Social, Economic And Cultural Aspects Of Asthma: An Exploratory Study In Andhra Pradesh, India.

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Social, Economic And Cultural Aspects Of Asthma: An Exploratory Study In Andhra Pradesh, India.

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INTRODUCTION[5] :

During the working group discussion of the socio-economic panel of the WHO-NIHLBI "Global Strategy for Asthma Management Project" , it became evident that very few studies on social, economic and cultural aspects of asthma has been done in the industrialized developed economies. In the developing world such studies were not available at all. Without any such studies the panel was very much handicapped in making recommendations about socio-economic impact of asthma all over the world. At the same time, the time table of the full project could not be held up because of this. Hence it was decided to go for a few quick exploratory studies. This study is a result of the decision. It seeks to develop tools to assess socio-economic aspects of asthma and to describe them.

The social impact of asthma advances far beyond the bar numbers of affected individuals. It creates a burden not only for the individual but also for society, with reduced productivity, quality of life, and economic costs. Social institutions, family practices and behavioral responses can all contribute towards coping with the morbidity. These social and cultural opportunities should not miss the attention of medical and public health professionals.

Psycho-social problems, for example anxiety depression is known to be associated with Asthma (Schneer[6] , 1963; Knapp[7] et al., 1976; Tietz[8] , 1975; Pinkerton[9] , 1972). In one study (Miller[10] 1987) approximately 25% of school-age childern with asthma admitted for treatment were found to be depressed and 33% were coping poorly in their lives.

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Dawson et al[11] (1990) observed that in case of primary school children with asthma or wheezing, more than four weeks of absence from school was associated with poor academic performance. Those who were labeled "wheezing" rather than "asthma" lost school time disproporitonately and suffered academically. Speight et al[12] (1983) also found that under diagnosis and under treatment of asthma was responsible for increased absenteesim from school by those who were wheezing. Particulary interesting was the finding that parents were quite receptive to the diagonosis of asthma contrary to traditional belief in pediatric practice. It would appear then, children who do not receive correct diagnosis and thus effective treatment, may have their academic performance placed at risk. Marion et al[13] (1985) reported that the direct costs of treating childhood asthma consumed 5.5% of the household annual income.

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OBJECTIVES

This is an exploratory study to identify social, economic and cultural processes that are of relevance for management of asthma. In particular this study seeks to :

1. Assess the socio-economic impact of asthma on the patients and their families.
2. Know to what extent the patient is able to cope-up with asthma.
3. Understand the reaction of the family members, work group members or school mates towords the patient.
4. Assess the work / school loss due to asthma.

METHODOLOGY AND TOOLS OF DATA COLLECTION

Selection of Sample

The study population was selected from the urban areas of Hyderabad and in a rural area near by the city. The urban sample was drawn from the register of asthma patients maintained at the allergy clinic of the Mahavir Research Center Hyderabad. This center maintains record of all out-patients attending its allergy clinic. These records provide information regarding , date of vist to the center , address , the diagnosis and serum Ig E levels. First an attempt was made to contact all persons registered from March 1993. It was found that among those who gave an address in the city , many had in deed come from distant places. They had given the address of their relatives or acquaintances. Hence we listed around 80 patients who were known to be the residents of the city , as per the knowledge of the physicians in the allergy clinic, hoping to be able to interview about 50 of them. This list includes persons registered from August 1992 to March 1993. Finally 50 were interviewed.

The rural sample has been drawn from around the Rural Health Center Narsingi which is the field practice area of the Gandhi Medical College at Hyderabad. Six, villages covering a population of 17,838 were surveyed. Opinion leaders like the village head, farm servants of village head and dais were asked to inform about persons suffering from wheezing or asthma. In addition door-to-door survey were done for about one third of the households. Thus 6024 people were covered by the door to door survey, out of the total rural population of the study area (17838).

The rural sample of asthmatics contained a larger proportion of dependents (33%) compared to the urban area (12%). Table -1 shows the age distribution of total population and the sample population in the two areas. The rural sample did not have many middle age people and had higher proportion of the elderly. On the other hand the urban sample did not have any elderly person. It may be noted that in view of the exploratory nature of the study and the short time available at our disposal we could not draw a representative sample. Hence these figures should not be used to infer any thing about the age pattern of asthma prevalence. We had to work with the sample, in view of the time constraints and the exploratory nature of the study.

Obviously for a fuller understanding of the problem a larger sample spread over different parts of the state will have to be taken up.

The family income status of each asthmatic was ascertained by a simple question about the type of ration card possessed by them. In Andhra Pradesh the government issues two type of ration cards based on the financial status of the family. Those who are considered poor with annual income of less than Rs.6000 are issude white card and those "not poor" (annual income more than Rs.6000) are issued pink card. The income criteria is based on a nationally determined poverty level[14] . The proportion of poor in the rural sample is higher compared to that in the rural population. The urban sample was biased in favour of "not poor" as they were taken from a pay for service hospital.

The literacy[15] level of each asthmatic was ascertained as this has implications regarding ability to follow directions in use of antiasthme medication. About 56% patients in the rural sample were found to be illiterate. All the patients in the urban sample were literate out of which 96% patients acquired secondary and above educational status.

Majority of the primary respondents did not smoke (84%). Another 9% had stopped smoking . Only 7% of thge sample were currently smoking. Those who smoked ever started to do so when they were 12 to 30 years old. The most common age period in which people started smoking was 15 - 20 years (64%) . Another 4% were exposed to passive smoking, parents were the common source of parrive smoke.

Identification Of Primary Respondent (Case Detection)

Persons with currrent or past asthma were the primary respondents. In case of the urban area diagnosis of asthma had already been established. This is because the sample was chosen from the register of confirmed asthma cases. However the diagnosis was reconfirmed by a physician, based on intensive history. In the rural areas each person suspected of asthma or reported to have had asthma was first examined by a physician. The physician first took an intensive history and then, if required, did a physical examination. A case of bronchial asthma was identified and diagnosed on the basis of clinical history and response to the bronchodilator treatment. The clinical symptoms looked for were recurrent episodes of cold, cough, breathlessness and wheeze mainly expiratory. A case with one year duration and not less than three episodes was considered as the minimum criteria or diagnosis of asthma. Chronic bronchitis cases were exclude. In case of children the cases of acute respiratory infection (ARI) were excluded on the basis of absence of response top bronchodilators and lack of correlation between the clinical severity of symptoms like, breathlessness, in drawing of lower chest, and the clinical signs in the chest.

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[14]Proverty level is assessed based on the consumer expenditure surveys of the National Sample Survey Organisation. Household are catego-rised according to percapita monthly expenditure. The average calorie intake in each expenditure class is estimated. If the mean calorie intake is less than 2400 Kcal/cu in urban areas which corres-ponds to a monthly percapita expenditure of Rs. 49.09 in rural areas and 56.64 in urban areas, all families falling in that expenditure class are considered as falling below the poverty line.

[15]The Indian census definition of literacy was used. According to the 1991 census operation guidelines a literate is defined as a person above 6 years and who is able to read and write understatnding in any language irrespective of wheather the person has received formal education.

Primary Interview

The primary respondent was first interviewed by a team consisting of a community physician and a medical sociologist. A semi structured interview format was adopted. The primary respondents questionnaire (patient schedule) consisted of two sections.

1. The first section was designed to collect some demographic and to establish the diagnosis of asthma.
2. The second part was designed to collect socioconomic information about asthma.

For example; through whom he came to know about the illness, first treatment present treatment, if there is any change reasons for change, expenduture on the present treatment, whether she wants to continue the present treatment. It asks questions about the hospitalization, special examinations and the expenditure incurred on those. A question was asked to know how he is coping up with asthma and whether due to adthma is he able to his best. The work / school days losth during the last month. To see the perception of the patinets relevant questions were asked about the family members reaction towards them, whether the asthma is a financial burden on the family, colleagues/classmates/boss reaction towards his sickness etc.

Family Member Interview

For each primary respondent a family member and a co-worker or school mate were interviewed Most of the family members interviewed were either spouse, parent, son or daughter (Table -3). The family member schedule is designed to ascertain details about the financial burden, money spent on medicines every month, whether the patient requires the family member's help if yes in what way? Is the sickness prerventing the patient to attend for work/school in their opinion, if yes, how long during severe attacks, and their feelings about the patient's illness. Whether the patie4nt is facing any problems with his collegues / classmates due to his illness and in their view, whether the patinet can do some work and in case of children he/ she is able to play well.

Coworker Interview

To understand the extent to which asthmatics were able to cope up with their work or studies, a coworker or a school mate was interviewed. Altogether 97 coworkers / schoolmates were interviewed. The balance three primary respondents were below 5 years age and the question of a coworker or a school mate did not arise for them. Majority of the "coworkers" (Table - 4) were either neighbors or residents of the same village, street or colony, followed by work mates. The coworkers was asked, if he / she is aware of any medical problems of the primary resondent, how he views about his / her work performance, and whether he / she needs his/ her help to overcome from those problems.

Interview Methods :

All interviews were in the language of the interviewee (Telugu mostly and Hindi in a few cases). Notes were taken by the interviews and the respective questions in the questionnaire were answered either simultaneously or at intervals during the course of interview. A semi structured approach was adopted for the interview. The questionnaire acted as a guideling for the interviewer to help remember various questions to be asked and their sequence. Questions were of three types. Some sought very specific information or an yes or no answer. For example; "Do you want to continue the same treatment?" , "Were you hospitalized any time due to severe asthma?"etc. Most of the questions were, however, open ended. For a good many of these questions the interviewers could anticipate possible alternatives either intuitively or no the basis of their experience during the pretesting. For all such questions the possible alternatives were assigned codes. However the alternatives were nto offered to the interviewee except by way of some examples to explain the question. If the interviewees reply fitted into one of the anticipated categories the preassigned code was used to fill int the questionnaire or else descriptive answer was written down. The last category of questions were completely open ended. No attempt was made to anticipate interviewee response. The reply of each interviewee were described in the schedule of each case. These questions were directed to gather purely qualitative information for example; "How do you cope with work when you have attacks?" , "How do your family members react to your illness?",etc.

The recall period for most of the questions were one month. For example; "How many times do you have to visit your doctor for treatment of your asthma during the past one month?", "How much money do you spend on transport to visit your doctor in one month?", "How much money do your have to spend on for these medicines on an average in a month?"etc. For questions dealing with major events like hospitalization, a recall period of one year was used. For example; "Did you have to visit hospital any time during the past one year for treatment of severe asthma?". For general history taking and life style questions the recall period extended till birth for example; "How many times were you smoking on an average when started smoking first?", "If you have stopped smoking completely, how many years did you smoke regularly?", etc.

RESULTS

Social Impact Of Asthma

LOSS OF WORK / SCHOOL

About 40% of primary respondents had to absent from work on account of asthma. About half (51%) of the children (<14 years) missed school on account of asthma. The absence from school by those who missed it ever ranged between 2 to 15 days (mean = 5.17 days) durig the recall period of one month. Many of them were absent for about two days (mode). The average loss of school for all children (<14years) including those who did not absent themselves at all was 2.66 days. In case of adults (> 14 years) absenteism on accountof asthma was less (34%). Among those adults who had to absent on account of asthma the average loss was about 4.86 days (range 2-20 days) of work per month. The average loss for all adults including those who did not have to stay away from work on account of asthma was 1.65 days per month per asthmatic person. Most of the elderly asthmatics had ot avoid work round the year. The five

such elderly patients in the sample were studied in detail to ascertain how much of the absence could be attributed to asthma. It was found that in case of the elderly with asthma 50% of the absence from work could be attributed to asthma.

ACCESS TO MEDICAL CARE

Awareness Of The Problem

About 60% of the primary respondents were informed about their disease through the doctor. 26% came to know about it through their parents and family members and 14% suspected asthma themselves.

Choice Of System Of Medicine

Majority (70%) first approached qualified allopathic doctor for the treatment, whereas 12% and 6% approached qualified Homeopathy or Ayurvedic doctor respectively. The remaining 12% patients approached herbal medicine men. Number of persons under modern medical care increased from 70% to 95% due to the change from other systems of treatment. This increase is about 25%. Out of 6 people who started with Ayurveda, only two are continuing while the remaining shifted to Allopathy. Out of 12 patients who started with Homeopathy. Only one is continuing and another has added allopathic medicine, while the remaining shifted to modern medicine altogether. When patients, who have shifted from one form of treatment to other, were asked for the reasons, out of the 28% patients 25% expressed that they did not get any relief so they had to change the form of treatment. Family members were the major source of information for patients (55%) about the availability of the present treatment. Around 17% patients came to know through their friends, neighbors and other villagers. 19% of the patients came to know about it only after they met the doctor. Only, 10% were themselves aware of the availability of the present treatment. Evidently majority of asthmatics are preferring modern medicine.

Choice Of Provider

In the urban area the sample was drawn from the register of a non governmental facility. Hence we can not make any inference about the choice of provider from the urban area data. In case of rural areas majority of patients used the public health facility for their treatment (Table-6). Except six persons all other persons from the rural area were spending money on their treatment. Evidently the public source of care does not meet the full cost of the treatment. Most of the expenditure by the clients of the local health center was on purchase of drugs. About 4% got their expenses reimbursed by their employer. Six percent either did not use any treatment or were using medicines only during emergencies.

We can classify the care availed by the urban patients specialty care, since they happen to receive the treatment from Mahavir Allergy clinic which is specialized in it. Among the rural patients a few (9) sought specialty care when their illness condition deteriorated. Out of the whole sample only 6 sought emergency treatment for asthma attacks. Five of them were from urban area (1 child case and 4 adult cases).

Choice Of Regimen

Except three persons all were taking some form of treatment. Majority (69%) were taking oral preparations. The rest (28%) of them were supplementing oral preparations with inhalers.

All were getting relief and were satisfied with their respective regimen. All those who were using inhalers had recieved some training about the method of its use. Those using both oral and inhalers were asked which is more convenient. Majority (66%) found both oral and inhalers to be equaly convenient. Another 38% had a clear preference for the inhalers. Only one patient (6%) expressed clear preference for the oral prepation. As many as 38% of those taking oral preparations experienced some side effects while only 14% of those who supplemented oral preparations with inhalers had some side effects. The use of inhalers was more prevalent in the urban area. Inability to afford and ignorance were the two main reasons for not using inhalers.

HOUSEHOLD EXPENDITURE ON ASTHMA

Majority of patients (84%) were found to be spending money on their treatment. This includes those availing services from the publicly owned rural health center. The average expenditure per household was Rs. 525 per anum (range 85 - 2580). This works out to 9.43 of te states percapite income (Rs. 5570 at 1991 prices). As the sample contained a higher proporion of "not poor" persons, the actual share of percapita income being spent tor treatment by asthmatics would be less than the aboue figure. About 52% patients of the sample did not spend any amount towards tarave charges. Among those who paid for it spent on an average Rs. 73.78 per annum (range Rs. 2 - 240). Similarly, 54% of the patients did not spend any amount towards the doctor's fee. Among those who paid doctor's consultation the expenditure was Rs 63.50 on the average. Evidently expenditure on drugs was the most flexible of all expenditures.

Majority (79%) of the primary respondents did not perceive any financial burden on their family on account of their illness. This perception was shared by the family members in 75% of cases. Among them 20% families were poor and the rest 55% were not poor. Family members in 6% if cases did not share the perception of the asthmatic. All of them were poor.

Those (21%) who grumbled about the burden ascribed one or more of the following reasons;

- Over all cost of treatment takes away a big chunk of the family income.
- During attacks requires presence of at least one family member and there by prevents him / her from going to work.
- For persons depending on the free medicine from the Primary Health Center, when medicines are not available, they have to either buy it from the market or write off expenses incurred for travel,
- High cost of medicines,
- High cost of treatment eroding in to capital stock of the family for example some families experienced gradually dwindling live stock, to pay for cost of treatment,
  Inability to earn and contribute to the family kitty.

When the patient's family members were asked whether they are feeling their family member's illness as burden the majority of them expressed that it is not the case. Only few (15%) said that they are feeling it as a burden. This perception was shared by the patients in 11% cases. Among the white card holders 24% of the patients and their family members felt it as a burden. When we analyze the views of family members as well as the patients about the burden aspect it is found that among them 9% of the family members felt it as a burden where patients did not express it so. In the case of "not poor" families there was not miss match of perception.

In all cases where the family perceived the disease as a burden, financial burden on account of the expenditure on treatment was considered to be the major cause of concern. Treatment of asthma was reported to be taking away a considerable amount of the family income. All of these families were from the rural area and were poor.

COPING UP WITH WORK

Majority of the respondents (75%) had to either avoid (40%) or restrict (35%) work. The rest 25% of the primary respondents expressed that they were not finding any problem or difficulty in coping with their work. Among those who can do work without any difficulty and problem 36% patients can work at the attack period only after consuming the medicine and taking some rest, and taking certain precautions. Interestingly certain patients changes work when they were in attack. For example patients started supervision work in the fields instead of doing the actual agricultural work, and participating in less strenuous jobs. This could be to get personal satisfaction that he is in a position (4%). Another set of patients thought they were willing to work, but their physical conditions and the familial factors did not allow them to work (4%). Reports by the primary respondents was generally confirmed by the coworkers or school mates (Table - 7).

Family support was found to be most significant contributor to patients capacity to cope with the morbidity on account of asthma. When primary respondents were asked about their family members reaction towards their illness, majority of them (88%) expressed that they are getting very good co-operation, help and encouragement. Some of the very frequently recalled supportive gestures are shown in the box.

Family members would help the asthmatic member avoid allergen by appropriate measures. For example a person was found to be allergic to detergent soap. So family members and friends would wash the clothes. Some patients were allergic to certain food. Family members would avoid such food items in home as a gesture of support to the asthmatic. They would be more vigilant and work harder to keep the house clean of dusts, when a member was found to be allergic to dusts. The family members were asked if the primary respondent required their help. Some of the supportive gestures like fetching medicines, helping avoid allergen etc. were in agreement with the perceptions of the primary respondents. In addition family members reported having to a) help in all works including elementary activities of daily living, b) do not expect help in instrumental activities of daily life such as shopping, house work, cooking etc., C) share the work of te asthmatic, d) be with him / her.

A few respondents perceived that they were not getting proper co-operation and care from the family members because of their illness (2%). One (1%) expressed that he has been isolated due to the illness and was not getting at least the minimum required care and support form the family. The other felt that since he is the family head no one in the family would openly grudge his illness, but most members would not willingly help him in his works. Another 2% of respondents perceived that their family members were indifferent. Interestingly another patient (1%) expressed that till now he did not require family members help since his attacks are not serious.

When family members were asked whether the patients require their help to carry out their work, majority of the responses suggested that the asthmatics were able to manage and they don't require help. But around 34% of respondents expressed the feeling that they have to help them during the attack periods since they would not be in a position to do any work. And some respondents expressed that due to their old age and other problems they have to help them in non-attack periods also. Patient's co-workes / classmates were asked if the subject was suffering from any medical problem. Nineteen percent of them did not know about the subjects medical problem. Rest of the co-workers and schoolmates knew about asthma and some other medical problems of the primary respondents. In one case schoolmates of an asthmatic child were surprised to see her with an inhaler, as they were not aware of her morbidity earlier. The child was hesitant use the inhaler in the presence of her friends. Encouraging children with moderate to severe asthma to share information about their disease to friends might help improve the transition to use of inhalers as and when they are required. Majority of the respondents expressed the opinion that the patients don's required help to overcome from their medical problems. Only 6% of patients required the help from their co-workers to overcome from their problems.

SUMMARY AND CONCLUSION

The study reveals that the illness 'asthma' is an easily identified problem both in rural and urban areas. Modern medicine is the most preferred system of therapy. Because of limitations of the sample, firm conclusions about choice of provider for treatment of asthma in urban areas can not be made. In the rural area, the poor preferred to avail services from the government health facility. Majority (75%) of those suffering from the disease had to either avoid (40%) or restrict (35%) work on account of asthma. The children among them lost on an average 2.66 days of school per month and the adults lost about 1.65 days work per month. In addition to te direct burden of asthma due to loss of school or work for the affected person, families with an asthmatic experience loss of work by other members of the family to attend on the affected person and quite significant expenditure for treatment of the disease. For example the top two causes cited by asthmatics who perceived their condition as a burden were ; (a) overall cost of the treatment takes away a big chunk of the family income, (b) the need for assistance by at least one family member during attacks. 84% of the families having as asthmatic had to incur expenditure in some form or other for treatment of the disease. Major part of the financial burden was on account of medicine purchase. Thus lowering of prices of asthma medication is likely to increase utilization of the drugs and reduction of morbiduty.

The study also revealed the positive contributions of social and cultural mechanisms in coping with the asthma morbidity. The institution of family was found to be a strong contributor to successful coping behavior. For example, despite the fact that families had to spend considrable amount of money for treatment of the disease, only very few showed evidence of any mismatch in perceptions of financial burden by the asthmatic and his / her family members. Families helped their asthmatic member by modifying their life styles to be compatible with the needs of the later. Supportive gestures like arranging treatment, sharing or relief form work, helping to avoid allergen were all very important factors in the coping up process. Many asthmatics coped up with their work by altering the types of work undertaken during the attack period.

In summary the study revealed that:

1. Asthma is an easily identified problem both in rural and urban areas.
2. There is a large social and economic burden on account of asthma. About two thirds of patients had to either avoid or restrict work or school attendance.
3. Burden on the family is real both in economic and social sense.
4. Cost of asthma medication is the single most important contributor to the financial burden of families.
5. There is an important existing social sharing of asthma morbidity. The institution of family is particularly useful means of the coping up process. The social and cultural processes revealed by the study may help physicians in management of asthmatic patients.