SOCIO-ECONOMIC BURDEN OF CHILDHOOD ASTHMA

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ABSTRACT

The socio-economic burden of childhood asthma has not been assessed in India. We interviewed parents of asthmatic 85 children in the age group of 6-17 years who were suffering from asthma. Socio-economic burden of asthma was assessed by using Pai and Kapur's interview schedule and the results were analyzed by using Chi square, Student's V test and Pearson's product movement correlation coefficient.

Severe burden was experienced by the family in 25.9% cases. Total burden score was significantly associated with severity of asthma \( p < 0.001 \) and socio economic status of the family \( p < 0.01 \).

These results indicate that there is need for health professionals and social support organizations to chalk out programmes to provide support to families of children with chronic/ recurring illness like bronchial asthma in order to reduce the anxiety and other hardships suffered by the families.

Keywords: Socio-economic burden, Asthma severity, Childhood asthma.

Asthma is the commonest chronic illness of childhood and accounts for more school absenteeisms than any other chronic illness\( (1,2) \). Chronic illnesses affect the whole family to an extent determined by the nature of the illness, its severity and prognosis, expenses and psychologic stress. Simultaneously, the extent to which burden is experienced, is determined by the social milieu, the socio-economic status of the family, family structure and so on. Previous studies have highlighted the burden experienced by families of children with asthma.

In a study in Andrew \textit{et al.}(3), families of children with severe asthma had more indicators of stress, including, resentment between parents, a trend towards fewer joint family activities, mothers who were less self reliant and others. Reddihough(4) reported that 57% of parents considered asthma to be a great stress on all members of the family. In Cosper and Erickson's(5) study, mothers of asthmatic children reported greater stress and worried about the future outcome" of the child. Vance and Taylor(6) and Marion \textit{et al.}(7) reported on the profound impact of childhood asthma on the economic well being of the family. Most of the developing countries are located in Africa and Asia where the cultural milieu and economic status is very different from Western countries from where the above works have been reported. In India, where the social environment is different and is undergoing many changes, no such studies have been conducted even though bronchial asthma is a very common childhood illness. We, therefore, calculated the effect of childhood asthma on the families of different socio-economic strata in North India.

Subjects and Methods

The study population consisted of 85 children suffering from asthma between 6-
17 years of age who attended the Allergy Clinic or the Emergency Department of PGIMER between January 1989 to August 1990. The children were divided into 3 age groups: Groups A: 6-9 years (n=30), Group B: 10-13 years (n=30) and Group C: 14-17 years (n=25). Criteria for inclusion in the study were: (1) Physician diagnosed asthma, and (2) duration of asthma of at least 2 years.

Family characteristics, socio-economic status (SES), severity of asthma and socio-economic burden were evaluated. The SES of the family was determined according to Gupta and Sethi's(8) SES scale. This scale is widely accepted in India and determines the SES according to education, income and occupation of the family members. The total score obtained on this scale was divided into high SES (>430), upper middle SES (330-420), middle SES (230-320), lower middle SES (130-220) and lower SES (<120). The severity of asthma was graded as mild, moderate or severe after obtaining detailed clinical history and examination in each case according to the criteria suggested by Ellis(9).

The socio-economic burden of asthma on the family was assessed by Pai and Kapur's interview schedule(10). The reliability and validity of the schedule were satisfactory. It assesses the burden on the family in the following areas: financial burden, disruption of family routine, disruption of family leisure, disruption of family interaction and the effect on physical and mental health of other family members. In addition subjective, burden experienced by the family is evaluated by asking a direct question at the end of the interview. The items are recorded as absent, moderate or severe on an ordinal scale of 0, 1 and 2, respectively. The scale was originally devised to assess burden in families of psychiatric patients but subsequently it has been extended to other illnesses(11). A slight modification in the language of certain items was made to make it suitable for application to families of asthmatic children. The score for each category as well as the total score were divided into three categories of no burden (<mean - 0.5 SD), moderate burden (mean ± 0.5 SD) and severe burden (>mean + 0.5 SD).

All interviews were conducted in a separate room by one of us (AL) with either the mother or the father of the patient, depending upon whoever accompanied the child to the hospital. Parents were explained the project, and consent obtained. Those who consented were interviewed in absence of the child. Statistical methods in the form of Chi square test (for frequencies) and Student's 't' test and Pearson's Product moment correlation coefficient (for scores) were used as applicable.

Results

Sociodemographic Data

There were 51 males and 34 females in the sample (1.5:1). The ratio was comparable in the three groups. Sixty-six (77.7%) patients were urban whereas 19 (22.3%) were from villages. The SES of the sample is depicted in Table I. Majority of the patients (57.67%) belonged to middle and lower middle SES. The three age groups were comparable. Fifty-six (65.9%) families were nuclear, 16 (18.8%) were joint and 13 (15.3%) were extended nuclear (usually one of the grandparents staying with the family). Among the 19 rural patients there were 7 joint families, 11 nuclear families and one extended nuclear family. Mother was employed in 17 out of 85 (20%)
**TABLE I- Groupwise Distribution of Socio-Economic Status (SES)**

<table>
<thead>
<tr>
<th>SES</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1 (1.2)</td>
</tr>
<tr>
<td>Upper Middle</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>10 (11.8)</td>
</tr>
<tr>
<td>Middle</td>
<td>10</td>
<td>11</td>
<td>9</td>
<td>30 (35.3)</td>
</tr>
<tr>
<td>Lower Middle</td>
<td>11</td>
<td>11</td>
<td>5</td>
<td>27 (31.8)</td>
</tr>
<tr>
<td>Lower</td>
<td>7</td>
<td>5</td>
<td>5</td>
<td>17 (20.0)</td>
</tr>
</tbody>
</table>

The number of children varied between 1-5 but the majority of the families (40, 54.1%) had 3 children.

**Clinical Data**

In 25 cases (29.4%) the onset of symptoms was before 3 years of age. A large number of children (28, 32.9%) had the onset of symptoms between 4-6 years. The duration of illness ranged from 2-12 years. Forty-six (54.1%) children had a duration of symptoms less than 6 years, whereas 39 (45.9%) had a duration more than 6 years.

The number of school days missed per month varied from 0-15. The mean (SD) was 2.08 (3.40) days per month with a majority of children (>50%) not missing a single school day in a month (median = 0).

In the various groups, the values were (mean, SD) Group A 2.70 (3.30), Group B 2.10 (3.63) and Group C 1.32 (3.07). The values for median and range (in brackets) were 2 (0-12), 0.5 (0-15) and 0 (0-5), respectively for Groups A, B and C. There was a decrease in school absenteeism in older children. The average number of attacks per year was 10.46 (SD 10.9). The median was 5 attacks per year with a range of 1 attack to continuous wheezing in two children. The responsibility for the care of the child rested with the mother in majority of the cases (55, 65.9%). Fathers alone were responsible for the child's care during illness in only 19 (22.4%) cases. In the rest of the 10 (11.8%) cases, this responsibility was shared by the two parents.

**Burden**

The groupwise distribution of total objective burden score and subjective burden is given in Table II. The difference between subjective and objective burden categories was not significant ($\chi^2 = 1.97$, $p=ns$). There was no significant difference between the three groups in the distribution of objective ($\chi^2 = l-97$) or subjective burden ($\chi^2 = 4.85$, $p=ns$).

**Figure 1** shows the groupwise distribution of severity of asthma. The number of children with severe asthma was only 5, while 32 (37.7%) had moderate and 45 (52.9%) had mild disease.
families (p<0.01, Fig. 2). There was no association with the working status of the mother, size of the family, nuclear versus joint family, urban versus rural background, duration of illness, sex of the child or age of the child (Table IV).

There were 22 asthmatic children whose families experienced severe burden. Out of these, there were 13 girls and 9 boys. None of these children came from SES Classes 1 or 2. Four belonged to SES Class 3, 9 to SES Class 4 and 10 to SES Class 5. Nine children came from joint/extended nuclear families and 13 from nuclear families. There appeared to be a trend towards larger family size with 14 cases coming from families with 3 or 4 children. Seven cases were from families with 2 children.

**Discussion**

There are differences in the epidemiology of childhood asthma between western countries and India. The incidence of severely affected cases is lower in this country (only 5 out of 85 patients were classified as severe in the present study). On the other hand widespread poverty exposes even the families of mild to moderately affected children to severe burden. This is brought out by
the fact that even though severe asthmatics constituted 5.9% of the sample, severe burden was experienced by the family in 25.9% of the cases. In McAndrew’s study(3) conducted in Australia, only the group consisting of severe asthmatics differed significantly from the control group in having more indicators of stress in the families. The less severely affected children were identical to the control group. Many previous studies highlight the greater involvement of mothers with the ill child than other family members(5). Mothers also experienced a greater degree of psychologic stress. In the present study, mother was responsible for the care of the child during illness in

<table>
<thead>
<tr>
<th>Severity of burden</th>
<th>Burden category</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>I</td>
</tr>
<tr>
<td>Low n (%)</td>
<td>56</td>
</tr>
<tr>
<td>Moderate n (%)</td>
<td>18</td>
</tr>
<tr>
<td>High n (%)</td>
<td>11</td>
</tr>
<tr>
<td>Total cases</td>
<td>29</td>
</tr>
</tbody>
</table>

**Key**

1 = Financial burden;  
II = Disruption of family routine;  
III = Disruption of family leisure;  
IV = Disruption of family interaction;  
V = Effect of physical and mental health of other family members.

![Bar chart](image)

**Fig. 2. Relation of objective burden to socio-economic status.**
65.9% cases. However, no significant difference in the response to the question on subjective burden could be found between the mothers and fathers interviewed. There was insufficient data to comment upon the differences between families where mother undertook responsibility for the child's care compared to those where the father alone or both parents were equally responsible. The incidence of single parent family was very low (2 out of 85) in the study.

There was a good correlation between total objective burden score and subjective burden ($r=0.632, p<0.01$). This showed that in a large majority of cases, the assessment of burden using the Pai and Kapur's interview schedule(10) was strongly predictive of the respondent's personal assessment of overall burden experienced by his/her family. The interview schedule was useful for exploring the different spheres of burden experienced by the family.

Burden experienced by the family was significantly related to the severity of the child's illness. As the number of cases of severe asthma was small, moderate to severely affected children were compared to those with mild disease, and their families had significantly higher burden scores (Table III). This may be on account of the effect of severe illness in the child on the following areas of family life (i) family finances, (ii) disruption of family routine, and (iii) effect on mental health of other family members.

Of these, the effect on mental health of other family members was most noticeable. Parents complained of loss of sleep, depression, irritability and episodes of crying. A number of mothers broke down during the interview or gave the impression of experiencing pain when probed on this aspect of burden. In addition to factors like physical safety of the child, ultimate prog-
nosis and unpredictable nature of the disease, other aspects that are important in Indian society may increase the mental stress. These include the social stigma attached to the disease, neglect of household and other children during periods of illness and financial difficulties where mother contributes significantly to the daily income of the family.

SES of the family was the other factor significantly associated with burden (Table III and Fig. 2). None of the high SES or upper middle SES families (11 patients) complained of severe burden. The majority of lower middle and low SES families experienced mild burden. Earlier studies (6,7) also mention the inability of low income group families to cope up with the child's illness. Financial problems might be expected to account for the majority of burden experienced by such families. This assumption was however, not entirely true. In India, where subsidized health care is available at state run hospitals, direct costs of asthma including expenditure on physician fees, hospitalization, laboratory tests and medicines probably do not constitute a big chunk of asthma related expenditure. However, for families belonging to low SES, the indirect costs which include transportation and time lost from work can be enormous—more so because most individuals belonging to this class are menial labor and have no regular job. Because good health care facilities are available at only regional hospitals, many patients have to travel a long distance. These families stand to lose the equivalent of several days income and it leads to irregular follow-up and delay in seeking medical help in case of acute attacks. The problem of disruption of family routine cannot be overestimated when the mother has to look after the child during an attack at borne or when she stays with the child in the hospital. Due to lack of social support in many cases, other children in the family are left with neighbors or to themselves during her absence.

There is no doubt that the lower SES families are the worst affected due to asthma. The situation is particularly bad when there is a child with moderate to severe asthma in a lower middle or low SES family.

Although it was postulated at the beginning of the study that joint families would experience lesser burden, this was not so. It is possible that the social and financial support forthcoming in a joint family setting may be less than what is generally assumed.

In India, lack of organized social support system and restriction of quality health care to regionalized urban medical centres contribute to the burden imposed by childhood asthma on the family. More medico-social services to educate and help the families of children with asthma should go along with medical treatment in decreasing the stresses experienced by these families.

REFERENCES


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