SHORT REPORT

Carers' perception of childhood asthma and its management in a selected Pakistani community

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Aims: To gather information on the level of disease awareness among the carers of asthmatic children and to determine whether it can help us draw inferences about the possible impact of prevailing perceptions on the management of asthma?

Methods: Subjects were children's parents/guardians visiting the asthma clinic, Children's Hospital, Islamabad. The questionnaire included items on general understanding of asthma, its triggers, and management.

Results: Two hundred carers of asthmatic patients participated. Thirty six per cent thought that asthma is a communicable disease. Rice and oily foods were blamed for asthmatic exacerbations in up to 57% of cases; 82% felt that inhalation therapy is effective in controlling asthma symptoms.

Conclusions: Asthma awareness is inadequate. The majority of the carers unnecessarily blamed and withheld many nutritious foods. Social stigmata can undermine the self esteem of growing asthmatics. Lack of awareness is not significantly related to the socioeconomic or educational background. Awareness raising strategies are needed in the community.

Asthma is a major public health problem, affecting over a hundred million people worldwide. The incidence of asthma is rising all over the world, especially in children, and where urbanisation is taking place.^{1–4} Pakistan is no exception and according to one report, up to 4% of children attending the outpatient department suffer from bronchial asthma.⁵ New insights into its pathophysiology have led to a better understanding of the disease and development of better treatment strategies.^{6,7} The new developments are being disseminated into the communities of the developed world by concerted efforts of personnel involved in asthma management, which is leading to a reduction in asthma related morbidity and mortality.^{8–10} Patient–physician partnership is one of the cornerstones of asthma management. In paediatric practice, involvement of the carers of asthmatic children is essential in achieving good disease control. Therefore the carer's knowledge about the disease and its management can have a significant impact on the quality of life of an asthmatic patient.¹¹

Currently there is little awareness about asthma in most of the developing countries, including Pakistan. Keeping in mind the fact that more and more people are now suffering from this disease, this lack of awareness is unfortunate. The fact that carers and patients of asthma in Pakistan do not have adequate knowledge about asthma, may lead to delays in instituting proper treatment and hence lead to a higher morbidity and mortality. The objective of this study was to obtain baseline information regarding asthma awareness among the carers of asthmatic children in a Pakistani community. How far removed are these perceptions from scientific truth and how serious could their repercussions be on the morbidity and

mortality caused by the disease? In order to answer this question we conducted a survey of the carers of asthmatic children visiting the Children's Hospital, Islamabad over a period of 14 months.

SUBJECTS AND METHODS

Between 1 September 1998 and 30 October 1999, 200 carers of asthma patients, from the Children's Hospital, Pakistan Institute of Medical Sciences, Islamabad, participated in the study.

All carers of patients between the ages of 2 and 13 years, who were registered with the Asthma Clinic, Children's Hospital, Islamabad, from a period ranging from three months to seven years were included in the study. Biological mothers and fathers of the patients were preferred. Most children were accompanied by both parents at the time of interview. People were enrolled irrespective of their social class and educational status. Carers were asked a set of questions specifically designed to evaluate their understanding of the disease. The interview lasted for an average of 15 minutes.

An easily comprehensible questionnaire was designed; most questions were closed, with yes or no answers, although one was open ended. The questionnaire was designed to obtain information regarding the carer's perception of aetiology, triggers, and effectiveness of treatment of asthma. The open ended question dealt with the carer's personal perception of the best possible management for asthma.

Analysis

Data were entered using the EPINFO-6 database program. Frequencies of different variables, with mean, mode, and median, together with standard deviation were calculated. These variables were analysed in a multivariate model to assess their relation to the carer's socioeconomic and educational background.

RESULTS

Two hundred carers completed the study. Males constituted 66.5% of the study population. The majority (82.5%) of the patients lived in the urban area of Islamabad.

Twenty four per cent of the parents had either minimal or no education at all. Almost half of the carers had been to the high school. Most belonged to lower socioeconomic strata. Although those belonging to a slightly higher status had better educational qualifications, when analysed their understanding of asthma was not significantly better than their less fortunate counterparts (table 1).

When asked about aetiology, 61 (30.5%) thought that it was caused by allergens, 73 (36.5%) thought it to be an infection, and 66 (33%) said that it could be caused by both. Thirty (15%) parents also held *saya/nazar* (superstitions/evil eye) responsible for the disease. When asked whether heredity has anything to do with the disease, only 19 (9.5%) replied in affirmation.

Carers were asked whether physical contact with an asthma patient predisposes the exposed to a higher risk of developing the disease; 73 (36.5%) felt that it does.

Table 1 Caretakers' level of education (n=200)

Education level	No. of caretakers (%)
None	26 (13%)
Primary	22 (11%)
Matriculate, intermediate	92 (46%)
Graduate, postgraduate	60 (30%)

A very high proportion (178, 89%) held various types of rice and oily foods and drinks responsible for the aggravation of asthma. The subjects were asked whether they found *parhaiz* (abstinence from certain foods) to be effective or not. Sixty seven per cent (134) responded affirmatively. Up to 85% of carers (170) felt that upper respiratory tract infections are responsible for triggering most of the acute attacks of asthma.

With regard to the effectiveness of medicines, 155 (77.5%) carers found the oral form of therapy to be effective in controlling the symptoms of asthma. One hundred and sixty four (82%) carers felt that inhalation therapy was superior to oral therapy. Sixty (30%) understood the importance of identification and avoidance of triggers.

One hundred and ninety six (98%) families preferred going to the doctor for treatment; however, 9.5% also consulted *Hakims* and 11% homoeopaths. Finally, the carers were asked whether they thought desensitisation was an effective treatment for asthma. Twenty per cent (40) responded positively, while 35% (70) responded negatively. However, 45% (90) were not familiar with the process or had not heard of it.

DISCUSSION

As this study was conducted in Islamabad where there is a constant rise in the number of asthmatic patients, it was expected that awareness about the disease may be increasing among the carers. However, a surprisingly high proportion of carers lacked sufficient information regarding asthma. This is similar to the observation made in a Chicago community survey, that knowledge about the disease of family members of asthmatic patients was no better than that of the general public.¹²

Our study revealed that there are several myths related to asthma attacks and their treatment. The carers had many misconceptions regarding triggers of asthma. Among them were rice and foods rich in oil. This belief leads to withholding of a wide variety of healthy nutritious foods from growing children, thereby having an adverse effect on their nutritional status and overall growth pattern. These misconceptions need to be clarified so that asthmatic children are not deprived of nutrition unnecessarily.

Up to 37% of the carers were of the opinion that asthma can spread from person to person. This stigma of asthma being communicable may put a considerable amount of social and psychological strain on the growing child, who may develop a low self esteem resulting in his inability to play his full role in the community as an adult.

Very few parents thought that heredity has anything to do with asthma; this was similar to the findings of Hsieh and Chiou,¹³ where most of the schoolteachers thought that asthma was an acquired illness.

In a study from Malaysia, most of the parents were concerned about the side effects of inhaled medication in addition to the fear of "inhaler dependency". Other concerns voiced by the parents were the cost of inhaled medication and difficulty in using inhalers.¹⁴ In our survey a very high percentage of the carers felt that inhaled medication was more effective in controlling the symptoms of the disease. It could be a result of the fact that most of the children were on inhalation therapy for many months or years, and the beneficial effects of the inhalation therapy were apparent to the carers.

Most of the parents had tried oral therapy in their children for a variable length of time before switching over to inhaled medication. The frequency of acute exacerbations and yearly hospital visits reduced with inhalation therapy. Children's school attendance also improved. According to the carers, when switched over to inhalation therapy, the children had fewer side effects, such as palpitations, tremors, and headaches. None of the carers found inhalation therapy difficult to administer once demonstrated. This dispels the prevailing concept among medical practitioners that inhalers are not acceptable to most people in our country, as they are considered to be addictive and supposed to be the last resort in the management of the disease.

Our study was conducted in a hospital, and therefore may not truly reflect the situation in the community. Pakistan is ethnically, culturally, and socially a very diverse country; there is therefore a need to conduct similar studies, preferably in community settings, in other regions of the country before any treatment strategy is developed.

This study was carried out in the Pakistan Institute of Medical Sciences, Islamabad, which is visited by people of different economic strata and education levels. It was observed, contrary to the results from a Puerto Rican community survey,¹⁵ that there was no notable difference in the understanding of asthma between people belonging to opposite ends of the economic or education spectrum. Therefore, we feel that some awareness raising intervention, which targets all segments of society, irrespective of socioeconomic or educational status, is required to create better awareness about this disease, so that timely medical advice is sought. This will help reduce the morbidity and mortality associated with asthma, in addition to improving the quality of life of asthmatic patients.

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COMMENTARY

WESTERN MEDICINE IN THE EASTERN MIND: A NEED FOR INTEGRATION

While the prevalence of asthma in the Western developed world has continued to increase steadily in the past decade, Asian countries have experienced an even more dramatic rise.¹ The explanation of this phenomenon is probably multifactorial, ranging from increasing exposure to house dust mite,² the diet,³ lack of exercise,⁴ and to decrease in early infection or infestation that so often accompanies improved economic conditions and westernisation of lifestyle.⁵ In many Asian countries there has been an improvement of medical care together with the widespread availability of Western medicine in the past decade. However, there is often a lack of understanding and trust among the people towards modern modalities of treatment. In Hong Kong alone there are more registered practitioners of traditional Chinese medicine (TCM) than are medical doctors. In one study, as much as 40% of Hong Kong residents admitted that they consult TCM practitioners at the same time as they see medical doctors for their ailments.⁶ Often people are trying to reconcile traditional beliefs and paradigms of understanding with modern science. The issue is often brought into sharp contrast in chronic and common problems such as asthma.

Hazir *et al* reported a group of carers' perceptions of childhood asthma and its management. The study population constitutes the families of patients attending a teaching institute in a Pakistani city. Although the educational background of the carers varies, they have attended the asthma clinic for some time, ranging from three months to seven years. Presumably they would have met the doctor and staff more than a few times and had received some education on asthma and its treatment. The answers they put forward concerning the aetiology of asthma reflected the traditional belief of disease shared by many Eastern cultures. The belief that asthma is an infection is understandable, as the disease has a familial tendency. The worry that contact with the patient may bring about the disease is one important reason why patients and parents may have a low self image as a result of the disease. That evil forces may be at work is also a common belief in many South East Asian countries. As Western medicine understands asthma to be a chronic inflammatory disease of the airway, TCM understands asthma and other diseases through the balance of "qi" (air), or forces of nature, a paradigm originating from Taoism. In our body, perfect homeostasis is achieved by the balance of "yin" and "yang" forces; any factors that upset the balance will lead to disease if unchecked.

In the asthmatic child genetic and other environmental factors have weakened the "qi" of the lungs, the spleen, and the kidneys. Further insults from the environment will lead to malfunction of these organs. In the kidneys it will be manifested as weakened physical ability. In the lungs, the manifestation is the accumulation of phlegm and dyspnoea. External evil forces, or "wai xie", that can upset the balance of the "qi" in the body, consist of factors like cold exposure, infection, lack of rest, and food. Therefore Chinese parents will ask whether they have unduly exposed the child to cold, or whether they have given the wrong food to their child as possible causes of their child's asthma. The asthmatic child in Hong Kong is often forbidden to eat many foods such as sweets, cold drinks, and fruits, as the parents think they precipitate asthmatic attacks. In Pakistan this is rice and oily food and some drinks. Such belief that some food is an important aggravating factor is common among Asian countries, as TCM has great influence on folk medicine in East Asia from Japan to Indonesia. The traditional understanding of asthma, with its deep cultural roots, has great bearings on our strategies of

patient education. Whereas there are many differences between the modern and the traditional explanation of events, there are also some remarkable similarities. It would make things much easier if we were able to integrate modern understanding of asthma pathogenesis into traditional beliefs, so as to present it in a way familiar to the Eastern ear. Perhaps each country should formulate a strategy of its own in order to cater for the respective cultural background.

The use of inhalers has always been a difficult matter among Asian countries. Many studies have highlighted the reluctance of parents in administering the inhaler to their children.^{7,8} It is therefore not surprising that oral bronchodilators still have a very large share of the asthma drug market in Asia. Common worries among parents about inhalers are not only related to steroids. Taking medicine orally has always been the "correct" way of drug administration in folk medicine. Moreover, inhaling a drug, to the Chinese in the past, is synonymous with smoking opium, a most devastating experience for the country in the nineteenth century. Not only is this like poisoning oneself with a narcotic, the idea is also linked to drug addiction and its vast social consequences.⁸ The parent often fears that using the inhaler will render their children forever dependent on the drug. The social stigma associated with using an inhaler can also be intolerable to some parents, not to mention the need of proper technique for inhaler use. One might have expected such unreasonable fears to be related to lack of education, but in two recent studies in Asia, there was no relation between social class, highest education achieved, occupation, race, asthma severity, duration of asthma, and the parents' attitude towards inhalation therapy.^{7,8} The study populations in these two reports were children attending university asthma clinics who were already on inhaled steroid for the control of their asthma or were prescribed inhalers for their condition. Moreover, most of these parents have experienced the good effects of inhalation therapy and agreed that inhalation was effective. Another study in Hong Kong found strikingly similar results.⁹

It is therefore not surprising that long term compliance on inhaled controller therapy is unpredictable. The fear of steroids and their side effects has become a reason for concern in the past decade as media coverage of inappropriate use by some unethical practitioners, especially in Asia, and many athletes caught the attention of the public. Hence in Asia the prescription of inhaled steroids for asthma is often delayed and meets with a lot of resistance. Extra attention and care has to be given to both parents and children in convincing them of the need for continuous usage of the inhaled steroid for their control. Even so, compliance is often poor.¹⁰ In a recent study in Hong Kong in which parents were asked what form the ideal controller should be in, most preferred an oral drug.⁹ Leukotriene receptor antagonists, such as montelukast, would seem to be a perfect answer. At present the price of the drug, in comparison to inhaled steroids, is the main hurdle against its popularisation.¹¹ Moreover, its efficacy in asthma control is not as good as that of inhaled steroids.¹² With further research, more potent controller drugs using the oral administration route would be a major breakthrough in improving compliance to treatment in the Asian region.

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TRANSATLANTIC TOPIC.....

Successful US paediatric public health campaigns

Three US public health campaigns focusing on issues important to the health and well-being of children—immunisations, supine sleeping for infants, and appropriate use of oral antibiotics—achieved success during the past decade. The campaigns have been similar, and valuable lessons have been learned.

Despite the addition of many new vaccines to the US immunisation schedule, hepatitis B, varicella, haemophilus influenzae type b, conjugate pneumococcal vaccine, and the switch from oral polio to inactivated polio, immunisation levels for most vaccines approach 90%. Despite some parental concerns about the link between measles–mumps–rubella vaccine and autism, and other potential complications of immunisations, the high rate of immunisation has been maintained because of the combined efforts of clinicians, professional societies, and governmental agencies. I would predict that despite the increasing complexity of the immunisation schedule, immunisation levels will remain high unless there is new information about potential side effects.

The number of infants dying from sudden infant death syndrome (SIDS) in the United States has declined from approximately 6000 per year to 2000 per year. Although the US was slower than the UK, Australia, and New Zealand to adopt the Back to Sleep campaign, the reduction in SIDS deaths is enormously gratifying. Despite the success, there appears to be some groups of infants, particularly

African-Americans, very low birth weight infants, and infants from large families, in which the campaign has been less successful. This points out the dilemma of health care disparities, particularly given the rapidity of advances in medicine. New public health approaches are being developed that will focus on these groups.

Oral antibiotic use in the US decreased by approximately 30% over the past 10 years. This equates to approximately 10–15 000 000 less antibiotic prescriptions each year. Several actions led to this success. Parents and physicians have clearly been re-educated. While in the past many parents may have pressured clinicians to dispense antibiotics, now they are much more accepting of not receiving antibiotics for colds and coughs. While some US clinicians are experimenting with a wait and watch approach to the treatment of acute otitis media (AOM), it has not yet won wide acceptance. It is possible that the new pneumococcal conjugate vaccine will further reduce the occurrence of AOM. In both the California and Finnish studies there was approximately a 7% decline in AOM in the group of children who received the vaccine. The decline of antibiotic usage in practice may be even greater since clinicians may be willing to withhold treatment from children with AOM (or more willing not to make the diagnosis if they are uncertain) if the child has received the conjugate vaccine.

These three campaigns are instructive. We can maintain certain behaviours (immunisation rates), change parent behaviour (Back to Sleep campaign), and change physician behaviour (antibiotic use) if professional societies, governmental agencies, parent groups, the media, and other stakeholders, such as health plans, acknowledge controversies, but speak with a consistent and unified voice. Just as direct to consumer advertising enhances the sales of specific drugs, a coordinated media approach to certain health care problems can be successful.

There are other common and significant medical problems that occur in US children and adolescents in which we have been largely unsuccessful in effecting change—obesity, smoking, sexually transmitted diseases, dental caries, exposure to guns, and the care of children with significant mental health problems. Admittedly, these problems are complex and often involve lifestyle issues as well as the organisation and financing of health services in the USA. Regardless, approaches to these morbidities should draw on the experience of the past decade in increasing immunisation rates, reducing mortality from SIDS, and curbing the use of oral antibiotics.

Howard Bauchner

US Editor