

# Impact of Childhood Asthma on Children and Mothers; Exploring the Sri Lankan Situation

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## Abstract:-

**Background:** The emotional and social effects associated with childhood asthma are often underestimated. The clinical presentation of childhood asthma, its complications and sequelae may vary from child to child. In addition, asthma being a chronic illness impacts on patient and their families too. It is very important to recognize the stresses and the burden experienced by families of these children. Many asthma patients and their families try to live as “normal” as possible by adjusting to their restrictions or suppressing them. Evidently, the chronicity of the childhood asthma with its transient disability during repeated attacks can adversely influence the child and the family.

**Methods:** The impact of the childhood asthma on the child and the family were assessed using Children Health Survey of Asthma (CHSA) questionnaire which was validated in the local setting. The questionnaire was administered to mothers of children aged 5 to 11 years or the person who spent the maximum time with the index child when the mother is not there to look after the child. The study was conducted in the Colombo Municipal Council area in the Colombo district. The study population was the children aged between 5 to 11 years who had asthma attack within two weeks prior to data collection and their mothers and/ or the caregivers.

**Results:** Assessment of the impact of the childhood asthma on the child and the family assessed using CHSA questionnaire the severity of the disease was significantly associated with mean scores of four of the five domains: Physical health of the child ( $p < 0.001$ ) Emotional health of the child ( $p < 0.001$ ), Emotional health of the family ( $p < 0.001$ ) and the Activities of the child ( $p < 0.001$ ). There was no association between severity of the disease and the activity of the child mean score ( $p > 0.001$ ).

**Conclusion:** Higher scores for all given domains were seen among the low symptom group children, means better health. With the increase of age, score of the physical health of the child is decreasing.

**Keywords:-** Childhood asthma, emotional impact, physical impact.

## I. INTRODUCTION

Asthma is derived from Greek word “azein” which means laboured breathing. It is a respiratory disorder in which breathlessness and wheezing occur, caused by excessive contraction of muscles in the walls of the air passage. An International Pediatric Asthma Group<sup>1</sup> defined asthma as a condition in which episodic wheeze and/or

cough occur in a clinical setting, provided that other rare conditions have been excluded. In simple terms, it may be explained as an illness where there are repeated attacks of difficulty in breathing and/ or cough which may be accompanied by a wheeze and this is the most common chronic respiratory disease in childhood<sup>2</sup>.

The emotional and social effects associated with childhood asthma are often underestimated. The WHO defines Health as “a state of complete physical, mental and social wellbeing and not merely the absence of disease”. For an individual to be viewed as generally healthy one should consider the total person. The clinical presentation of childhood asthma, its complications and sequelae may vary from child to child. In addition, asthma being a chronic illness impacts on patient and their families too. It is very important to recognize the stresses and the burden experienced by families of these children. Many asthma patients and their families try to live as “normal” as possible by adjusting to their restrictions or suppressing them. Evidently, the chronicity of the childhood asthma with its transient disability during repeated attacks can adversely influence the child’s freedom in playing and in their education. The parent’s anxiety and concerns further complicate this situation. This is likely to be due to a lack of awareness of the true nature of the disease among affected children’s parents. Such restrictions indirectly affect the inherent rights of a child to engage in the normal activities of the childhood.

Parents have a significant role to play in the management of children with a chronic illness like asthma. They have to cope with their careers and personal lives and other obligations while caring for their sick child. A study conducted by Donnelly et al<sup>3</sup> among parents with children who suffered from asthma and parents of children without asthma found that both groups were of the opinion that asthma disrupts holiday arrangements, restricts social life, constitutes a financial burden, interferes with parental relationships and reduces the time that the parents give to the other children. These findings indicate the general attitudes towards the disease.

The worldwide economic cost associated with asthma is estimated to be more than that of HIV/ AIDS and tuberculosis combined. Even with recent advances in management, it is the leading cause of hospitalization and school absenteeism in children. Annual deaths from this disease exceeds 180,000 worldwide and tragic truth is that a very large proportion of fatalities are preventable.

The WHO has identified asthma as a disease of major public health importance. The WHO plays a unique role in coordination of the international efforts to combat the

disease. In 1992, the WHO and the United States based Heart Lung and Blood Institute jointly formed GINA (Global Initiative for Asthma) to reduce the number of deaths by developing and implementing an optimal strategy for asthma management and prevention. The main goal of the GINA is to build active networks with multiple organizations involved in all aspects of the disease in order to ensure better patient care worldwide. To highlight the plight of asthma sufferers and to raise public and professional awareness about this disease, the WHO launched the “World Asthma Day”. The World Asthma Day is marked each year under different themes<sup>4</sup>.

To assess the impact of the disease on the child and the family, several validated questionnaires have been developed<sup>5,6,7</sup>. However, there is no single universally accepted questionnaire<sup>9</sup>.

The presence of a disease can cause distress and concern. Therefore, any disease may be expected to have some impact on the social and the emotional aspects of the lives of the sufferers and their carers. In addition, there may be an impact on the physical health of the sufferers. It may be greatest where symptoms are inadequately controlled. Prevention and management strategies themselves can create difficulties in people’s everyday lives. All these factors are true for the childhood asthma as well.

When considering the children and their families, social impact of asthma can be subdivided into four main categories; social and leisure pursuits, schooling, practical aspect of daily life and emotional effects<sup>10,11</sup>. had done a study on the impact of childhood asthma in 17,110 households in the United States to determine the disease burden resulting from asthma and to determine the functional status of children with and without asthma. The age group they have selected is children less than 18 years in age while the respondents were the adults in the household. On this study, they found that the asthma have additional 10.1 million days missed from school, 12.9 million contacts with medical doctors and 200,000 hospitalisation. About 30 percent of children with asthma had some limitations of activity when compared to the 5 percent of non asthmatics. Ten percent of children with severe disease accounted for 35 percent of hospitalization for asthma and 77 percent of days in hospital. A child’s functional status also was measured with regard to limitation of activities and restriction of activities. Limitation of activities measures what they are capable of performing in terms of major activities appropriate to their age. An example in the under-5 year children is that they consider appropriate for age as playing, above 5-17 years it as schooling.

Asthma affects the child’s ability to take part in sports. The restriction of participation in sports activities may be due to the inability to complete a game involving exertion or due to advice given to avoid some sports because of asthma<sup>12</sup>. in their study found that 30 percent of children with asthma had some level of activity limitations. The limitation of activities was measured by the respondent’s (mother’s) report of the children’s activity to engage in usual childhood activities such as playing with other

children or attending schools. Sometimes, a child may have to avoid trigger factors like pollen, smoke and it restricts the playing and the leisure activities of the child.

The child’s disease may affect the social and leisure pursuits of the family as well. Siblings may be affected because of the restriction on the affected child. Some children have to avoid contact with animals and therefore families have to get rid of the pets. The holiday arrangements of the family like going on trips/ holidays can be affected due to child’s asthma. Some families are prevented from going on trips/ holidays because of child’s asthma. Parents are prevented enjoying a life of their own<sup>13</sup>.

Children who are frequently absent from school tend to perform poorly in school. Poor coping or inadequate management of the chronic disease may be one cause for excessive school absenteeism<sup>11</sup>. A study among 200 asthmatic children of low income families of New York City found that the absence rate of these children was 24 percent higher than the overall absence rate of the children in the district. Forty percent of the children had some school problems and some children needed a repeat of school years. The difficulties encountered at school setting included how to handle asthma symptoms during school hours, how to make up the missed school lessons and how to decide when to keep a child out from school<sup>12</sup>. in their study on the impact of childhood asthma, found that annual burden experienced by the 2.7 million children with asthma was that , they had missed 10.1 million days from school.

Depending on the specific provoking factors of asthma, a child has to avoid some foods, be away from dusty or smoky environments and be protected against catching colds. Sometimes they have to avoid playing with soft toys or animals and it deprives the child’s source of pleasure and comfort.

The emotional effects of the child due to the disease includes stigma, loss of self esteem (self pity and poor self opinion) and poor relationship with the peers<sup>13,14</sup>. Parents of the children have to do extra housework like additional dusting, cleaning and washing in order to prevent child is exposed to irritants. Because of nocturnal attacks, parents will loose sleep and be physically exhausted. Sometimes, parents have to give up their jobs or have to be absent from their work. If it is a daily paying job, it affects the whole family. Transport costs to the hospital, cost for the accompanying person if the mother is unable to go alone and baby sitter cost for the other children when the child is at the hospital directly affect the wellbeing of the family. A study on parental perception and attitudes towards asthma stated that an asthma child is a financial burden to their parents<sup>13,14</sup>.

The disease is a constant worry to the parents and they are unable to relax even if asthma in the child is completely under control. It has an adverse effect on their own relationships. Sometimes, they feel a sense of guilt that they are to blame about their child’s susceptibility to asthma attacks. They tend to overprotect the sick child and fail to exercise adequate discipline on them. All the activities of

the family are centered on the child’s asthma and this creates a sense of oppressive closeness for the child. It means that other children are more affected<sup>13,14,15</sup>.

**II. METHODS**

A community based descriptive cross sectional study was conducted in the Colombo Municipal Council area in the Colombo district. The study population was the children aged between 5 to 11 years who had asthma attack within two weeks prior to data collection and their mothers and/ or the caregivers.

Study instrument was the Children Health Survey of Asthma (CHSA) questionnaire which was validated in the local setting. The questionnaire was given only to the mothers of children aged 5 to 11 years or the person who spent the maximum time with the index child when the mother is not there to look after the child. If three visits were unsuccessful in meeting the mother or the caregiver, or the mother or the caregiver refused to participate in the study, such persons were excluded from the study. If three visits were unsuccessful in meeting the mother or the caregiver, the mother or the caregiver refused to participate in the study or if the mother or the caregiver looked after the child for less than six months period such persons were excluded from the study.

The study sample was selected using the cluster sampling method which was considered as the only practical solution of getting a probability sample in a cross sectional survey where a proper sampling frame was not available (Benett et al 1991). The clusters were allocated on the basis of probability proportionate to size (PPS) of the population. Each municipal ward has a separate road map which includes all the roads in that area. By using this map, one road was selected randomly. In the selected road, a house was selected randomly. The interviewer visited the first identified house and inquired whether an eligible child aged

of 5-11 years resided. If such a child was available, the mother or the caregiver of the child was selected as the respondent. Out of the children who had asthma during past twelve months prior to the data collection (n=177), only 97 had asthma attacks two weeks prior to data collection.

Two areas were selected for the pilot test which was outside the study area. One area was Wellawatte where Sinhala, Muslim and Tamil communities reside. This was done mainly to assess the clarity of questions, the average time taken to complete the answers and to observe other practical problems like the compliance during the interview. The other area selected was Deans Road, Maradana to assess the practical problems which would arise during the data collection inside the cluster.

**III. RESULTS**

To assess the impact of childhood asthma on children and their caregivers, validated Children Health Survey of Asthma (CHSA) questionnaire was administered. Children who had asthma attack within two weeks prior to data collection were selected for administration of the CHSA. Out of the children who had asthma during past twelve months prior to the data collection (n=177), only 97 had asthma attacks two weeks prior to data collection. The results of each domain; physical health (child), emotional health (child), activity (child), emotional health (family), activity (family) are presented. The means scale scores were compared for each domain of the original CHSA.

Table 1 gives the CHSA scores and the symptom activity of the disease. The mean physical health (child) score was higher among children with low symptoms of the disease group and it is statistically significant. There is a significant difference between mean scale score of the Physical Health (Child), Emotional health (child), Emotional Health (family) and Activities (Family) with the severity of the disease.

Domains of CHSA	Low		Moderate		High		Significance
	Mean	SD	Mean	SD	Mean	SD	
Physical Health (child)	69.6	18.6	54.6	17.6	35.8	15.7	P<0.001
Emotional Health (child)	93.8	28.1	68.1	11.6	42.7	16.0	P<0.001
Activities (child)	63.7	32.6	54.1	31.0	53.1	23.9	P > 0.05
Emotional Health (family)	77.2	20.3	55.7	17.3	37.4	17.3	P<0.001
Activities (family)	72.9	25.2	65.9	13.1	49.6	25.9	P<0.001

Table 1: CHSA scores and the severity of the disease

CHSA mean scale score according to age is presented in Table 2. A stepwise decrease in mean scores was observed for physical health (child) and emotional health of children from 5-6 years to 11 years. The mean scores obtained for each domain was higher in children aged 5-6 years compared to those aged 11 years. The physical health& activities of the child and Activities of the family shows a significant difference. (P<.05)

Domains of CHSA	5 – 6 years		7 – 8 years		9 – 10 years		11 years		Significance
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Physical Health (child)	60.6	15.0	59.9	19.6	51.0	23.4	44.9	16.5	P<0.05
Emotional Health (child)	73.3	26.14	71.8	27.9	65.8	24.7	60.0	31.9	P > 0.05
Activities (child)	56.0	38.7	65.4	29.5	39.3	29.5	54.8	26.2	P<0.05
Emotional Health (family)	56.2	22.8	58.2	24.1	55.5	24.6	52.1	15.3	P > 0.05
Activities (family)	68.0	23.3	71.9	25.9	49.7	25.5	65.6	21.6	P<0.05

Table 2: CHSA scores and age of the child

Table 3 gives the distribution of CHSA mean scale scores with the sex of the child. There is no significant difference found between CHSA mean scale scores and the sex of the child.

Domains of CHSA	Male		Female		Significance
	Mean	SD	Mean	SD	
Physical Health (child)	51.8	19.7	55.2	19.6	P > 0.05
Emotional Health (child)	64.3	31.3	69.8	25.6	P > 0.05
Activities (child)	59.0	28.0	51.4	33.5	P > 0.05
Emotional Health (family)	57.1	22.9	54.1	20.3	P > 0.05
Activities (family)	66.5	22.8	63.1	26.6	P > 0.05

Table 3: CHSA score by sex

Table 4 gives the relationship between CHSA mean scale scores and the type of respondent. There is no significance difference between CHSA mean scale scores and the type of respondent.

Domains of CHSA	Mother		Other		Significance
	Mean	SD	Mean	SD	
Physical Health (child)	53.9	18.7	46.6	46.2	P > 0.05
Emotional Health (child)	67.0	20.5	76.6	20.8	P > 0.05
Activities (child)	54.7	31.6	55.0	40.9	P > 0.05
Emotional Health (family)	55.6	21.4	50.0	25.5	P > 0.05
Activities (family)	64.8	24.8	59.7	34.9	P > 0.05

Table 4: CHSA mean scale scores and the respondent

Table 5 gives the relationship between CHSA mean scale scores and the ethnicity. Only the activity of the child shows a Significant difference with the ethnicity.

Domains of CHSA	Sinhalese		Tamils		Muslims		Significance
	Mean	SD	Mean	SD	Mean	SD	
Physical Health (child)	54.6	19.3	51.2	19.6	51.1	21.1	P > 0.05
Emotional Health (child)	66.3	28.3	63.1	32.6	71.0	25.5	P > 0.05
Activities (child)	60.1	31.3	55.6	30.3	35.5	25.5	P < 0.05
Emotional Health (family)	53.6	22.2	62.8	21.9	51.5	16.0	P > 0.05
Activities (family)	65.1	25.5	70.0	25.2	55.2	20.1	P > 0.05

Table 5 : CHSA mean scale scores and the ethnicity

Table 6 shows the relationship between CHSA mean scale scores and the educational level of the care giver. Emotional health of the family and the activity of the family shows the significant difference. .

Domains of CHSA	No education		Formal		Higher		Significance
	Mean	SD	Mean	SD	Mean	SD	
Physical Health (child)	56.9	14.9	52.8	20.6	54.4	19.2	P > 0.05
Emotional Health (child)	54.2	34.1	68.5	24.6	67.8	32.1	P > 0.05
Activities (child)	84.1	25.7	54.2	32.1	51.0	30.0	P > 0.05
Emotional Health (family)	75.7	25.0	58.4	20.5	48.3	19.5	P < 0.05
Activities (family)	85.4	23.5	67.3	23.0	57.7	25.7	P < 0.05

Table 6: CHSA mean scale scores and the educational level of the care givers

#### IV. DISCUSSION

The impact of a chronic physical illnesses on the emotional and physical health of the child had been well documented. At different stages of the development of the childhood, these may be varied. During infancy there is a disturbance of sleep and feeding and it directly effect on the growth of the child. The preschoolers found that their autonomy, mobility and self-control impaired. Early school going children are prone to have problems with association of classmates and difficulties in academic performances<sup>16</sup>. In addition, distress experienced by the family and disturbed

family functioning directly influences the emotional outcomes of the child and the family. Parents also have a significant role to play in management of children with chronic asthma because they have to provide emotional support to the asthmatic child while coping with their financial and other difficulties.

A study on impact of childhood asthma among American children found 30% of children with asthma had some limitation in activity. The present study activity of the child is measured by using a score. Activity (Child) scores were low among high symptom activity children when

compare to the low and moderate symptom activity group. But it couldn't prove any significant association.

The children with chronic physical illnesses are differ in many ways from the adults with Chronic physical illnesses. Chronic physical illnesses not only leave impact on the child and the parents it also has impact on the family as well. In addition to the impairments of normal growth, they have additional needs also. These additional needs are tremendous burden to the caregiver; therefore, it is equally important to recognize the stresses and burden experienced by the family of the sick child.

The physical health(child) component in the CHSA assessed the symptoms due to asthma and the effects due to asthma medicine. The present study shows that there were no association between the physical health score and the sex of the child. When considering the mean physical health score and the ethnicity, for the Sinhalese it was 54.6 which was higher than the Tamils (51.2) and the Muslims (51.1) but the difference was not significant. A study in America by using CHSA found that the physical health of the Puetrorican group and Mexican children had worsen parent reported asthma physical score compared to Latino group, the difference was significant<sup>17</sup>. The present study also shows that the mean score for the physical health domain of the child is decreasing with increasing age, which shows that once the age is increasing, the perceiving of symptoms of the disease may be more. It is also decreased with increased symptom activity( $p < 0.001$ ). Physical health of the child does not differ among the type of the respondent or the educational level of the respondent.

Under the emotional health of the child, the main aspects that inquire about is how frustrated the child about the disease (asthma), the treatment he is getting and the activities which limited due to asthma. In the present study, the mean score for the emotional health of the child decreases with the increasing symptom activity of the disease. With the increasing age the mean score of the emotional health of the child is decreasing, but this not significant. These scores are not significantly different among girls and boys and the ethnicity of the child. The emotional health mean score of the child did not differ significantly by the type of the care giver or the educational level of the care giver.

The worries, the asthmatic children have regarding the severity of the symptoms, depend on the functions of the family<sup>18</sup> and have found that improvement of the family functions reduces the worries regarding their symptoms. Malhotra & Singh<sup>16</sup>, on their study have found that the distress experience by the family and disturbed family functions directly influence the emotional outcome of chronic physical illnesses. And American study, it was found that 10% of the children with asthma worried about their diseases<sup>17</sup>.

Regarding the activities of the child, the CHSA questionnaire inquired about the physical exercises and the physical activities when at home (eg. riding a bicycle). There is no significance in the present study, though the

symptom activity decreases with the mean score of the activity (child). Also, no association could be found between the activity (child) score and sex of the child, ethnicity or age of the child. Taylor et al<sup>12</sup> in their study found 30% of children with asthma had some limitations in activity compared with 5% non-asthmatic ( $p < 0.05$ )

With regard to the emotional health of the family, caregivers' opinion about the child's health, medical care for asthma and feelings related to the child's asthma were inquired. Emotional health of the family score increases with symptom activity of the disease, this difference is significant ( $p < 0.001$ ) but there was no difference of the mean scores were found in the sex, ethnicity and the age of the child, among the caregivers the emotional health (family) score was decreasing with increasing educational level. That variation is understood because once they know more about the disease, they are more concerned about the sequelae of the disease or as they come to know the progression of the disease.

Under these domains, mainly the care giver inquires about how the care givers and family activities are disturbed due to child's asthma. When looking for the mean scores of the activity (family), it reduces with the symptom activity of the disease but it couldn't prove any association with the child's age, ethnicity and the sex. Once the educational level of the care giver taken into account, the mean score decreases with the higher educational level. Though there are no data available for comparison of these findings, this is understandable in a culture like Sri Lanka, the caregivers are more concerned about the disease of the child than the other activities of the family.

The present study findings shows that higher scores for all given domains were among the low symptom activity group. This means better health among them.

With the increase of age, score of the physical health of the child is decreasing. That is understandable because these children once they grow older, they feel symptoms and signs more than when they were small.

## V. CONCLUSINS

Higher scores for all given domains were seen among the low symptom group children, means better health. With the increase of age, score of the physical health of the child is decreasing.

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