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Sociological Understanding of Asthma: A Growing Concern in Delhi

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ABSTRACT

For over a decade now, we have observed an increase of patients affected by asthma. Asthma has become a persistent social reality, drawing extreme public concern, however, we do not have any dedicated sociological analysis of the topic at hand. Keeping the same in mind, this research attempts to deep dive into the issue by analysing its impact from the perspectives other than medical: that is social and economical. The research also uncovers different notions and myths attached to asthma in our society.

Keywords: Asthma, impact, myths.

I. INTRODUCTION

“Asthma” is a Greek word which means ‘breathless’ or ‘to breathe with open mouth’. It is a common, non-communicable chronic (long-term) inflammatory disease of the airways. Asthma was first defined in 1959, as “a disease characterized by wide variation over short periods of time in resistance to flow in the airways of the lung”. (Ciba Guest Symposium, 1959). Currently, GINA defines asthma as a heterogeneous disease, usually characterized by chronic airway inflammation and respiratory symptoms such as wheezing, shortness of breath, chest tightness and cough that vary over time and in intensity, together with variable expiratory airflow limitation. (Global Initiative for Asthma, 2015)

Asthma is a serious global health problem affecting people of all ages, ethnic groups, classes, and sexes. Data regarding the prevalence of asthma varies with a world-wide estimated prevalence ranging from 1-18% of the population. Globally, it is estimated that there are more than 300 million asthmatics with 5-10% of the patients having severe asthma. (Global Initiative for Asthma, 2015). In ISAAC (International Study of Asthma and Allergies in Childhood) survey, the highest prevalence (more than 20%) was observed in Latin America and in English-speaking countries of Australia, Europe, North America and South Africa while the lowest prevalence (less than 5%) was observed in the Indian subcontinent, Asia-Pacific, and Northern and Eastern Europe. The prevalence of asthma in India is around 2% with an estimation of about

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17 million asthmatic patients currently. (Guidelines for Diagnosis and Management of Bronchial Asthma, 2015)

Though asthma can occur at any age but in about half of the total cases, it occurs before the age of 10 years. The prevalence of asthma is increasing rapidly, especially among children. The International Study of Asthma and Allergies in Childhood (ISAAC) in its latest survey (2000-03) found that 14% of the world's children experienced asthma symptoms. 1 out of every 10 children in India is suffering from asthma. In Delhi, about 12% children are having Asthma. The number of boys suffering from this disease is more before puberty than the number of girls. While among adults, women are more prone to it.

II. ASTHMA: SYMPTOMS, CAUSES AND RISK FACTORS

Asthma is usually associated with hyper responsiveness of airways to various stimuli resulting in airway obstruction which is reversible. During an asthma attack, the airways become narrow due to the swelling of the lining of the bronchial tubes, causing a reduction in the flow of air into and out of the lungs. These features of inflammation and hyper responsiveness usually persist, even when lung function is normal or symptoms are absent.

Though the causes of asthma have not been completely understood, however, the risk factors for asthma include 'non-modifiable factors' which are (i) Age and gender with more in children and adults; and more of females in the adult population having asthma, (ii) Atopy i.e. production of abnormal amounts of IgE (Immunoglobulin E) antibodies in response to common environmental allergens (strongest risk-factor), (iii) Genetic risk factors/Family history of asthma (which often commences in childhood). Low birth weight is also a risk modifier as it might be associated with narrow airways.

The 'modifiable risk factors' include: (i) Tobacco smoke: Both active as well as passive smoking. Even foetus can be exposed to tobacco smoke as a consequence of mother being exposed to it. Tobacco smoke also exacerbates the attacks. (ii) Biomass exposure: Indoor air pollution due to combustion of solid fuels for cooking and heating has been shown to significantly increase the risk of asthma. This is one of the reasons why asthma prevails more in rural areas than urban areas. All housewives, in our survey, have committed that cooking arises asthma symptoms in them. (iii) Infections: Respiratory viral infections happened in early life are also associated with asthma. (iv) Obesity- Obese people have narrow pathways to inhale the air which causes respiratory problems.[3] Other habits like eating unhealthy food, reduction in physical activities etc. can aggravate this disease. (v) Industry related occupation: workers in cotton industries, rice mills, bangle industries, chemical industries, construction sites, etc. are

more prone to asthma. It is claimed that 5 to 20% of asthma is due to occupation exposure (Global Burden of Asthma Report).

The triggers for asthma include several factors such as cold air or viral infections, extreme emotional arousal, physical exercise, intake of oily and sticky food, changes in weather, medications (aspirin, beta-blockers), indoor allergens (pet, house dust mites in bedding, carpets and furniture), outdoor allergens (especially molds and pollens), tobacco smoke, chemical irritants in the workplace, strong smells and air pollution. Most of the individuals, in our survey, have committed that due to their own habits, lifestyles and practices they are more prone to the allergens. 5 out of 40 asthmatics are addictive to smoke. While some persons, especially women, are enforced to be surrounded by these triggering factors because of their obligations, responsibilities and limitations. Like housewives can't avoid cooking, a sweeper can't excuse from sweeping, social individuals can't avoid passive smoking much, poor can't afford personal vehicles for their comfort and use public transport like bus, auto etc. 10 out of 40 asthmatic patients admitted that mere remembrance of their horrifying past produces emotional outbursts in them which often induces asthma attacks. Many respondents accepted that because of the work stress and fights in the house, they get frustrated easily and then suffer from breathlessness and feeling of suffocation.

The symptoms of asthma include cough, breathlessness, wheezing, chest tightness and expiratory airflow limitation which tend to be variable, recurrent and seasonal. Symptoms may vary in terms of its frequency and severity. They often get worse at night or early in the morning. None of these symptoms are specific for the diagnosis of asthma, and at the time of initial evaluation a patient may be completely or temporarily asymptomatic. There is no specific investigation test which confirms the diagnosis of asthma. The tests which an asthmatic is usually subjected to includes chest x-ray, spirometry and sometimes allergy testing. A normal spirometry demonstrates obstruction and/or bronchodilator reversibility which supports a clinical diagnosis of asthma. Spirometry is just a supportive test for the diagnosis of clinically suspected asthma as it does not exclude asthma.

Asthma may not be curable, but it can be eminently treatable. The management of asthma aims at preventing further progression of disease and providing relief of patient's current symptoms through controller medications (taken on daily long-term basis) and reliever medications (taken on as needed basis to relieve symptoms quickly) which can be broadly divided into three types- oral corticosteroids (pills), Inhaled Corticosteroids (ICS) and Injections. The inhaled medications can be taken through pressurized metered dose inhalers (commonly known as pumps) or through dry powder inhalers or nebulizer. Along with medicines, patients need to

take precautions as well.

The most important challenge to asthma treatment is compliance and adherence to therapy. Patients do not adhere to the prescribed medications regularly because of forgetfulness and busy life schedules. Most of the patients who do not take their medicines regularly (15 out of 40) belong to this category. Others felt unnecessary to adhere as soon as they start feeling better. Some patients find the inhaled medications too complex to handle or have never been given clear guidance by doctors and parents. While some people discontinue dosing because of attached side-effects to ICS (Inhaled Corticosteroids) and other medications which include obesity, increase in stress, weakening of bones, nausea, headache, rashes on body, frustration and anger etc. Also, certain social taboos and myths are associated with asthma like fear of getting addictive. Due to these inhibitions and side-effects, people start inclining towards other therapies like yoga, homeopathy etc.

It is not clear what exactly causes asthma, although it is likely to be a combination of both genetic and environmental factors such as pollution, temperature and humidity.

A large number of studies have shown a close link between air pollution exposure and asthma. Air pollution simply means the contamination of air due to release of any hazardous substance like pollutants, caused by natural as well as anthropogenic sources. United Nations Environment Program in 2002 has estimated about 1.1 billion people are breathing unhealthy air in the world. According to WHO, Delhi is the most polluted city in India. It has been estimated that as a result of degraded air quality, Delhi is witnessing 30% rise in respiratory diseases. As per CPCB report 2008, Delhi is the asthma capital of India. This may highly affect the possibility of migration. Out of 40 interviewed asthmatics, 21 expressed their desire to migrate from Delhi due to the increasing pollution.

Asthma is triggered by both outdoor and indoor air pollution. Pollen, commonly known as 'allergen', is a natural pollutant and a common but one the strongest trigger of asthma. Pollen is the mass of tiny grains which is produced by the plants for fertilization. Plants use air to spread their pollen and this pollen may interact with other pollutants to create particles that can easily enter into lungs through breathing. Therefore, many asthmatics are at a great risk during the pollen season.

There are many man-made sources of outdoor air pollution. Increasing population and rapid growth in urbanization and industrialization are primarily responsible for the increase of outdoor air pollution and its intensity is more felt in developing countries. According to the World Health Organization (WHO) outdoor air pollution causes around 800000 deaths and 4.5

million healthy life year loss every year all over the world. Smoke emissions from vehicles, factories, cigarettes release the most harmful pollutants like sulfur dioxide, nitrogen oxide, carbon monoxide, particulate matters, hydrocarbon and ozone inducing asthma in individuals. Hence, the increasing number of vehicles, poor solid waste management, chemical effluents from large number of industries are major inducing factors of asthma in Delhi as these contribute to the increase in pollution which can trigger asthma. The use of crackers during the festival of Diwali also affects asthmatic patients to a great extent. The pollution caused as a result of burning of crackers releases many gases and pollutants in the air which causes suffocation in asthmatics.

Pollutants can be found within the houses such as radon, house dust mites, certain household products, building materials like asbestos, lead etc. It has been estimated by World Health Organization (WHO) that in developing countries indoor air pollution is responsible for around two million deaths (mostly women and children) a year. As women and children spend most of their time at home, is the most vulnerable group to indoor air pollution. Approximately 3 billion people use solid fuels for cooking and other purposes that lead to an increase in indoor air pollution which is composed of harmful pollutants like fine particles and carbon monoxide.

Also, the domestic products like antibacterial soap, air fresheners, incense sticks sunscreen etc. contain harmful chemicals like Volatile Organic Compound (VOCs) and thus, asthmatics are recommended to avoid them. Studies have also shown that people who have cockroach allergies are at risk of developing acute asthma. According to the asthma and allergy foundation of America (AAFA), from 23% to 60% of urban people who have asthma are sensitive to the cockroach allergen. The saliva and droppings from cockroaches and dust mites can trigger asthma. Dust mites are settled under the beddings, upholstered furniture, carpets and curtains. The mixture of tiny fiber shed, tiny particles of food, plant and insect parts, feathers from birds, mold and fungus spores, dander from pets constitute dust found in the house.

III. SOCIAL IMPACT OF ASTHMA

Based on these facts and observations, Air pollution seems to affect the health of individuals enormously. But asthma does not have impacts only on health. It also affects social lives of individuals. The social impact of Asthma includes how it affects people's quality of life, their daily routines, lifestyle choices and everyday performances and how the social lives get worse due to the social factors like myths.

Asthma acts more as a limiting factor rather than as a disease and penetrates deeply into the daily affairs of people. Many asthmatics complained of not being able to run, dance, laugh

loudly, use stairs, climb mountains, participate in their favourite outdoor games like (basketball, volleyball, kho-kho etc), join a gymnasium due to the physical strain caused leading to severe asthma attacks. Children suffering from asthma specifically find themselves depressed and frustrated at the thought of not being able to participate in their favourite school activities and different types of swings and amusement rides in the recreational parks. Various social limitations are linked to these restrictions like non-eligibility of asthmatic individuals in certain government and sports related jobs due to their assumed natural incapability. Thus, employment is also affected as result of this disease.

Considering lifestyle patterns, differences are seen in the diet, clothing, choice of interiors and other preferences of asthmatic individuals. These changes accounts in a major way for changed lifestyle of asthmatic people. Looking at different examples, we noticed that nearly all Asthmatics avoid cold, sticky and oily food, like lady finger, rice or cold milk. Such food is seen to trigger asthma in patients with regard to their properties that harm them. Medically, it's found that asthmatics have deficiency of vitamin A, D, C, Magnesium, Zinc, and Selenium and have more content of salt in their blood. Clothing choices also vary in asthmatics depending upon the type of allergy that they suffer from. Asthmatics suffering from allergy caused due to a certain cloth material or its fibre, always avoid using such clothes (allergy from silk or synthetic). Almost all asthmatics preferred cotton as their clothing material. Some patients got their first asthma attack due to introduction of certain cloth fibre (wool in one case) in the air, at their workplace, hence considering their occupation as the cause. Two of the total 40 interviewed person left their respective occupations (clothing business) as a result of occurrence of asthma; one worked at a woollen factory while the other at a synthetic one.

Asthmatics also tend to prefer specific interiors for their house, ones that do not cause them allergy. For example, half of the interviewed asthmatic people avoid the use fur carpets in their house interiors, as the dust collected in it causes allergy. The different choices regarding house decoration suggest a different lifestyle of such people. They are sometimes unable to compete with the new fashion statements that are most prevalent at that time in society. They are also restricted in terms of keeping pets (especially dogs and cats) at house. So, pets are avoided by asthmatics in all the cases interviewed by us. Some respondents have also expressed disappointment for their inability to use perfumes because strong smells cause irritation and usually trigger asthma attacks.

Moreover, stigma is attached to asthma. It is considered to be a disease of 'breath' by society and thought to spread through the germs present in the breath of an asthmatic person. Many people avoid contact with asthmatic patients and believe it to be a contagious ailment. On

interviewing asthmatics, 6 out of 40 considered asthma to be communicable. Many non-asthmatics consider those suffering from asthma as carriers of infection and think that they might catch the disease by sharing of food or closed spaces with them. 17 out of 18 surveyed non-asthmatics, who did not have anybody in relation suffering from asthma refused to share their food (or eat in a common plate) with asthmatics, bringing in light the fear of contagion. The most shocking factor is that such a response was made equally by literates as well as illiterates. There are also cases of social exclusion observed. Example- in one case, an asthmatic was ditched out by her best friend when her disease was exposed publicly. Asthmatics also reported the feeling of embarrassment in the use of inhalers in front of everybody while occurrence of asthmatic symptoms because of the fear of social exclusion. All this is a result of unawareness of the exact nature of diseases in people.

Asthma also has adverse impacts on the marriage probability of an individual. Asthma becomes a serious cause of concern for the entire family if a young female member of marriageable age suffers from it. The reason for this is that it reduces her marriage prospects resulting in reduction of her value in the marriage market. Usually in society like ours, girls suffer more than boys in such cases as a result of gender inequality. The most common response collected during our survey research was the unacceptability of asthmatics as marriage partners by non-asthmatics as 'nobody wanted to get married to a person already suffering from a disease'. The passing on of the disease through marriage to the entire future generation was also a related cause of concern. Stunted growth (short height) is also an impact of medicines on asthmatic children, and is a contributing social factor in judging individuals on the basis of appearance. Factors like low self-confidence and low physical capabilities are a product of such stigmas faced by asthmatic individuals which makes them less capable of performing the daily activities done normally by others.

Due to the social limitations and prohibitions, asthmatics are affected psychologically to a great extent. Individuals with asthma, especially adults, tend to have higher level of stress and negative emotions such as panic, anger, fear, irritability, anxiety and depression. Inability to accomplish a task, burden of education, relationship issues, future goals and family pressure- all act as a stressor to an asthmatic, and fear and tension which emanate from the stressor easily exacerbate the symptoms of asthma.

Family of the individuals suffering from asthma can make their lives easier and comfortable by supporting and motivating them. The family members help them with the tasks that limit or restrain them in different ways and provide a source of increased love and affection. All the 40 respondents (whose relative has asthma and who does not know anybody suffering from

asthma) agreed to the fact that the asthmatic patients need more love and care and extra attention in order to be satisfied and happy. On one side, the family is seen as the provider of all support and care, but on the other side, sometimes the family or close members feel burdened by the responsibility of asthmatic person. In most of the cases, it was found that the family of asthmatics have to undergo a lot of changes in their daily routines to suit health situation of patients which may bring frustration and anger in them at some occasions.

However, due to the lack of awareness and careless attitude of the parents or family members of asthmatics, the severity of the disease unnecessarily increases. The unacceptance of the fact of child suffering from a long-term disease causes delay in the detection of disease. Also, the notion that small 'children outgrow their asthma' with the growing age also leads to the avoidance of proper medications and correct diagnosis. Yoga and meditation are good stress-management techniques which help to calm the mind, and improve oxygen intake and blood circulation. Nevertheless, only 5 asthmatic respondents out of 40 opt for yoga. Thus, there is an urgent need of spreading awareness so that the adverse impact of asthma on social and psychological lives can be reduced.

IV. ECONOMIC IMPACT

Besides social and psychological issues, the other problem faced due to asthma is the economic costs associated with treatment. Financial loss which occurs in the management of a patient involves direct as well as indirect costs associated with it. Direct costs include the costs of medication, medical bills, hospital admissions and cost of health service utilization such as clinic visits while indirect costs include in terms of loss of productivity, premature deaths, transportation expenses, occurrence of costs in changing the housing conditions etc.

As these costs are incurred by the family members, asthma has an adverse economic impact on the family. In a study by Lodha in 2003 among Indian children, it was found that the median monthly expenditure on the child's therapy was Rs 333.3 which was a third of the monthly per capita income. The expenditure in children with moderate (Rs. 400) or severe (Rs. 540) persistent asthma was more than that in children with mild intermittent asthma (Rs. 100). But our study found the monthly expenditure of patients with mild and moderate asthma ranging from Rs 200- 2500. While expenses on treatment of patients having severe asthma occur around Rs 4-5000 per month as they visit clinics frequently and the acute attacks of asthma need hospitalization for immediate case management. Thus, burden in the form of medical expenses or costs depends on the severity of the disease as the more severe the disease is, the more the health care utilization is needed.

The variation of the burden of asthma is based not only on severity and frequency of symptoms but also on the socio-economic status of individuals. Socio-economic status can be evaluated on the basis of income, education and occupation of the families. The same severity level of asthma can affect two individuals differently based on their varied economic positions. Through our survey, we have noticed that the worst condition is of the patients with moderate or severe asthma belonging to a low income family as they are limited by the financial resources and work in polluted areas which intensifies asthma. High income families, having sufficient financial resources to buy costly inhalers and medications, can easily cope up with the disease as compared to low income families. The high cost of medicines, inhalers and delivery devices (like spacers) to the low income families, acts as a barrier to asthma control. There have been efforts to define a threshold of family expenditure on health, beyond which a family will slide into deeper poverty. World Health Organization has estimated that families who spend 50% or more of their non-food expenditure fall into this category. On an average, asthma treatment consumes 24% of family total income.

Poor people especially children are greater exposed to outdoor air pollution, traffic, harmful products (like tobacco, smoking), unhealthy environment (like poor ventilation, more stress, crime, poor housing conditions) and have limited access to opportunities and means to protect their health. Poor are less likely to benefit from early detection of asthma and proper management due to illiteracy and lack of sufficient knowledge and awareness. Because of this lacking knowledge, sometimes a nebulizer is preferred over inhalers, in spite of the fact that inhalers are safe and less costly. A nebulizer costs Rs 60 to 80 per day, where as an inhaler costs only Rs 6 a day. This unnecessarily increases the household cost of a family. Therefore, it is clear that families with low socio-economic status are the worst affected due to asthma. In addition, there is a misconception related to the use of inhalers in the minds of people. It is thought to be highly addictive as a result of which many asthmatics tend to avoid the use of inhalers.

No doubt medical expenses cause heavy burden on patients and their family, but indirect costs exacerbate this burden to large. Individuals, in our conducted research, claimed that travelling expenses and costs occurred in the renovation of houses, due to the required demands of asthma patients, have increased their financial burden. Asthma causes a fall in the productivity in two ways, first, in the form of number of working days being lost and second, the decrease in efficiency to work due to stress, frustration etc. This double productivity loss is faced by both asthmatic patients as well as the concerned working family members. It causes reduction in the overall income of the family and GDP of the country at large. With the decrease in productivity,

the overall production, and thus, per capita income of a country also reduces. In Europe, the estimated direct costs of asthma management are about 17.7 billion Euros each year while the indirect cost due to loss of productivity is about 9.8 billion Euros annually. In India, the estimated cost of asthma treatment for the year 2015 is calculated at 139.45 billion Indian rupees per year (approximately 2.3 billion US dollars), excluding indirect costs. World Bank study 2010 estimated that without NCDs (Non-Communicable Disease), GDP in India would be 4 to 10 % higher.

Due to the loss of productivity, asthma imposes a tremendous burden on the society, especially due to the fact that young individuals in their most efficient phase of their life are affected. Another reason for the reduction in GDP of a nation is decreasing number of productive members of society or increasing mortality and morbidity rates.

Asthma is recognized as an important cause of morbidity and mortality worldwide. It is the 14th most important disorder in the world in terms of extent and duration of disability (Global Disease Burden, 2008-10). World Health Organization has estimated that 15 million disability adjusted life years (DALYs) are lost per year due to asthma representing 1% of the total global disease burden. There has been a rise in premature deaths due to asthma. It is estimated that asthma accounts for about 1 in every 250 deaths worldwide. World Health Organization has estimated that an additional 2% reduction in national level chronic disease death rates in India over the next 10 years result in an economic gain of 15 billion dollars for the country. The effects of a disease on the countries are not similar. (The Global Asthma Report, 2011).

People from low and middle income countries are found to be mostly affected. The annual death rate due to asthma is estimated to be 250,000 and the majority of deaths occur in low and middle income countries. The reasons for this disparity are poverty, lack of awareness and education, and low level of investment or expenditure on health and development. High income countries are found to ensure services covered by health insurance and to afford protective products nearly 4 times more than low-income countries. Also, in low and middle-income countries, there is lack of consensus around asthma as a priority, lack of diagnostic equipment and management techniques. Thus, health inequality prevails in relation to exposure to risk, access to protection and care. Such inequality seems to magnify the burden of asthma in future.

It is estimated that there will be an additional 100 million asthmatics worldwide by 2025. Thus, in order to avert this ill-growth, certain immediate steps need to be taken. Firstly, asthmatics should be encouraged to take precautions as little precautions can make their life easier. A good careful parenting is required to be enhanced. Through educational programs and spreading

awareness, myths existing in the society regarding asthma can be shattered which makes social lives of asthmatics difficult. Certain stress-reducing techniques need to be adopted. The Government should also adopt various schemes to help the weaker sections of society and health should be given priority so that individuals can lead their lives better.

V. RESULT OF THE STUDY

- There is no causal link between asthma and air pollution. Air pollution is a triggering factor of asthma but not the only trigger. However, asthma is genetically caused.
- Various social, psychological and economic factors of asthma have a significant influence on the patients, their families and community.
- Several myths and perceptions attached to asthma prevail in the society, restricting the lives of affected individuals.
- Habits, practices and attitude of asthmatic individuals often become a barrier to asthma control.
- In spite of the huge development and educational advancement, people in Delhi lack sufficient knowledge and appropriate awareness about the issue.

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