQs for younger children who, because of their immature cognition and psychological development cannot express themselves. It is therefore, necessary to use parents (parents/care-takers) as a proxy. This is in contrast to the basic expectations of the QOLQs that rely on an individual's perceptions. Studies in older children have shown that the perceptions and judgement of adolescents and their parents differ [6,7]. However, another study in younger children shows that asthma status and changein asthma status over time, following treatment, are best studied by parent-reported symptoms and parent-reported utilization of functional health status measures [8]. Therefore, this study was planned to construct a parent answered QOLQ for asthmatic children below 5 years of age and to assess its relation to symptoms of children.

MATERIALS AND METHODS

This pilot study was conducted in asthma clinic of an urban teaching hospital between January and December 2011. The study was cleared by the ethics committee of the hospital. A written informed consent was obtained from the parents of eligible children. Asthmatic children, below 5 years, who had at least three asthma attacks in the past year were included in the study. Children with any other illness, immunocompromised children, children on any other medication except inhaled steroids, and parents not understanding the English language were excluded from the study.

Construction of the QOLQ

A most rigorous approach is necessary to obtain a good construct validity of the QOLQ. This depends on measures

(items) chosen, the purpose of the study and the age of the study population. Items from diverse sources were compiled i.e., reputed web publications [9-13], 4 pediatricians, 4 pediatric postgraduates, 4 pediatric nurses, and 10 parents of asthmatic children below 5 years age. I included parents to ensure the face and the content value of QOLQ, by capturing all the areas of functions important to an individual child (content validity) along with age-specific health impairments (sensibility).

Then questionnaires were short-listed by removing items with similar meaning. Further reduction was feasible by converting each item into a product score (PS), by multiplying an item score with its frequency of occurrence. Items with the lowest PS were removed. The item of cold foods was removed because most Indian parents introduce many food restrictions, which they believe will ward off illness, especially bananas and cold foods. The item of sleep was already included in the domain of symptoms as "wakes up at night with cough" and as parents gave the following answers (children continued to sleep even when breathless or wheezing). Therefore, I framed the question as "Does your child gets up at night with a cough."

The final QOLQ had 18 items, written in easy-to-understand questions beginning with the following phrase before every question: In the past 15 days, how much did your child suffer from - The questionnaire was pre-tested on 20 parents for the ease of understanding and consistency. They were tested again after 30 min to see if they revised their initial answers.

Validity of the QOLQ

The internal consistency of the QOLQ was calculated using the formula for Cronbach's alpha provided in the statistical program of Excel. Overall Cronbach's alpha was 0.8 showing a good internal consistency. I calculated inter-item coefficients of variance (range = 0.30-0.70) and the coefficient of correlation for each pair of items and total mean of pairs of items. Then a single item at a time was removed to see whether its removal caused any change in total mean. There was no change in total mean again showing good internal consistency.

Demographic profile including age, sex, and weight of the children was included. A demonstration of the method of scoring the QOLQ was given to parents (Table 1). Help was given when asked, but no leading answers were given. Parents were asked to score all the 18 items from 1 to 7 (1 = not bothered at all and 7 bothered a lot) and the total score was calculated. Non-weighted means in all four domains were compared between cases and controls.

Then final weightage given to the means of domains as follows: (3x to the domain of symptoms, 2x each to domains of environment, physical activity, and 1x to behavior. There were four domains with weightage of 3, 2, 2, and 1, respectively,

Table 1: Quality of life questionnaire for asthmatic children below 5-years

Before each item the following sentence was repeated: - In past 15 days did your child feel child	All the time	Most of the time	Good bit of time	Some of the time	Little of the time	Hardly any of the time	None of the time
Breathless	7	6	5	4	3	2	1
Make wheezing sound	7	6	5	4	3	2	1
Wake up with cough	7	6	5	4	3	2	1
Coughs a lot	7	6	5	4	3	2	1
Cough during day time	7	6	5	4	3	2	1
Cold makes my child wheeze	7	6	5	4	3	2	1
Bothered by dust in surrounding	7	6	5	4	3	2	1
Bothered by smoke	7	6	5	4	3	2	1
Bothered by strong odors	7	6	5	4	3	2	1
Bothered by weather	7	6	5	4	3	2	1
Sticks to mother	7	6	5	4	3	2	1
Becomes irritable	7	6	5	4	3	2	1
Becomes withdrawn	7	6	5	4	3	2	1
Refuses to eat	7	6	5	4	3	2	1
Gets restless in bed	7	6	5	4	3	2	1
Not able to run around the house	7	6	5	4	3	2	1
Not able to play with other children	7	6	5	4	3	2	1
Not able to play outdoors	7	6	5	4	3	2	1

for a total of 8. As the maximum score in each domain was 7, the total would thus be to the base of 7*8=56. For easy comparison and understanding, this base was converted to 100, by multiplying the weighted score for each individual by 100 and dividing by 56. After arranging these derived scores in a descending order, an individual child was classified into severe (score of 60 or more), moderate (30-59) or mild asthma (score below 30).

RESULTS

The study population consisted of 41 asthmatic children (mean age = 3.7±1.1 years) with 26 (63.8%) male and 15 (36.5%) females. 15 age-matched (mean age 4±1.2 years) normal controls were also taken. As the mean and median were close to each other, our data were following the Gaussian curve. The mean unweighted scores (Table 2) were significantly higher ($p \leq 0.005$) for the domain of symptoms (4.2±2) than the domain of environment (3.6±0.8), and behavior (3.6±1.6), which in turn were significantly higher ($p \leq 0.05$) than the mean domain of physical activity (3.2±2.65).

The standard deviations were very high indicating the need for a larger data sample to reach a better conclusion. It also shows that the mean domains of asthmatic children were significantly higher than their controls, suggesting that the QOLQ was measuring what it was supposed to measure. Table 3 shows the final weightage given to the means of domains. Table 4 shows that there was a great consistency between the scores and the severity of the disease.

DISCUSSION

Childhood asthma is one of the most common chronic disorders in children. Previous studies have shown that early childhood wheezers and asthmatics have poor QOL as compared to non-wheezers [11]. Apart from the hospitalizations due to acute attacks, food restrictions, disturbed sleep, and daytime somnolence contribute to the poor QOL in these children. Therefore, assessment of QOL of an asthmatic child is very important and desirable. However, no study is available for measuring the QOL in asthmatic children <5 years of age especially in Indian children; therefore, this study was planned to formulate QOLQ to be used in Indian children.

It is difficult for small children to perform physiological tests that could be used as a gold standard for comparison. In the absence of a gold standard, the usual practice is to put forward a hypothesis or construct to provide predictable relations between the domains. I hypothesized that the various domains were moving in a similar fashion. I gave appropriate weightage to individual domains of asthmatic children and controls according to their clinical importance. Mean scores of all the individual domains were between 30% and 33%, except for the domain of behavior, which was higher (54%) than other domains. To account for this, I reduced the weightage of the domain of behavior from 2 to 1, which lowered the percentage to 34% comparable to that of other domains. Probably items in the domain of behavior were exaggerated with asthma and some of the controls also had behavioral problems such as sticking to mom, irritability, not eating, restless in bed.

There was a good consistency between scores and severity of the disease. All the scores of domains were higher to a similar extent as compared to controls. Hence, it would be possible to follow these scores in asthmatic children and correlate them with improvement following treatment. Cross-sectional studies were carried out to see if the QOLQ could discriminate between different levels of impairment of asthma. The domain means were moving according to changes in the domain of symptoms. Thus, the means of the domains were moving in a similar fashion.

Limitation of the present study was its small sample size, and I could not assess the relation of QOLQ and response to treatment. Therefore, large-scale studies are needed before its generalization to all asthmatic children and to confirm these observations.

Table 2: Non-weighted mean domains in asthmatics and controls

Participants	Symptoms	Environment	Behavior	Physical
Asthmatic	4.2±1.5	3.6±1.8	3.6±1.6	3.2±2.2
Controls	1.3±0.8	1.2±0.5	1.9±1.2	1.0±0.3
% difference	30	33	54	31

Table 3: Comparison of the weighted means of asthmatic children and controls

	Mean of domains				Total weighted mean
Mean domains	Symptoms	Environment	Behavior	Physical activity	Domains* 100/56
	4.2	3.6	3.6	3.2	
Initial weightage	3x=12.6	2x=7.2	2x=7.2	2x=6.4	53
Final weights	3x=12.6	2x=7.2	1x=3.6	2x=6.4	47
Weighted controls	3x=3.9	2x=2.4	1x=1.9	2x=2.0	20

Weight age given 3, 2, 1

Table 4: Comparison of thresholds with mean scores of the domains

Threshold	Symptoms	Environment	Behavior	Physical
>60%	5.4	4.3	3.8	5.2
SD	1.9	2.5	2.7	2.4
59-30%	4.2	3.1	3	3
SD	2.0	0.017	0.017	0.019
<30%	3.13	1.4	1.2	1
T-test		p≤0.05	p≤0.05	p≤0.05
Controls	1.3	1.2	1.9	1
SD	0.3	0.3	1.6	1

Thresholds=60%, 59-30%,<30%

CONCLUSION

The present study showed good correlation between QOLQ scores and severity of the disease. In the absence of a non-invasive gold stasssndard for children under 5 years, we could use the thresholds for severity of asthma derived from the questionnaire. The parents and caretakers were able to answer the questions after the demonstration.

REFERENCES

1. McSweeny AJ, Creer TL. Health-related quality-of-life assessment in medical care. Dis Mon. 1995;41(1):1-71.
2. Richards JM, Hemstreet MP. Measures of life quality, role performance, and functional status in asthma research. Am Respir Crit Care. 1987;40:465-71.
3. Juniper EF, Guyatt GH, Feeny DH, Ferrie PJ, Griffith LE, Townsend M. Measuring quality of life in children with asthma. Qual Life Res. 1996;5(1):35-46.
4. Rutishauser C, Sawyer SM, Bowes G. Quality-of-life assessment in children and adolescents with asthma. Eur Respir J. 1998;12(2):486-94.
5. Reich W, Herjanic B, Welner Z, Gandhy PR. Development of a structured psychiatric interview for children: Agreement on diagnosis comparing child and parent interviews. J Abnorm Child Psychol. 1982;10(3):325-36.
6. Rothman ML, Hedrick SC, Bulcroft KA, Hickam DH, Rubenstein LZ. The validity of proxy-generated scores as measures of patient health status. Med Care. 1991;29(2):115-24.
7. Sharek PJ, Mayer ML, Loewy L, Robinson TN, Shames RS, Umetsu DT, et al. Agreement among measures of asthma status: A prospective study of low-income children with moderate to severe asthma. Pediatrics. 2002;110(4):797-804.
8. Juniper EF, Svensson K, Mörk AC, Ståhl E. Modification of the asthma quality of life questionnaire (standardised) for patients 12 years and older. Health Qual Life Outcomes. 2005;3:58.
9. Juniper EF, Guyatt GH, Ferrie PJ, Griffith LE. Measuring quality of life in asthma. Am Rev Respir Dis. 1993;147(4):832-8.
10. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. Ann Intern Med. 1993;118(8):622-9.
11. Li Z, Huang IC, Thompson L, Tuli S, Huang SW, DeWalt D, et al. The relationships between asthma control, daytime sleepiness, and quality of life among children with asthma: a path analysis. Sleep Med. 2013;14(7):641-7.
12. Juniper EF, Guyatt GH, Feeny DH, Ferrie PJ, Griffith LE, Townsend M. Measuring quality of life in children with asthma. Qual Life Res. 1996;5:35-46.
13. Juniper EF, Guyatt GH, Epstein RS, Ferrie PJ, Jaeschke R, Hiller TK. Evaluation of impairment of health-related quality of life in asthma: development of a questionnaire for use in clinical trials. Thorax. 1992;47:76-83.

Funding: None; Conflict of Interest: None Stated

How to cite this article: Pherwani A. Evaluating the quality of life in asthmatic children less than 5 years in an urban setting in Mumbai: A pilot study. Indian J Child Health. 2015;2(2):64-67.