What Do Parents of Asthmatic Children Know About Asthma?: An Indian Perspective

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ABSTRACT

Background. Despite the magnitude of the asthma problem, very little is known about the public perception about asthma.

Methods. This descriptive study was conducted to evaluate the knowledge, attitude and practice about the causation, treatment and prognosis of asthma amongst the parents of children with asthma. Subjects were parents of asthmatic children attending two exclusive paediatric hospitals at Chennai, India. A semi-structured pre-validated questionnaire, which included their general understanding on asthma, its triggers and management, was administered.

Results. One hundred parents of asthmatic children participated in this study. A diagnosis of asthma was accepted only by 39%, of which only three knew exactly what asthma means. Perception that asthma is contagious was observed by 26%, and 35% believed asthma to be a hereditary disease. Various dietary items were perceived as triggers. Most of the parents (62%) administered oral beta-agonist medication at home before proceeding to hospital, but majority were using them as cough medication. Only 13 were administering aerosol therapy at home. Nearly one-third of the parents opined that the disease might remit with advancing age.

Conclusions. General awareness of asthma in the community is poor. Patient education programme should augment awareness, eliminate social stigma and misconcepts in the community regarding asthma. Knowledge about the prevailing perception in the community would be the first step in achieving this.

Key words: Asthma awareness, Patient education programme.

INTRODUCTION

The World Health Organisation recognises asthma as a major health problem. Parents’ perception of their child’s disease is a significant factor influencing the acceptance of the disease and compliance to therapy. Therefore, patient education programme (PEP) forms an integral component in the long-term management of asthma. Despite the magnitude of the problem, very little is known about the public perception to the diagnosis and the impact of asthma on individuals, their families and communities.

The objective of the present descriptive study was to evaluate the knowledge, attitude and practice of the parents of asthmatic children about the causation, treatment and prognosis of asthma.

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MATERIAL AND METHODS

The study was conducted at Chennai City in South India, in two exclusive children’s hospitals, namely, Kanchi Kamakoti CHILDS Trust Hospital (KKCTH) and Institute of Child Health and Hospital for Children (ICH & HC). Patients attending the out-patient department, emergency room and pulmonology department were enrolled for the study from June 2001 to September 2001. A diagnosis of asthma was based on history of recurrent reversible bronchospasm responding to bronchodilator drugs.

Children between 2 to 15 years of age having more than four documented episodes of wheeze, with two episodes in the last six months, with at least two emergency room visits and one hospitalisation were enrolled for the study. Children with chronic illness, on therapy for tuberculosis, bronchiectasis, and cardiac diseases were excluded from the analysis. Children who were not accompanied by their parents were also excluded.

An informed consent was obtained from all the participants. A semi-structured pre-validated questionnaire (see Annexure) was administered to the parents of these children. The questions were designed to elicit a short answer or response to a multiple-choice format. The parents were asked about their perception of asthma/their child’s illness as to what they perceived. The questions dealt with the nature of illness, natural history, aetiology, treatment and prognosis. The parents were asked to identify and describe possible causes of asthma with no limit being placed on the number. The same person (S. Shivbalan) conducted the interview in a separate room with the parents of the child. Each interview lasted for 30 to 40 minutes. No attempt was made to correct a wrong answer or response until the completion of the interview.

RESULTS

A total of 100 cases were enrolled for the study and the interview was completed. Fathers were the respondents in 37 and mothers in the remaining 63. The socio-economic status was assessed as per Gupta’s classification (based on per capita income). Majority of the respondents belonged to the middle strata (87%), with most of them living in urban areas (urban 61% semi-urban 26% and rural 13%). Amongst asthmatic children, 61 were boys and 39 were girls, with age ranging from 26 months to 14.5 years. Among the participants 73 were literate (able to read and write a single language with understading) with 27 being illiterate.

Does your child have asthma?

More than a third of the parents responded to the question saying that their children have asthma (39%) and all of them had come to know of the diagnosis through a physician only. The physician was the only source of information regarding the diagnosis and disease related scientific knowledge to these patients. Other responses to this question were wheeze (46%), recurrent respiratory infection (8%), eosinophilia (3%), primary complex (2%), allergy (1%), and respiratory distress (1%).

What do you know about asthma?

Majority of the respondents (54%) were not aware of what asthma is. Asthma as a disease causes difficulty in breathing, due to cold, dust and congestion in the chest was the commonest perception (16%) in those who answered that they were aware of what asthma is. A few (14%) opined that it is a disease of adults, which causes growth retardation and decreased work capability. Only three respondents knew the correct definition of asthma (reversible bronchial obstruction). Other answers, like incurable disease (3%), disease secondary to decreased immunity (2%), tuberculosis (2%), wheezing (2%), contagious disease (2%) and recurrent respiratory infection (1%) were obtained. One of the respondent attributed the illness to be an aftermath of infection acquired antenatally due to ingestion of food substances like citrus fruits and iced drinks by the mother.

Is asthma/their child’s illness hereditary?

One-third of the respondents (35%) believed
that asthma is a hereditary disease. Family history of asthma was elicited in 45 percent. Parents of nine children with a family history of wheeze/asthma failed to accept a diagnosis of asthma in their child, despite being informed by the physician, as they considered it to be a disease affecting only adults.

Is asthma/their child's illness contagious?

The perception of asthma as a contagious disease was observed in 26 percent. “Can my younger daughter play and mingle with my son with wheezing” was a common doubt amongst parents. The other opinion elicited in the interview included perception of asthma as air borne disease (20%), water borne disease (3%), due to fomites (7%) and dust (2%).

What caused asthma/their child's illness?

Majority attributed the illness to be due to exposure to various perceived triggers, most of them being dietary items. Dust, cold air (60%) and tobacco smoke (61%) were identified as triggers. Cool drinks, iced water and ice creams were perceived as triggers (68%). Parents also perceived a variety of other triggers as depicted in the table below. Those parents who attributed the asthmatic symptoms to various food substances said that they avoided giving these to their children.

<table>
<thead>
<tr>
<th>Perceived triggers</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cool drinks</td>
<td>68</td>
</tr>
<tr>
<td>Iced water</td>
<td>68</td>
</tr>
<tr>
<td>Sweets</td>
<td>44</td>
</tr>
<tr>
<td>Exercise</td>
<td>30</td>
</tr>
<tr>
<td>Rainy season</td>
<td>29</td>
</tr>
<tr>
<td>Chocolates</td>
<td>26</td>
</tr>
<tr>
<td>Strong odour</td>
<td>25</td>
</tr>
<tr>
<td>Curd</td>
<td>20</td>
</tr>
<tr>
<td>Banana</td>
<td>18</td>
</tr>
<tr>
<td>Grape</td>
<td>17</td>
</tr>
<tr>
<td>Head wash</td>
<td>16</td>
</tr>
<tr>
<td>Orange</td>
<td>14</td>
</tr>
<tr>
<td>Tomato</td>
<td>10</td>
</tr>
<tr>
<td>Cockroaches</td>
<td>10</td>
</tr>
<tr>
<td>Animal dander</td>
<td>10</td>
</tr>
</tbody>
</table>

Table. Perceived triggers by parents of asthmatic children (n=100)

What will you do if your child gets attack of asthma/their child's illness?

The most common response (62/100) was that they would administer oral beta-agonist medication at home and proceed towards the hospital, with most of them (45/62) using these as cough medications. Visit to the neighbouring physician/hospital was the next common response (20%). Administering of beta-agonist medication using a spacer device at home was reported by eight of the parents interviewed. The other responses elicited included perceived triggers as air borne disease (20%), water borne disease (3%), due to fomites (7%) and dust (2%).

Awareness of aerosol therapy?

All the 100 children had required aerosol therapy of beta-agonist with a nebuliser at least once for control of acute symptoms. Use of nebuliser for therapy was declined by 18% of parents in the out-patient services, saying that it caused nerve weakness because of the vibrations and felt that it should be used only in very sick children. Only 13 children were using aerosol at home. One of the enrolled children was on home nebuliser therapy and the remaining 12 were using spacers (9 on beta-agonist and steroid; 3 on beta-agonist alone). All the parents (n=9) whose children were on aerosol therapy uniformly expressed the opinion that aerosol therapy was addictive and continuous use of medications during symptom free interval will impair their child’s ability to outgrow the disease. One of them felt that aerosol therapy increases the symptoms during exacerbations and was giving oral bronchodilators. Forty respondents felt that these devices should be used only in very severe cases, as a last resort. Majority were not aware (47%) that aerosol therapy can be given at home.

Prognosis of asthma/their illness

Once-third of the respondents (34%) thought
that asthma wanes off with increasing age due to increasing immunity and one-fourth felt that the disease was not curable and requires lifelong treatment during episodes. The other opinions were: (i) asthma is a treatable disease, which decreases in severity with age (19%), (ii) asthma is treatable (6%), and (iii) it can be controlled (3%). Those who were not aware of the prognosis of the disease (19%) blamed their fate for the suffering of their children.

**DISCUSSION**

More than half of the population of parents of asthmatic children we interviewed had no real idea about the disease. The diagnosis of asthma was accepted by only 39% of the parents, most of them having a family history of wheeze. The perception of asthma as a disease due to allergy causing narrowing of airways was observed only in 3% of parents interviewed and a few perceived asthma only as an adult oriented disease. Parents easily accepted the diagnosis of asthma if there was a family history of asthma. Inspite of 46 respondents accepting that their children had wheeze, only two of them equated the same with a diagnosis of asthma. The lack of awareness of correct diagnosis is significant, since all children included had recurrent episodes resulting in hospitalisation and emergency room visits. This is a pointer towards the poor asthma awareness prevailing amongst the asthmatic population in Indian children.

In our series, only the physician had disseminated the knowledge of asthma to parents who knew and accepted that their children had asthma. This reinforces the need for the role that can be played by media, non-governmental organisations (NGOs) and health workers in health education regarding asthma. Formulation of national programmes, conducting continuing medical education (CME) programmes and frequent reminders, such as newsletters, are initial steps in improving asthma knowledge and awareness in the community.

The perception of asthma as a hereditary disease (35%) and as a contagious disease (26%) were other significant observations. The concept of the disease being hereditary and the social stigma attached to the disease hamper the acceptance of the problem in their children. In view of this parents and physicians in particular, intentionally use different entities like ‘allergic bronchitis’, ‘cold allergy’, ‘chronic bronchitis’ to label the disease. A previous KAP study in India in the last decade documented almost similar observations. Allergen control helps in improving asthma and reducing the need for medication. In our series the correct identification of triggers like exercise, strong odour, animal dander, cockroach and tobacco smoke is encouraging. In India 14.8% of asthmatics have been reported to show asthmagenic response on allergic food challenge test. Studies have identified food triggers like grapes (57%), banana (53%), guava (51%), citrus fruits (28%), ice creams (21.5%) and tomatoes (12.5%). Our series too had similar observations. Similar observations have been made from neighbouring Pakistan and Saudi Arabia, where nutritious foods have been reported as perceived triggers for asthma. The cause-effect relationship between triggers and wheeze needs to be further looked into. But the perception that asthma is a disorder precipitated by triggers can be used to our advantage in patient education programmes.

Self-administration of oral beta-agonist for acute symptoms at home was the commonest action plan reported by parents (62%). This is encouraging as it forms a right step toward therapy of acute asthma. An earlier study from India also recorded similar observation that 89.4% of parents either gave bronchodilator at home or consulted a doctor. Even in a developed country like USA only 25% of hospitalised adult patients had written action plan for asthma management. In our series, administration of topical proprietary antihistamine preparations, antibiotics, antihistamine and prayer were other modalities of treatment practiced by patients. None in our study had reported administering corticosteroids by themselves for an acute attack. The observation that only 2% administered antibiotics on their own for acute exacerbation is heartening. The attitude that all
episodes irrespective of severity have to be seen by their physician needs to be changed. It has been earlier reported that patients who did not report a history of asthma were more likely to be treated with antibiotics and anti-tussives in place of drugs indicated for asthma15.

Very few children (13%) in our study group were on aerosol therapy at home. The notion that these devices are addictive or harmful has lead to the non-acceptance of these modalities of therapy amongst the patients in our series as has been reported earlier2,4. Though all children received aerosol through a nebuliser at least once for the control of acute symptoms, acceptance of aerosol therapy overall is poor. It is a common misconception that aerosol therapy is the end to the road2, and this scenario remains unchanged in our cases. In the management of chronic asthma, patient’s acceptance of the disease and compliance to therapy play a major role2. It has been observed that parents hesitate to use long-term preventive medications particularly in symptom free interval because they consider asthma to be a series of acute episodes rather than a chronic disease4. Parents in the study also held the view that continuous medicines impair the child’s ability to outgrow the disease.

Parents held diverse views regarding the prognosis and treatment of asthma. One-third thought that the disease wanes off with age while one-fourth thought that the disease was not curable. The concept of asthma being ‘not curable’ like tuberculosis or malaria impedes the acceptance of the disease2. Few felt that asthma was treatable or controllable reflecting the prevalence of wrong concepts about the disease amongst parents. However, the perception that children outgrow the problem with age by one-third of the parents interviewed is encouraging.

In conclusion, information about asthma has not percolated enough towards parents of asthmatic children in our setting. Misconceptions about the disease and the paucity of information about current trends in management among parents are a significant finding. Asthma management programmes as incomplete without a good tailored patient education programme. Such a programme should augment awareness, eliminate social stigma and misconcepts in the community regarding asthma. Knowledge about the prevailing perception in the community would be the first step in achieving this.

**Annexure**

**Proforma**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date of Birth:</th>
<th>Age:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td>Sex:</td>
<td>Hosp. No.:</td>
</tr>
<tr>
<td>Literacy of the parent (Respondent):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Able to read and write a language with understanding]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural/Urban/Sub-urban:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-economic status (per capita income):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Gupta’s classification]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of onset of wheeze/presenting illness:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family H/O asthma/similar illness:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings/Parents/Grand parents/Others (cousins/uncle/aunt)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your child have asthma?: Y/N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If yes, how did you come to know that your child has asthma?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If no, what disease do you think your child has?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What do you know about the disease asthma?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Is asthma/your child’s illness, a hereditary disease?

Is asthma/your child’s illness, a contagious disease?

What do you think asthma/your child’s illness is caused by?

Who is regularly treating your child for asthma/your child’s illness?
  G.P./Pulmonologist/Pediatrician/Other’s [specify]

What will you do if your child develops acute wheezing/breathlessness with cough, at the middle of the night at home?

What measures have you taken so far to prevent asthma/your child’s illness?

Who advised you these methods?

What medicines do you have at home for this illness (asthma/your child’s illness)?

Which of these factors precipitate asthma/your child’s illness?

  Tobacco smoke Y/N
  Dust mite (mattress/pillow/curtain/stuffed toys) Y/N
  Animal dander Y/N
  Cockroach Y/N
  Indoor mould Y/N
  Pollen/outdoor mould Y/N
  Strong odour (sprays/perfume/talcum powder) Y/N
  Other smells Y/N
  Exercise Y/N
  Sports Y/N
  Cold air Y/N
  Medicines Y/N
  Swimming Y/N
  Sulfite in food (dried fruits/processed potato/sauces) Y/N
  Any other [specify in their own words]
  Do you know about aerosol therapy Y/N
  Is your child on aerosol therapy? Y/N
    If yes, the device used: MDI/MDI + spacer/MDI + spacer + mask DPI/Nebuliser

Who initiated aerosol therapy?
  G.P./Pulmonologist/Pediatrician/Other’s [specify]

What aerosol drug is your child been given?
  Beta–agonist/Salmeterol/Steroids/Sod. Cromoglycate

Do you think aerosol therapy (MDI/DPI/Nebuliser) is
  Addictive: Y/N
  Harmful: Y/N

If harmful what are their side effects (in their own words)?

How did you come to know about the side effects of aerosol therapy (MDI/DPI/Nebuliser)?

Is your child receiving any regular daily oral medication for more than a month?: Y/N
  If yes, what medication?
  Advised by whom?

Do you think asthma/your child’s illness is curable?

Do you know about peak flow meter? Y/N
  If yes, are you using one? Y/N

Any alternative system of medicine attempted? Y/N
  If so, details:
REFERENCES


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