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Parental perception about the severity of asthma in their children vis a vis the objective assessment based on Global initiative of Asthma (GINA) guidelines

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Abstract

Parental perceptions about severity of a disease in their child are important to enhance the acceptance of disease and ensure compliance of interventions. However these perceptions, generally reliable, might not always correlate with more objective assessments. Severity of childhood Asthma is usually assessed as per Global initiative for Asthma (GINA) guidelines and studies have shown only a modest correlation between GINA based assessment and parental perceptions.

Objectives: To assess perception of the parents regarding severity of asthma in their children and correlate it with objective assessment as per GINA Guidelines.

Methods: In a cross-sectional observational study involving 77 children with Asthma, severity of the disease was assessed as per GINA guidelines, termed as Clinical Severity score (CSS-GINA). Then, one of the parents was interviewed for their perception about it, using a pre-validated questionnaire including fifteen questions in three fields - Day-time symptoms (DTSS), Night-time symptoms (NTSS) and Disability status (DDS).

Results: There was a significant difference in PPSS between children with well-controlled asthma

(08.52±5.17) versus those with partly-controlled (13.91±4.89) or uncontrolled disease (21.31±0.51). There was also a good correlation between CSS-GINA and PPSS as well as all of its sub-groups, being strongest with DTSS (r: 0.62) and weakest with DSS (r: 0.38).

Both parents had excellent perception of their ward's illness, though the mother's perception had marginally stronger correlation than that of fathers. Perception of the severity was better among parents who themselves had disease (R-value 0.67 vs. 0.54).

Conclusions: Parents have reasonably good perception of the disease status in their asthmatic children, though it might be inadequate regarding the disability or the impact of the disease on the quality of life. Reliability of this subjective perception also depends on certain demographic features of the child and parents, which should be considered while interpreting these observations in practice.

Keywords: Asthma, severity of disease, Parental perception, Subjective assessment

Introduction

Bronchial Asthmais one of the common estchronic diseases in children with extremely wide clinical spectrum in terms of the severity and substantial morbidity in terms of the poor quality of life and health-care costs. Severity of the disease and status of its control is usually measured objectively according to the Global Initiative for Asthma (GINA) guidelines, based on the frequency of symptoms and medication age, effect on the activity and status of lung function tests (1). However, Children with this disease as well as their parents and families are often troubled not only by the clinical symptoms but a lobby other physical, social, educational and emotional consequences that they experience. Studies have shown that the correlations between these conventional clinical outcomes and how the patients and their parents feel about the disease are only modest (2-5)

Assessing the parental perception of the disease is important not only to ensure the compliance of medical and life-style interventions but al so to enhance acceptance of the disability despite the presence of disease. Factors influencing the perception of disease by the parents of asthmatic children have not been fully addressed and might include those related to the characteristics of the child as well as of the parents themselves. (6)

Present study aims to assess perception of the parents regarding the severity of asthma in their children and correlate it with objective assessment of the severity based on GINAGuidelines2018 (1). Study also aims to assess the effect of selected patient and parent characteristics on this correlation between parental perception and disease severity.

Material & Methods

Present study is a cross sectional observational research conducted at a medical college hospital of the western India after due approval from the institutional ethics committee. Sample size included total 77 newly diagnosed children with bronchial asthma on clinical grounds, aged 3-12 years, calculated using Daniel's Formula with Zas the level of confidence=1.84,Porprobability as 0.05 and do precision as 0.01 and presuming 05% as the prevalence of asthma in study population. (7) Cases were enrolled using convenient sampling method after obtaining informed consent and those with other chronic co-morbidities or uncooperative parents for interview were excluded.

A pre-designed case-record form was used to collect detailed demographic and clinical characteristics of the

enrolled cases along with details of relevant investigations. Subsequently, the severity of the asthma was classified according to status of asthma control as– Well controlled, Partly controlled or Uncontrolled, as per GINA guidelines.

One of the parents of each enrolled case was interviewed to assess his or her perception about severity of the disease in the child, using a pre-validated questionnaire modified but based on the original questionnaire devised by User wood et al (8).

This questionnaire includes total1 5 questions related to the disease status and the responses are to be marked by the parents on a scale of 0–4, with 0 denoting "not at all" and 4 denoting "every day or night" (Table3). These statements assessed parental perception regarding these verity of disease in three major sub-components– a)Day-time symptoms (statements Number1-4),b) Night-time symptoms (statement number 13-15) and c)Disability status (statement number 5-12).

Selected demographi c characteristics of the interviewed parents were also recorded, with special reference to their age, educational status and own asthma status, if any. All patients were managed according to the standard hospital protocols, largely based on GINA guidelines.

Collected data was transferred on a MS Excel sheet and analyzed further using standard statistical techniques. Ordinal data regarding severity of the disease as per GIN A guidelines was converted in to nominal data within creasing order of severity on a scale of1-3, scored as– "1" for well controlled, "2" for partly controlled and "3" for uncontrolled disease. This score was termed as Clinical Severity score-GINA or (CSS-GINA).

Ordinal data regarding parental perception on the study questionnaire was also converted into nominal data as the Parental perception of the severity score (PPSS), scoring the responses with increasing order of severity on a scale of 0-4 as follows– "O" for not at all, "1" for few days, "2" for some days, "3" for most days and "4" for every day.

Thus, the minimum PPSS score was 0, while maximum score was 60. PPPS responses from each case were further analyzed item-wise into three groups–a) Day time severity score (DTSS) for statementno.1-4, Night-time Severity score (NTSS) for statement no.13-15 and Disease Disability severity score (DDSS) for statement no.5-12. Thus, the minimum score for each category was 0, while maximum score for DTSS was 16, NTSS was 12 and DSSS was 32.

Results

Mean age of overall enrolled cases was 6.8 ± 2.7 years, with majority being above 5 years of age (70.1%) and Males (67.5%). Of them, 20.8% had family history of asthma. Two-third of the study cases (67.5%) had well-controlled disease as per GINA guidelines, followed by 28.6% partly controlled cases and 3.9% uncontrolled cases.

Out of the 77 questionnaires, 61% were filled by mothers, with 87% respondents being in middle-age group of 25-45 years and 93.5% being literate to some extent. Among respondents, 15%themselves had asthma.

Table 1 depicts parental responses to different questions included in the questionnaire, reflecting their perception about overall severity of the disease (PPSS) as well as DTSS, DSSS and NTSS. Over four-fifth (81.8%) responses for DSS were in the lowest score category (<8), while over half of the responses in DTS and NTS sub-component were in mid-score categories respectively.

Mean PPSS score among overall cases was10.57 ± 6.04, including mean DTS, NTS and DSSs cores were04.31 ± 2.02, 02.33 ± 1.41 and03.92 ± 3.16 respectively. There was a significant difference (p<0.0001) in PPSS between children with well-controlled asthma (08.52 ± 5.17) versus those with partly-controlled (13.91 ± 4.89) or uncontrolled asthma (21.31 ±0.51), as shown in table 2.

Table 2 also indicates a strong correlation between PPSS score and CSS-GINA at R-value of 0.50. A significant correlation was also found between CSS-GINA and all sub-groups of PPSS, strongest with DTSS (r value 0.62) and weakest with DSS (r value 0.38). Item-wise, Study reveals significant correlation between CSS-GINA and 12 of the 15 statements in the questionnaire, strongest for statement number 2 (your child has coughed during the day, r value 0.54).

Table 3 and 4 depict effect of various case characteristics on correlation between PPSS and CSS-GINA. Both, the mothers and father so asthmatic children had excellent perception of their ward' silliness, though the mother's perception had marginally stronger correlation with CSS-GINA (R-value: 0.57) than that of fathers or others (R-value:0.55). Perception of the disease severity was better among parents who themselves had/ has disease than in those without it(R-value0.67vs.0.54) (Table 4).

Discussion

Present study revealsa good correlation between PPSS score and CSS-GINA, suggesting that perception of the parents regarding severity of the asthma in their children is a fairly reliable indicator of the disease severity and control status in their wards. Significant differences in PPSS between cases of well-controlled asthma versus partly-controlled or uncontrolled asthma further strengthen this observation.

Study also reveals that though there were significant correlation between CSS-GINA all sub-components of PPSS i.e., DTS, NTS and DSS; it was weakest with DSS (r value 0.38) as compared to that with DTS and NTS (r value 062 and 0.46 respectively). This observation indicates possibility of the under-perception of disability in asthmatic children due to their disease, by parents in study population.

Many studies have shown a positive correlation between parental perception of the severity of the asthma *vis a vis* objective assessment based on GINA guidelines (2-5, 9) but with significant discrepancies. These discrepancies may lead to over estimation of the control within adequate treatment or under-estimation of the control with increased financial burden of the disease and adverse effects of stepped- up treatment.

Mittal V et al. In their study on subjective symptom perceptual accuracy in asthmatic children and their parents found that symptom perception by children was as reliable as that by their parents but parents and children tended to under estimate the severity when the child was unstable. (6) Holgateet al. In their review of asthma surveys, including adult patients, pointed out that patients' perception of disease control and frequency of symptoms were often mismatched, namely patients often under state their symptoms and tolerate poor disease control. (10)

Carroll et al.(2012)studied parental misperception of control is childhood or adolescent asthma with the Room to Breathe survey. In this study, 73% parents described their child's asthma as mild or intermittent but only 40% of the cases had C-ACT scores ≤ 19 (required to indicate adequate control), only 14.7% achieved complete GINA-defined control and only 9.2% achieved British Thoracic Society (BTS)-defined control. (11)

Reliability of Parental perception regarding severity of the disease might also depends on the same factors related to the child as well as parents themselves and was explored in this study.

Perception of the disease severity was also better among parents who themselves had/ has disease than in those without it. It appears that parents are better versed with problems related to the disease if they have faced the same problem in themselves. Similarly, perception was also better when the child was younger than five years. Betterparentalperceptioninyoungerchildrenmaybeduetoth efactthatparentsareoftenmoreconcernedandmore actively involved in their care than the care of older children.

While both parents of asthmatic children had excellent perception of their child's illness, the mother's perception had stronger correlation with CSS-GINA than that of fathers or others. It appears that fathers are not as involved in the care of asthmatic children as mothers though they are able to fill in for the mother when needed.

In a study by Hederos CA etal ,there were no major gender differences in indices at any occasion, but mothers were more disturbed at night, felt more helpless and frightened and the child's asthma interfered more with their work. (12)To conclude, present study indicates that parents have reasonably good perception of the disease status in their asthmatic children, though it might be in adequate regarding the disability or the impact of the disease on the quality of life in their children. Reliability of this subjective perception also depends on certain demo graphic features of the child and parents, which have to be taken in account while interpreting these observations in practice

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Table 1: Parental responses to statements in the study questionnaire

	Responses in Numbers out of total 77 cases(%)				
Statement	Not at All	Few days	Some days	Most days	Every
Day-time symptoms(DTS)					
Your child has been wheezy during the day	10(12.98%)	55(71.42%)	11(14.28%)	01(01.29%)	0
Your child has coughed during the day	04(05.19%)	59(76.62%)	12(15.58%)	02(02.59%)	0
Your child has complained of being short of breath	23(29.87%)	47(61.03%)	07(09.09%)	0	0
Exertion(eg, running) has made your child breathless	12(15.58%)	31(40.25%)	30(38.96%)	04(05.19%)	0
Disability status Score (DSS)					
Your child has stayed indoors because of wheezing or coughing	37(48.05%)	39(50.64%)	1(1.29%)	0	0
His/her asthma has stopped your child from playing with his or her friends	49(63.63%)	28(36.36%)	0	0	0
During term time, your child's education has suffered due to his or her asthma	46(59.74%)	30(38.96%)	1(1.29%)	0	0
Asthma has stopped your child from doing all the things that a boy or girl should at his or her age	48(62.33%)	27(35.06%)	2(2.59%)	0	0
Your child's asthma has interfered with his or her life	42(54.54%)	35(45.45%)	0	0	0
Asthma has limited your child's activities	36(46.75%)	41(53.24%)	0	0	0
Your child's asthma a has limited your activities	35(45.45%)	42(54.54%)	0	0	0
Your child has stayed indoors because of wheezing or coughing	31(41.25%)	45(58.44%)	1(1.20%)	0	0
Night-time symptoms (NTS)					
Your child has coughed at night	13(16.88%)	54(70.12%)	09(11.6%)	01(01.2%)	0
Your child's sleep has been disturbed by wheezing or coughing	26(33.76%)	47(61.03%)	04(05.1%)	0	0

Your child has been woken up by wheezing or coughing	31(40.25%)	45(58.44%)	01(01.2%)	0	0

Table 2: PPSS and sub set values versus CSS-GINA

CSS-GINA	**PPSS**	**DTS**	**DSS**	**NTS**
Well controlled	08.52±5.17	3.51± 1.55	3.01± 3.18	1.92± 1.39
Partly controlled	13.91±4.89	5.34± 1.96	5.47±3.15	2.96± 1.40
Uncontrolled	21.31±0.51	9.33± 1.88	7.33± 2.99	4.66 ±1 .33
P value*	< 0.0001	< 0.0001	<0.0003	<0.0002
r value**	0.50	0.62	0.38	0.46

*On Unpaired t test between well controlled v/s partly controlled+ uncontrolled cases

** On Pearson's Correlation test (vs CSS-GINA)

Table 3: Effect of case characteristics on correlation of PPSS With CSS-GINA

Case Characteristics	Number of cases	rvalue*
Age of the child		
< 5 years	23	0.54
>5years	54	0.43
Gender of the child		
Male	52	0.54
Female	25	0.54
Family History		
Present	16	0.67
Absent	61	0.54
Past Hospitalization		
Yes	34	0.50
No	43	0.54

Table 4: Effect of Parent's characteristics on correlation of PPSS With CSS-GINA

Case Characteristics	Number of cases	R value*
Relation of the interviewed parent with case		
Mother	47	0.57
Father/others	30	0.55
Age of the interviewed Parent		
<45years	71	0.23
>45years	06	0.45
Educational status of the interviewed Parent		
Illiterate	05	0.51

Literate (Non-graduate)	72	0.54
History of Asthma in interviewed Parents		
Yes	12	0.67
No	65	0.54

*Pearson's correlation test