

This article was downloaded by: [Uppsala University Library]

On: 9 November 2009

Access details: Access Details: [subscription number 786945401]

Publisher Informa Healthcare

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Journal of Asthma

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title~content=t713597262>

Comparison of Asthma Knowledge, Management, and Psychological Burden among Parents of Asthmatic Children From Rural and Urban Neighborhoods in India

D. Rastogi ^a; S. Gupta ^b; R. Kapoor ^b

^a Children's Hospital at Montefiore, Albert Einstein College of Medicine, Bronx, New York, USA ^b Regency Hospital, Kanpur, India

Online Publication Date: 01 November 2009

To cite this Article Rastogi, D., Gupta, S. and Kapoor, R.(2009)'Comparison of Asthma Knowledge, Management, and Psychological Burden among Parents of Asthmatic Children From Rural and Urban Neighborhoods in India',*Journal of Asthma*,46:9,911 — 915

To link to this Article: DOI: 10.3109/02770900903191323

URL: <http://dx.doi.org/10.3109/02770900903191323>

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: <http://www.informaworld.com/terms-and-conditions-of-access.pdf>

This article may be used for research, teaching and private study purposes. Any substantial or systematic reproduction, re-distribution, re-selling, loan or sub-licensing, systematic supply or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.

ORIGINAL ARTICLE

Comparison of Asthma Knowledge, Management, and Psychological Burden among Parents of Asthmatic Children From Rural and Urban Neighborhoods in India

D. RASTOGI, M.B.B.S.,^{1,*} S. GUPTA, M.B.B.S.,² AND R. KAPOOR, M.D.²

¹Children's Hospital at Montefiore, Albert Einstein College of Medicine, Bronx, New York, USA

²Regency Hospital, Kanpur, India

Introduction: Asthma prevalence is increasing in developing countries such as India. Little is known on parental knowledge of asthma severity, management and psychosocial impact, particularly among rural dwellers. Further, it is not known whether the female asthmatic child is particularly vulnerable. **Objective:** To evaluate parental asthma knowledge and psychological impact of having an asthmatic child. **Methods:** 134 consecutive caregivers were surveyed at the visit for their child's asthma exacerbation at an urban hospital in Kanpur, India between 3/2007–3/2008. **Results:** The child's age range was 5.7 ± 2.7 years. 76% were urban city dwellers with significantly higher number having a college degree. 23% children had moderate to severe persistent asthma; however, only 42% were on inhaled steroids. Parental severity perception was comparable to National Heart, Lung and Blood Institute (NHLBI) classification. While 67% identified bronchoconstriction occurred with asthma, only 8.9% recognized that inflammation played a role. There was no difference in the perceived stress by area of residence with 89% reported not or only sometimes feeling stressed with having an asthmatic child. Similarly, the concern among those with a female asthmatic child did not differ with 73% of caregivers believing that asthma would not affect their daughter's future. **Conclusion:** In an urban Indian hospital, 23% of asthmatic children had moderate to severe persistent asthma but only 9% were on controllers. Their parents were well educated, able to identify asthma severity appropriately and denied being stressed with having asthmatic children, irrespective of the gender of the child. However, their understanding of asthma pathophysiology was sub-optimal. Increased disease knowledge may lead to greater medication adherence among asthmatic children in India.

Keywords pediatric asthma; developing countries; India; rural; female child

INTRODUCTION

Asthma is one of the most common chronic diseases of childhood, causing substantial morbidity and loss of quality of life (1–3). While asthma prevalence has been increasing and is the highest in developed countries, its increase in the developing world is evident in a growing number of children in countries such as India. Self-reported prevalence among 13- to 14-year-old children ranges from 2.1% in developing to 32.2% in developed countries (4). Pediatric prevalence within India also ranges between 0.5% to 1.8%, as reported by International Study of Asthma and Allergies in Childhood (ISAAC) (5).

Parental understanding of disease pathology and its management has been associated with greater adherence to the preventative regimen and decreased unscheduled medical visits or hospitalizations in developed countries (6). Few studies have been published on the parental understanding of asthma and its acceptance among Indian families. As reported by Lal et al. many parents believe that asthma is contagious or hereditary (7). The impression that aerosol therapy is addictive and that daily medication use impairs the child's ability to outgrow the disease are a few of the misconcep-

tions that lead to noncompliance with prescribed preventative medications (8). Moreover, parents have varied views on asthma prognosis such as identifying it as a chronic morbidity, further hampering disease acceptance (9). Whether these beliefs are associated with increased parental stress has not been evaluated thus far.

In addition to the understanding of disease pathophysiology, an accurate evaluation of symptom severity is indispensable for optimal asthma management. Poor perception of asthma severity or underestimation of the severity of exacerbations may lead to inadequate and inappropriate home management (10). A study conducted in the metropolis of New Delhi, India, demonstrated that there was a good correlation between the severity perception by the child and his/her parents at baseline. However, the accuracy of severity assessment decreased during an exacerbation, often associated with underestimation of symptoms (11). Whether this is similar in other areas of India, particularly among families residing in rural neighborhoods has not been evaluated yet.

As with any large country, the social structure of India is diverse, including urban and rural areas. The difference in asthma beliefs among the individuals residing in these two areas and the effect of parental education level has not been reported. In addition, there has been a long-standing tradition of preferential concern and care for a medical condition in a male child as compared to a female child. The extent of this occurrence, particularly among asthmatic children, remains poorly defined. A cross-sectional questionnaire-based study was designed to study the impact of these intrinsic social

S.G. is now at Children's Hospital of Michigan, Detroit Medical Center.

*Corresponding author: Deepa Rastogi, M.B.B.S., Children's Hospital at Montefiore, Albert Einstein College of Medicine, 3415 Bainbridge Avenue, Bronx, NY 10467; E-mail: drastogi@montefiore.org

aspects on parental understanding of asthma pathophysiology, its management, and perception of stress associated with having an asthmatic child.

METHODS

A 59-point questionnaire was administered to parents of 134 children, 3 and 11 years of age, who visited the Regency Hospital for an asthma exacerbation between March 2007 and March 2008. The hospital is located in the urban industrial city of Kanpur in northern India and has a large catchment area with access to both urban and rural middle-class families. The questionnaire was based on the National Cooperative Inner City Asthma Study intake questionnaire with some modifications to adapt to Indian society (12). The questionnaire addressed the parents' understanding of asthma pathophysiology, their perceptions of asthma severity among their children, and their beliefs on use of medications as well as complementary therapy such as tea and rubbing ointments on the child's chest. They were also questioned on the presence of triggers in the household, such as common indoor allergens and passive smoke. Ease of access to medical care and satisfaction with the primary medical care provider was also queried. Most responses were categorical (yes/no), but responses to psychosocial questions addressing their perception of stress, helplessness, and concern of side effects with chronic medication use were measured on a Likert scale. Specific areas where questions were modified include the section regarding pets. Buffaloes and cows and their food are commonly present near patient residences, perhaps acting as triggers not present in the western nations.

As there are studies suggesting that single parents with an asthmatic child perceive more stress (13), we examined the family structure to identify if residing as a joint family provided added family support and potentially altered the perceived parental stress of having an asthmatic child. Further, as the medical care provided to a child might be affected by gender, two questions were added to better identify any parental concerns associated specifically with having a female child with asthma. The questionnaire was administered by one of the two physicians comprising the research team on the day of the outpatient visit. The study was approved by the Review Board at the Regency Hospital. Oral consent was obtained before administering the questionnaire.

Statistical analysis was performed using STATA software, version 10. Numerical variables are reported as mean $\pm$ SD. Chi-square and Fisher's Exact test were applied to study the difference in proportions and difference in means across groups was evaluated by using the Student's *t* test and analysis of variance (ANOVA). Non-parametric tests were applied where the assumptions of normality were violated.

RESULTS

Demographics

The mean age of the children was 5.7 ± 2.7 years, with a male to female ratio of 2.3:1. About 80% of the children had been diagnosed with asthma by the age of 3 years, and 49% had a family history of asthma. The primary respondents for the questionnaire were parents with fathers responding in 48% and mothers in 50% of the cases. Of the 134 families, 103 were urban residents and 31 hailed from the rural neighborhoods.

As shown in Table 1, the mean age of children, as well as the number of girls presenting with asthma exacerbations, residing in the rural neighborhoods was significantly different from those from the urban areas. There was also a significant disparity in the educational status among the caregivers with a significantly higher number of those residing in the urban areas reported having a postgraduate degree than those residing in villages ($p < 0.0001$). However, the proportion of families residing as nuclear or joint families did not differ by area of residence or by gender of the child.

Parental Understanding of Asthma Pathophysiology, its Severity, and its Management

While 67% of guardians correctly identified muscle constriction as an integral part of asthma, only 8.9% of the primary caregivers recognized inflammation and 27.6% acknowledged mucus formation as part of asthma pathophysiology. This did not differ by area of residence or by level of education. Despite this, 60% identified use of daily preventive medications as moderately to extremely helpful in preventing future episodes of asthma. Further, although 62.6% of the parents appropriately acknowledged that albuterol had no role to play in asthma prevention and knew its use as a rescue medication; 44% were using albuterol daily. In addition, over 90% of families recognized that use of cough suppressants, rubbing of ointments such as Vicks Vaporub (Procter and Gamble, Cincinnati, OH) and administration of tea do not help with an asthma exacerbation. Yet, only 26% knew that avoidance of exposure to allergens is important in asthma prevention.

In the setting of the ongoing exacerbation, whereas 50% families started albuterol with onset of cough, 20% started treatment at the onset of wheeze and 15% of the parents waited until they noticed shortness of breath before initiating therapy. A significantly higher percent of caregivers residing in urban neighborhoods initiated early albuterol treatment as compared with those from rural areas ($p = 0.009$). Among those who appropriately started albuterol with cough, 45% also started prednisone at home before coming to the hospital. This did not differ by area of residence or education level.

The caregivers were also questioned on their perception of their child's asthma severity, classifying it as mild, moderate, or severe. Simultaneously, objective asthma severity was classified based on the frequency of daytime and nocturnal symptoms using the National Heart, Lung and Blood

TABLE 1.—Demographics, asthma knowledge, and beliefs of the study population based on their area of residence.

	Urban (n = 103)	Rural (n = 31)	p value
Age of child	5.4 $\pm$ 0.23	6.7 $\pm$ 0.63	0.01
Gender (M:F)	1.86:1	5.2:1	0.049
Age of caregiver	33.67 $\pm$ 5.19	35.71 $\pm$ 2.27	0.11
Parent present at visit (Father: mother)	0.66: 1	3.5:1	0.003
Family structure (Joint: nuclear)	1.51:1	1.58:1	0.91
Parents with college degree	90%	52%	<0.001
Family history of asthma	52.4%	38%	0.18
Confidence in physician	98.1%	80.6%	<0.0001
Perceived language barrier	1.9%	22.5%	<0.0001
Received asthma education	59.2%	35.4%	0.02

Institute (NHLBI) guidelines (14). The severity was appropriately identified as mild, moderate, and severe by 55%, 46%, and 53% of families, respectively. There was a trend noted among those who perceived that their child had severe asthma to have poorer control of symptoms as compared to those who classified their child's asthma severity to be mild or moderate ($p = 0.19$). The perception of severity or control did not differ by the level of education and area of residence.

Correlation between Asthma Medication use and Asthma Severity

Based on the asthma severity classified using the NHLBI guidelines, 23% children had moderate to severe persistent asthma of which only 42% were on daily inhaled corticosteroids. The asthma severity did not differ by gender or by area of residence. As shown in Figure 1, patterns of parental perception of asthma severity were overall comparable to objective classification using NHLBI guidelines, although more with mild asthma were classified as having moderate severity. The prescription of inhaled steroid was used as a surrogate marker of physician asthma severity classification. Physicians under classified severity among those children who had mild or severe persistent asthma, specifically among children who had higher frequency of nocturnal symptoms as compared to daytime symptoms.

Parental Identification of Asthma Triggers

Similar to the reports from developed countries (15), most parents identified weather change and upper respiratory infection as the most common triggers for their child's asthma. To elucidate if childhood asthma is potentially triggered by exposure to indoor allergens, the caregiver was asked about the presence of roaches, mice, pets, dust, and mold. All denied exposure to roaches, mice, and pets, and 30% recognized exposure to dust being a major trigger for their child's asthma. In addition, although 12.6% reported smoking, the majority did not smoke in the same room as the asthmatic child.

Psychosocial Impact of the Illness

The average number of school days missed in this cohort was 14.87 ± 3.4 days with about 40% reporting no missed school days. Although the parents recognized the need for albuterol use with an exacerbation, only 6.7% had an asthma action plan and only 8% mentioned that the school was equipped to give the child rescue medication in the setting of an exacerbation.

Stress associated with having an asthmatic child was reported by 13.8 % of those with graduate education as compared to 28% by those with no graduate degree ($p < 0.00001$). The degree of stress reported was not affected by whether the family was a nuclear or joint family and did not vary by the child's gender. Additionally, irrespective of the perceived stress and helplessness, 98% did not limit their child's physical activity and 96% believed that the asthma symptomatology would decrease, as their child grew older.

Beliefs on Effect of Asthma on the Girl Child

Of the 45 girls presenting with an asthma exacerbation, 73% of the parents believed that they would not need to hide the fact that their daughter has asthma and it would not affect her future. This did not differ by the area of residence, family structure, or education status of the caregiver. The perceived asthma severity was no different among girls as compared to boys, and an equal proportion of girls as boys were reported to be using inhaled steroids suggesting that there was no difference in the medical care given to girls in our cohort as compared to boys. The stress reported by parents of asthmatic girls was also similar to that among parents with male asthmatic children and did not differ by area of residence, education level, or family structure.

DISCUSSION

Asthma prevalence is increasing, particularly among children in developing countries such as India. Understanding of parental perception of disease and its acceptance is important as compliance with a preventative regimen is directly affected by these factors (16,17). Whereas studies in developed countries have demonstrated a relationship between

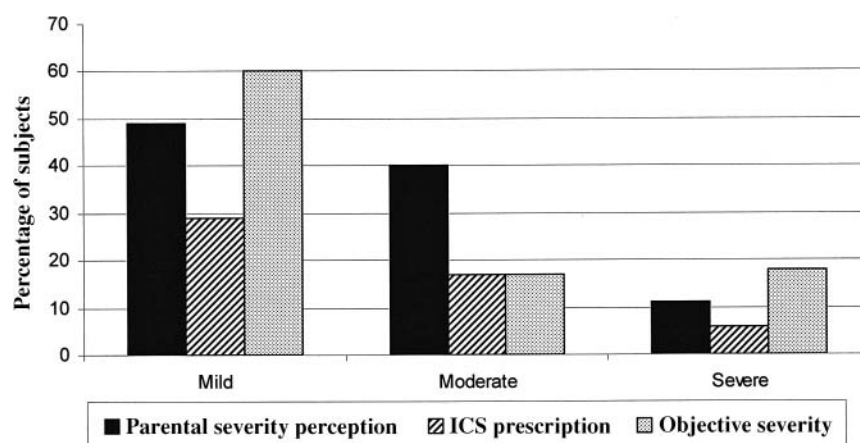


FIGURE 1.—Relationship between parental perception of asthma severity, objective asthma severity and prescription of inhaled steroids. The parental perception was similar to NHLBI classification. Using inhaled steroid prescription as a surrogate marker of physician asthma severity classification, the physicians under classified those with mild and severe asthma, particularly among those who had nocturnal symptoms.

caregiver's asthma understanding and home management, similar details are not as available for caregivers in developing countries such as India.

Our study shows that with increasing prevalence of asthma among Indian children, there seems to be greater acceptance of the diagnosis as well as a need for chronic medical management. We also identify a lack of difference in the care provided to daughters as compared with sons. There are striking similarities in childhood asthma management in rural and urban communities despite a difference in the parental educational level. These findings are contrary to the common beliefs that are quite prevalent in the medical society in India. In addition, the parents of these children are quite aware of their children's symptom frequency, at times more than the pediatrician as measured by prescription of the preventative medications. Similar to the results of a study conducted in a large metropolitan city in India (10), in the setting of an exacerbation, about 50% of the caregivers in our cohort appropriately initiated albuterol as well as prednisone. This was noted both among families hailing from an urban residence as well as from rural areas. However, there remains a lack of understanding of asthma pathophysiology that may be hampering the recognition of need for chronic medication use. As research in the developed countries have shown that greater understanding of asthma physiology increases the compliance with preventative medication regimen, it may be worthwhile to educate Indian families caring for asthmatic children, in addition to prescribing medications. While not evaluated in our study, previous reports from India on parental perceptions on asthma (8) had demonstrated the presence of unsubstantiated beliefs such as asthma being contagious and medications being addictive. Better understanding of asthma will also clarify and thereby decrease the prevalence of such beliefs. It will also give rise to improved quality of life with greater compliance with inhaled steroids (18).

The correlation of parental stress with increase in unscheduled medical visits among asthmatic children has been extensively studied in the developed countries (13). It has been correlated with maternal education as well as family support with increased stress reported by single parents. While there were no single parents in our study, we found that perception of stress was directly related to the educational status of the care provider with those with a graduate degree reporting less stress as compared to those without a graduate degree. However, this did not lead to limitation of physical activity or lack of adherence to preventative medications. With better understanding of asthma pathophysiology and management, it is likely that the perceived stress could be decreased further facilitating better home management of the disease.

Our study has certain limitations. As we only surveyed parents in a single city, it may not be completely reflective of the general Indian population. The difference between our results and those of Lal et al. (7) may be partly reflective of geographical differences and beliefs. In addition, we did not investigate their beliefs about food products and their link with exacerbation, an aspect that would have potentially identified findings similar to Lal et al. However, as reported before, general education on asthma will likely be beneficial for all families irrespective of their geographic location and local beliefs. Moreover, our findings substantiated those of Mittal et al. (10) evaluating the caregivers' response to an

asthma exacerbation suggesting certain similarities between populations, irrespective of area of residence. Further, as our total number of families studied is limited, whether the lack of difference was due to too few subjects is not evident. However, our study offers pilot data on the knowledge base and asthma management patterns of caregivers with female children with asthma and also among those from a rural community. More studies are needed to substantiate our findings.

In summary, we found that the primary caregivers of asthmatic children in India are aware of their children's disease severity and recognize the need for chronic medications. However, they lack the basic understanding of asthma pathophysiology and are stressed due to their child's illness, particularly if they reside in rural neighborhoods with limited education. Better understanding of the disease process may further increase use and compliance with preventive medications and decrease the perception of anxiety among these parents. Additionally, it will further empower these families to provide care for their children at home and may decrease the need for unscheduled medical visits and hospitalizations. Future prospective studies are needed to validate our findings as well as quantify the impact of education on decrease of perceived stress as well as asthma exacerbations among Indian asthmatic children.

DECLARATION OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

REFERENCES

1. Anderson HR, Bland JM, Patel S, Peckham C. The natural history of asthma in childhood. *Epidemiol Community Health* 1986; 40:121-129.
2. Speight AN, Lee DA, Hey EN. Underdiagnosis and undertreatment of asthma in childhood. *Br Med J (Clin Res Ed)* 1983; 286(6373):1253-1256.
3. Lodha R, Puranik M, Kattal N, Kabra SK. Social and Economic impact of childhood asthma. *Indian Pediatr* 2003; 40:874-879.
4. Asher MI, Weiland SK. The International Study of Asthma and Allergies in Childhood (ISAAC). ISAAC Steering Committee. *Clin Exp Allergy* 1998; 28 (suppl 5):52-66; discussion 90-91.
5. The International Study of Asthma and Allergies in Childhood (ISAAC) Steering Committee. Worldwide variation in prevalence of symptoms of asthma, allergic rhinoconjunctivitis, and atopic eczema: The International Study of Asthma and Allergies in Childhood (ISAAC). *Eur Respir J* 1998; 12:315-335.
6. Brook U, Mendelberg A, Heim M. Increasing parental knowledge of asthma decreases the hospitalization of the child: A pilot study. *J Asthma* 1993; 30:45-49.
7. Lal A, Kumar L, Malhotra S. Knowledge of asthma among parents of asthmatic children. *Indian Pediatr* 2002; 32:649-655.
8. Shivbalan S, Balasubramanian S, Anandnathan K. What do parents of asthmatic children know about asthma?: An Indian perspective. *Indian J Chest Dis Allied Sci* 2005; 47:81-87.
9. Gupta SK, Sen Mazumdar K, Gupta S, Sen Mazumdar A, Gupta S. Patient education programme in bronchial asthma in India: Why, how, what and where to communicate. *Indian J Chest Dis Allied Sci* 1998; 40:117-124.
10. Mittal V, Khanna P, Panjabi C, Shah A. Subjective symptom perceptual accuracy in asthmatic children and their parents in India. *Ann Allergy Asthma Immunol* 2006; 97:484-489.
11. Barnes PJ. Poorly perceived asthma [editorial]. *Thorax* 1992; 47:408-409.
12. Mitchell H, Senturia Y, Gergen P, Baker D, Joseph C, McNiff-Mortimer K, Wedner HJ, Crain E, Eggleston P, Evans R 3rd, Kattan M, Kercsmar C, Leickly F, Malveaux F, Smartt E, Weiss K. Design and methods of the

- National Cooperative Inner-City Asthma Study. *Pediatr Pulmonol* 1997; 24:237–252.
13. Klinnert MD, Kaugars AS, Strand M, Silveira L. Family psychological factors in relation to children's asthma status and behavioral adjustment at age 4. *Fam Process* 2008; 47:41–61.
 14. National Heart, Lung and Blood Institute 2007. Expert Panel Report 3: Guidelines for the diagnosis and management of asthma. National Institute of Health, Bethesda, MD.
 15. Wassall HJ, Devenny AM, Daud Khan S, Ninan TK, Russell G. A comparison of virus-associated and multi-trigger wheeze in school children. *J Asthma* 2005; 42:737–744.
 16. Graves MM, Adams CD, Bender JA, Simon S, Portnoy AJ. Volitional nonadherence in pediatric asthma: Parental report of motivating factors. *Curr Allergy Asthma Rep* 2007; 7:427–432.
 17. Bender B, Milgrom H, Rand C, Ackerson L. Psychological factors associated with medication nonadherence in asthmatic children. *J Asthma* 1998; 35:347–353.
 18. Singh M, Mathew JL, Malhi P, Srinivas BR, Kumar L. Comparison of improvement in quality of life score with objective parameters of pulmonary function in Indian asthmatic children receiving inhaled corticosteroid therapy. *Indian Pediatr* 2004; 41:1143–1147.