

ABC OF ALLERGOLOGY

IS THERE A NEED FOR ALLERGY SELF-MANAGEMENT?

Adrian Morris, MB ChB, DCH, MFGP, Dip Allergy (SA)
Allergy Clinic, Constantiaberg MediClinic, Cape Town

Professor William Osler observed 100 years ago 'It is more important to know what sort of person this disease has than to know what sort of disease this person has.' Constraints on current clinical practice dictate that we allow too little time to communicate adequately with our patients and then we get bewildered when they don't use the prescribed medication correctly.

We currently have an armoury of superb allergy medication readily available, but if we cannot persuade our patients to take it correctly and appropriately then the whole treatment exercise becomes futile. This was borne out by the 'Asthma in America' population survey published in 2002¹ which showed that despite all the advances in treatment, asthma is still generally poorly controlled:

- 49% of children and 25% of adults with asthma missed school or work as a result of asthma during a 1-year period
- 30% of asthma patients reported awakening with breathing problems
- 48% said their asthma limited their ability to take part in exercise and recreation
- 70% of doctors reported using spirometry to measure airflow, but during the same period only 35% of patients reported having a lung function test
- 92% of doctors said anti-inflammatory medication was 'essential' or 'very important' but only 18% of asthma patients reported using anti-inflammatory medication
- 83% of doctors said they prescribed peak flow meters to allow patients with chronic asthma to monitor their condition, but only 28% of patients had one and only 9% had used it at least once in the preceding week
- 70% of doctors said they prepared a written action plan for all, most or some of their patients, but only 27% of patients said their doctor had developed a written action plan for them.

The Global Initiative in Asthma (GINA) goals for successful management of asthma is the benchmark to which we all adhere, and these goals are relevant to all forms of clinical allergy. Their aims broadly include:

- Achieving and maintaining control of symptoms
- Prevention of exacerbations
- Maintaining normal activity levels, including exercise
- Avoiding adverse effects from medications
- Preventing development of irreversible disease.

The GINA general goals have relevance to all allergic diseases. But successful long-term treatment of persistent asthma, atopic dermatitis, food anaphylaxis and allergic rhinitis is limited without individualised and

Correspondence: Dr A Morris, 112 Constantiaberg MediClinic, Plumstead 7800. Tel 021-797-7980, fax 021-683-5335, e-mail adrian-morris@absamail.co.za

Problems with patient education

Told, but not heard
Heard, but not understood
Understood, but not accepted
Accepted, but not put into practice
Put into practice, but for how long

Konrad Lorenz

structured self-management provided by patients themselves.

Adherence to treatment

Adherence (concordance or compliance) to treatment is a major problem in allergology and needs special attention. Patients may be prescribed the most effective state-of-the-art medication and provided with a superb treatment plan for their allergy, but if they fail to diligently follow the advice, their disease will be poorly controlled.

A patient's knowledge of the effect of the medication, plus the effect of irregular use and side-effects will have an impact on adherence. Treatment instructions should be both understood and *agreeable* to the individual patient. A culture of open communication about dosage and adjusting this to daily life is important. Tailoring the medication regimen to the daily routine and using less conspicuous formulations improves adherence.

One of the biggest problems in asthma, allergic rhinitis and atopic dermatitis is the irrational fear of corticosteroids and non-adherence to the therapeutic doses of prescribed medication. Patients confuse topical corticosteroids with oral anabolic steroids and their doctor and pharmacist may further fuel this fear by issuing excessive precautions regarding the regular use of topical corticosteroids and potential side-effects. This is compounded by the media perception that topical steroids are dangerous and will cause skin thinning and growth retardation. Both of these side-effects have been shown in well-conducted clinical studies to be unlikely to occur at normal therapeutic dosages with non-fluorinated steroid creams or inhaled steroids, and if they do occur, the effects are usually reversible. In a study by Charman *et al.*² who interviewed 200 patients in a dermatology clinic, 72.5% were anxious about using topical steroids and more than 24% were non-adherent, admitting that they did not use their prescribed corticosteroids. In a similar Australian study,³ 40% of parents perceived their children's prescribed topical steroids to be dangerous and 20% thought they were too dangerous to use on their children.

Different approaches and models for patient-educational programmes have been explored from those providing basic allergy information to those developing empowered patients in complete control of their disease:

- Information the informed patient
- Promotion of adherence the obedient patient

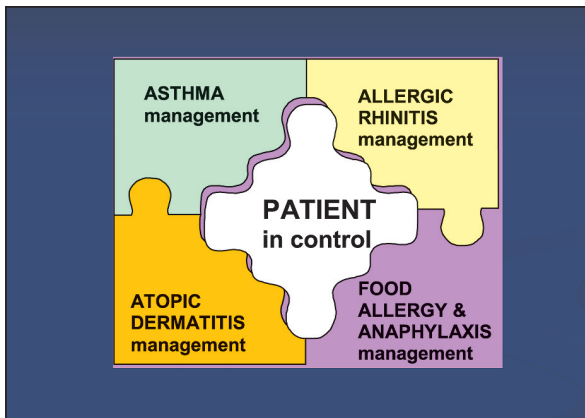
- Training the capable patient
- *Empowerment the responsible patient*

The ultimate goal should be to empower the patient to work as a partner with the doctor and competently self-manage their own or their children's allergic disease – the 'expert patient'.

Specific aims of patient education programmes

Structured patient education should enable both patient and parent to:

- Have realistic short-term goals for their allergic disease
- Enter into a process of productive problem solving
- Accept living with their chronic allergic disease
- Appropriately utilise available medical support
- Enhance motivation to use therapy correctly.



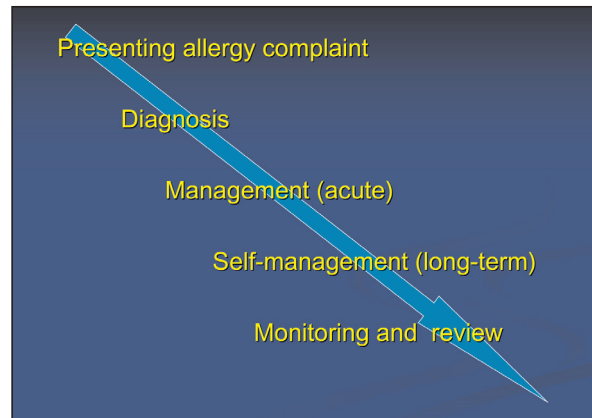
The European 'asthma school' success stories⁴

In Germany and Scandinavia, asthma education courses have grown since first started in the early 1990s to a remarkable 1 395 courses in Germany by 2002. The first participants in these 'asthma schools' were initially admitted to hospital for 5 days, each undergoing 30 hours of asthma group training for the children and 15 hours training for the parents by a team consisting of a medical doctor, a psychologist and a sports physiotherapist. There are now over 2 000 certified asthma trainers (mostly paediatricians and psychologists) in Germany. These programmes are standardised with similar programmes available throughout the country, all are quality controlled and have a set curriculum for trainers. The optimal programme duration currently is 20 hours for children and adolescents, and 10 hours for parents over a minimum of 3 days with a follow-up session after 6 months. The number of participants who completed asthma training programmes between 1992 and 2002 is now in excess of 10 000. Similar group programmes dealing with atopic dermatitis have been highly successful, with group interaction providing additional support and insight into chronic allergy.

Kamps et al.⁵ examined the outcomes of nurse-led follow-up of children with diagnosed asthma. They did a one year follow-up of newly diagnosed asthmatic children following their education protocol. Outcome measures assessed included lung function, inhaled corticosteroid use, number of exacerbations, emergency visits to the GP, absence from school and quality-of-life issues. Their findings were that a nurse-led childhood asthma management plan was as effective as that provided by a paediatrician while it cost less.

Educational programmes for the self-management of

asthma and allergic rhinitis in children and adolescents improve lung function and feelings of self-control, and reduce absenteeism from school, the number of visits to an emergency department, and possibly the number of disturbed nights. Educational programmes should be considered an integral part of the routine care of young patients with asthma, allergic rhinitis and atopic dermatitis. Extending these programmes to educate children and adults with severe food allergies and anaphylaxis is also essential.



Communicating Evidence for Participatory Decision Making

Steps in discussing evidence with patients

1. Understanding the patient's experience and expectations of their allergy
2. Building partnership
3. Presenting evidence, including uncertainties
4. Providing recommendations based on scientific data
5. Checking for understanding and agreement

Epstein RM et al. JAMA 2004, 291;19: 2359-2366.

Getting the health authorities and medical aid societies 'on board'

All programmes such as asthma schools, food allergy and atopic dermatitis management programmes need constant evaluation of their outcomes. Health insurers are keen to explore these programmes and support them financially, but will ask us critical questions and they will need hard evidence before releasing funding for these programmes. Quality management and standardisation is imperative, and each 'trainer' needs regular updating through refresher workshops. Accurate cost/benefit analysis will be a prerequisite from all health economists who will then advise their respective health authorities or medical aid society. The experience in Europe and the USA is that despite the initial start-up costs of these educational programmes, they reduce overall direct and indirect health costs and long-term morbidity. The concept of allergy self-management is certainly worthy of investigation and support in the future health care structures in Southern Africa.

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