

Asthma: individual patient perspective and current unmet needs

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Summary

Today there is an array of medication options to treat asthma and state-of-the-art guidelines to help diagnose and manage this chronic disease. Despite this, asthma morbidity and mortality rates are rising. There is an urgent need to direct educational programmes and health resources to address this disparity. A recent US survey of asthma patients and health-care providers disclosed that a large number of asthma patients do not fully understand what control of asthma really means and what treatments are available. They underestimate the severity of their condition and over-estimate how well their asthma is being controlled. More treatment choices provide the opportunity for better asthma control for more patients. However, more choices also mean an increased need for education so that the practitioners can determine the best treatment plan for each patient. Provider/patient communication must be enhanced to address patient cultural and lifestyle practices, including environmental exposures. These factors are as important as medication options for successful patient compliance in asthma control. This will require a change in clinician educator skills or more extensive use of ancillary asthma education in clinics. An interactive seminar for physicians on how to communicate better led to patient–physician encounters that were of shorter duration, had significant impact on the prescribing and communication behaviour of physicians, led to more favourable patient responses to physicians' actions, and led to reductions in health care services use. Not all patient educational needs can be met in brief medical visits. Patient education and patient advocate organizations are essential to supplement education given by the physician. Patient organizations help develop culturally and linguistically appropriate educational materials and they organize patient assist systems that help patients exchange information, practice advice and emotional support.

Keywords: asthma, education, communication, compliance, patient outcome, patient organizations, lifestyle changes

Introduction

There is so much good news about asthma management today. It is well understood that asthma is a chronic disease and there is now an expanded array of medication options for asthma. Most importantly, internationally and in the USA, state-of-the-art guidelines have been introduced to help physicians diagnose and treat asthma. Therefore, medical practitioners have at their disposal the information and an expanding array of tools to treat patients for optimal asthma management outcomes. Despite this, asthma morbidity and

mortality around the world are rising. In Europe, only one out of four patients with mild, moderate or severe asthma are receiving treatment. Recent statistics from the USA show that between 1980 and 1993/4, the age-adjusted prevalence of asthma increased 75%. In particular, there has been an increase in prevalence of 160% for children aged 0–4 years [1]. Although overall hospitalization rates have decreased in recent years, they were three and one-half times greater for blacks than for whites in [1] and hospitalization among young children continues to increase. A recent survey showed extraordinary over-use of hospital emergency rooms by children under 4 years of age [2]. Asthma mortality rates have increased over the last 15 years after a 10-year decline, and are higher and have increased faster among blacks than whites [1]. Thus, in the US, there is a disparity in asthma

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Table 1. Findings from 'Asthma in America' survey

National guideline goals	Actual occurrences reported in 1998 for adults and children with asthma
No (or minimal) need for emergency room visits or hospitalization	9% hospitalized overnight for asthma 23% emergency room visits related to asthma (30% children) 29% other unscheduled asthma emergencies (visits to doctor, clinic or other)
No missed work or school because of asthma	25% of adults missed school or work 49% of children missed school or work
Maintain normal activities	48% limit sports participation and other recreational activities 31% limit lifestyle 25% limit social activities
No sleep disruption	30% awakened with breathing problems at least once a week

outcomes by age and among races. It appears that there is a critical link missing to improve asthma outcomes. There is an urgent need to direct educational programmes and health resources to address this disparity.

'Asthma in America' survey

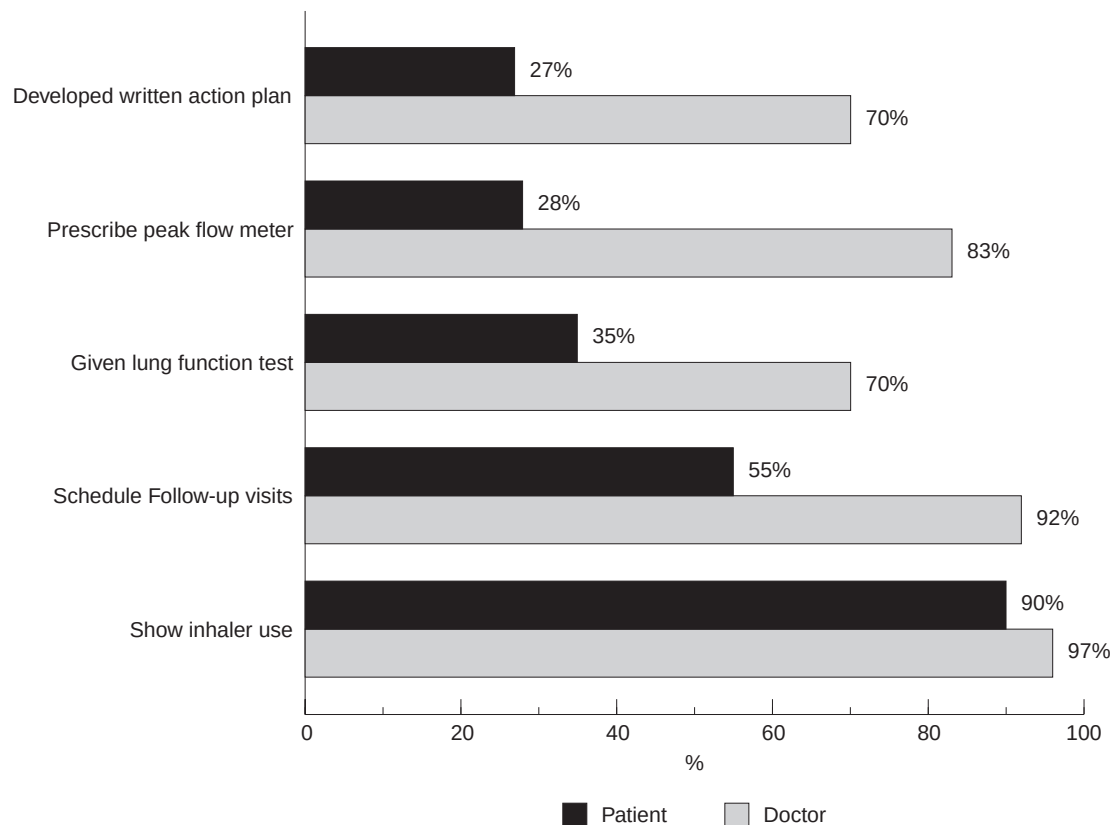
The recent 'Asthma in America' survey [3] showed that the goals for asthma management established by the most recent (1997) guidelines from the National Heart, Lung and Blood Institute (NHLBI) are not being met (Table 1). In particular, asthma is one of the leading causes of school absenteeism accounting for more than 10 million days of school missed [4]. One of the aims of the asthma guidelines is that patients with asthma should maintain normal activities. However, many patients limit their lifestyle and activities because of their asthma (Table 1). Further information on quality of life issues is needed. The survey also showed that there is continuing sleep disruption. The report concluded that there is widespread misunderstanding by patients of their condition, the causes of their symptoms, appropriate and available treatments, and other aspects of asthma management.

The 'Asthma in America' survey included 2509 patients (either adults or parents of children with asthma) and over 700 healthcare providers including specialists, primary care physicians and pharmacists. From the symptoms reported by patients, 19% would be characterized as having severe persistent asthma. However, of that 19% only 22% reported that their symptoms were severe and 32% considered that their asthma was well controlled. This demonstrates that patients significantly underestimate the seriousness of their disease. In addition, another conclusion of the survey was that poorly controlled asthma led people to accept a lower quality of life than is necessary. For example, 47% of adults and 34% of children said that asthma caused them to change the expectations of what they could do.

There is a range of treatment choices that allow for better asthma control for more patients. However, more choices lead to more responsibility and an increased need for education so practitioners can determine what is the best asthma management plan for each patient. Provider-patient communication has to be enhanced to include cultural lifestyle differences including environmental exposures. It must be emphasized that these factors are *as important* as medication options for successful patient compliance of asthma control. The 'Asthma in America' survey highlighted that there is a serious discrepancy between the level of care that doctors say they provide (most of whom say they are providing care in accordance with the guidelines) and that which the patients are reporting receiving from the physician (Fig. 1).

Impact of physician education on patient outcomes

To fulfil this need for increased provider-patient communication, changes are needed in the way that clinicians educate patients. Using more ancillary asthma educators in a physician's office and clinic may enhance this. Recently, Clark *et al.* [5] performed a randomized controlled study of 74 general practitioners and 637 of their paediatric patients with asthma. The aim was to assess the impact of an interactive seminar based on self-regulation theory on treatment practices and communication and education behaviour of physicians. In addition, health status and medical care utilization by asthma patients was assessed, and the subjects' parents satisfaction with care provided. After the seminar, the physicians reported that they were more likely to address patients' fears about medicines, review written instructions with the patient, and were more likely to write down for the family how to adjust the medicines at home when symptoms change (Table 2). Notably, the physicians reported that they spent less time with their patients at follow-up visits. The



D41. How often do you prepare a written set of recommendations or Action Plan for patients to manage their asthma?
[Do that for all, most or some]

P57a. Has (your child's/your) doctor developed a written action plan for (his/her/your) asthma treatment?

D18. Do you prescribe peak flow meters for patients with chronic asthma?

P44b. Do you (or your child) have a peak flow meter?

D15b. Do you use spirometry measures to monitor patient status on an ongoing basis?

P55c. How often has (your child's/your) lung function been tested in the past year?

D24a. After you have prescribed a long-term drug for an asthma patient, would you normally schedule a follow-up visit or tell the patient to call if the conditions recur?

P51a. Does the doctor ever schedule follow-up visits to see how (your child/you) are doing or only see doctor when having trouble with asthma?

D19c. Do you or someone in your practice teach patients how to use an inhaler?

P56a. Has a doctor or nurse ever shown (you/your child) how to use an inhaler for asthma?

Base: All patients (*Unweighted N* = 2,509) All doctors (*Unweighted N* = 512)

Fig. 1. Asthma practices – two perspectives: patients and doctors. Reproduced with permission from the ‘Asthma in America Survey Project’ [6].

performance of physicians suggests that the patient–provider interaction was more focused, sequenced and targeted to patients’ problems and needs. Thus, there was a more efficient and effective encounter.

From the parents’ perspective, the physician had been reassuring, had described as a goal that the child be fully active, and gave information to relieve specific worries. Compared with the control group, more patients received a

prescription for inhaled anti-inflammatory therapy (83% vs 70%) and were asked by the physician to demonstrate metered-dose inhaler use (34% vs 18%). The study also found that children placed on inhaled corticosteroids during the study had significantly fewer symptoms and fewer follow-up office visits, non-emergency physician office visits, emergency department visits and hospitalizations. Therefore, this kind of educational intervention, guiding

Table 2. Post-programme differences in paediatricians' behaviour*

Variable	Adjusted mean of treatment group†	Adjusted mean of control group†	P value (ANCOVA)
Treat newly diagnosed patients with inhaled inflammatory therapy	67.77%	56.27%	0.044
Address specific fears about the new medication	5.14	4.68	0.026
Given written instructions for later reference about using the medication	4.52	3.91	0.058
Go over the instruction for the new medication	5.04	4.43	0.01
Write down for the family how to adjust the medicine when the symptoms change	4.30	3.46	0.001
Provide guidelines for patients to use to adjust therapy when clinical conditions change	80.39%	65.34%	0.003
Time spent on a visit for a newly diagnosed child with asthma (min)	22.8	27.1	0.007

* Analysis of covariance with baseline data as a covariate. No significant differences between treatment and control groups at baseline were identified for these variables † Likert type response format, where 1 = never and 6 = always.

physicians to educate and communicate more effectively with their patients, can have successful outcomes.

Role of patient support organizations

Patient organizations have an increasing role in providing support services to the clinician. Specifically, they can provide culturally and linguistically appropriate information/education materials designed to address patient needs. They can extend education beyond the clinical setting to the home, workplace, school, day-care setting and the community. They can provide consistent messages to the patients reinforcing those given by medical professionals. Moreover, patient associations can provide a supervised patient-to-patient network for information, practical tips and emotional support. This can be of invaluable assistance in ensuring good compliance with a good asthma management plan.

One area that remains to be addressed is that asthma must be legitimized as a health problem. Most people do not consider asthma as a serious condition and do not understand that you can die from this disease. Patients must be encouraged to accept their asthma and to want to manage it well. Patient associations must play a key role in raising public awareness of asthma.

Conclusions

Despite the availability of effective medications and asthma management guidelines, there are clearly unmet needs in asthma, particularly in certain groups of the population.

Improvements in patient education and in provider–patient communication, covering all factors involved in asthma control, may improve patient compliance and outcomes. Patient organizations are important for supplementing the information given by physicians.

Discussion

Chung: To be provocative, how far do you think we would be able to improve things by using patient associations and education?

Worstell: Until we raise the level of public recognition of the seriousness of asthma as a health condition, people will continue to be reluctant to acknowledge they have the disease. Consequently it will also be hard to educate people in their capacity to manage asthma to achieve patient adherence. Beyond this, we also need to improve the way we work with patients so that they can and will adopt lifestyle changes to improve their asthma management.

Björkstén: This is not the public view of asthma and allergy in Scandinavian countries. It raises one point that the doctor may not be the key person. Trained staff and nurses and the active involvement of patient organizations in the advisory board of our Allergy Centre has had a great impact in reducing hospital admissions and in reducing sick leave caused by adult asthma. Thus, it is practically feasible and is what is missing in guidelines.

Worstell: A patient puts enormous trust and confidence in what the physician says and a sense of open communication between patient and physician is very important. However, some education can be provided by other staff.

Björkstén: The doctor can sell the concept of the team and you can transfer the confidence of the patients to include the team rather than merely the doctor.

Hirst: One of the problems we have is in controlling poorly controlled asthma. There is some evidence emerging suggesting that, if you can treat children or young people early enough, their lifetime outcome in terms of asthma severity will not be so bad. Perhaps one way to impact on that with current therapies is to improve patient education.

Holgate: In the UK, one difficulty is the barrier of the patient going to see the doctor. It is actually seen as being quite a big step for someone to take a child to see a doctor. There are strong moves in the UK to set up organizations within supermarkets and community settings that offer advice and information, thus removing the barrier of going to see the doctor. It softens the interface and makes it easier for the patient if they have worries to get access to the information they need.

Djukanovic: I feel that there is too little emphasis on patient choice. I agree that there is a need to shift the decision processes towards the patient. This is probably cultural and varies between countries. However, in some cases the patients are not allowed to have enough say in how they are to be managed. It is a question of choice.

Barnes: The evidence from around the world is that if you implement the asthma guidelines, they are fantastically successful. Scandinavia is the best example; there has been a huge fall in asthma mortality and a fall in hospital admissions for asthma. It has occurred in the UK, although not quite as dramatically. The key problem is in implementing the guidelines. It needs both the doctors and the patients to re-set their expectations about what can be done.

Holgate: We don't know for sure that the treatment and the effects (i.e. the morbidity statistics in Sweden) are directly related to each other.

Barnes: There is no other plausible explanation for the rapid fall in mortality that has occurred in the Scandinavian countries and in the UK. You can't explain it in terms of demographic trends.

Holgate: You talked about the difference in asthma morbidity

between black and white populations in the US and that asthma and allergic disease have not yet been recognized as public health problems. In public health terms, when one makes interventions at the level of housing, schooling, diet, etc., there is often a bigger impact on chronic diseases than forcing populations to take drugs. History has shown this for other diseases such as tuberculosis. In the asthma guidelines we are still thinking about drug intervention as the way of coping with the problem. We do not think of it in terms of the possible public health issues involved.

Barnes: Apart from stopping people smoking, we don't know what public health interventions to make to decrease the prevalence of asthma.

Worstell: Recently, the Department of Health and Human Services in the US released a draft public health response to asthma. This represents the first initiative of government agencies – beyond those dedicated to research – to demonstrate an interest and a commitment to put resources behind asthma – and to collaborate in this effort. Patients must see a doctor for a diagnosis and a medication plan, but they must also understand what causes their signs and symptoms and reduce their exposure to these. They must change their lifestyle. We cannot look at these diseases and not contemplate choices that patients have to make. There is a responsibility to change the dynamic between the patient and provider in terms of education. Patients must assume a responsibility for managing their condition and adopting lifestyle changes.

References

- 1 National Asthma Education and Prevention Programme (NAEPP), National Heart, Lung and Blood Institute (NHLBI) National Institutes of Health, USA.
- 2 Mannino D, Homa D, Pertowski C *et al.* Highest rate in children 0–4 years. Surveillance for Asthma – United States 1960–95. *MMWR* 1998; 47:1–28.
- 3 Asthma in America. National Survey. Glaxo Wellcome Inc. 1998.
- 4 Asthma: a concern for minority populations. National Institutes of Allergy and Infectious Diseases, January 1997.
- 5 Clark NM, Gong M, Schork A *et al.* Impact of education for physicians on patient outcomes. *Pediatrics* 1998; 101:831–6.
- 6 www.asthmainamerica.com/execsum