

Artigo original

Education of the Person with Asthma as a Fundamental Part of the Management Strategy

Educação do Indivíduo com Asma como Parte Fundamental da Estratégia de Manejo

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RESUMO

Os demais capítulos do presente suplemento demonstram os principais avanços na compreensão da patogênese e no manejo ideal da asma nas últimas décadas. Muito desse progresso representa uma compreensão científica amplificada, mas a extrapolação e a implementação dessa compreensão, apesar de levar a melhoras, geralmente reflete a atividade da indústria farmacêutica na produção e na promoção de medicamentos eficazes. Em muitos países, isso levou a uma queda no número de mortes por asma e, em parte deles, à redução no número de hospitalizações causadas por exacerbações. Agora, entretanto, esse declínio se estabilizou, e uma melhoria dos desfechos somente deverá ocorrer se os médicos abraçarem componentes não prescritivos do cuidado ao asmático de forma mais ampla. Tais componentes incluem aumentar a comunicação, dividir o processo decisório, apoiar o automanejo e tornar o acompanhamento mais simples e conveniente. Esta revisão foca um desses componentes — que é vital dentro desse grupo de cuidados — o automanejo.

Descritores: Asma/terapia; Autocuidado; Tomada de decisões; Educação de pacientes como assunto.

ABSTRACT

As the other chapters in this asthma supplement have demonstrated, there have been major advances in the understanding of the pathogenesis and the optimal management of asthma over the last few decades. Much of that progress represents enhanced scientific understanding, but extrapolation and implementation of that understanding, whilst leading to improvements, often reflects the activity of the pharmaceutical industry in producing and promoting efficacious medications. In many countries, this has led to a decrease in the number of those dying from asthma and in the number of those being admitted to hospital with exacerbations. That decline may now have plateaued, and further improvement in outcomes is only likely to occur if doctors embrace the wider non-prescription elements of care. Such elements include everything from enhanced communication, shared decision-making, self-management support, and easier, more convenient follow up. This review concerns one vital element of that wider package of care, namely self-management support.

Keywords: Asthma/therapy; Self care; Decision making; Patient education as topic.

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The authors declare that they do not have any potential conflict of interest.

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It is possible to find several definitions of self-management within the published literature. Some suffix the term as self-management *education*, whereas others would regard this as being pejorative, as it implies inadvertently that our clients are “uneducated”. We should instead think of this subject as being self-management support and it is important from the outset to stress that any such intervention is of limited value unless it is associated with a resulting sustained behavioural change by the patient.

One recent study of patients with asthma surveyed 1,022 patients with asthma in five European countries (1). The survey was concerned with patient expectations of their interaction with health care professionals. As one part of that study, those with asthma were asked to recount how often they went to see their general practitioner for review of their asthma and their recalled duration of the consultation: 83% of those with asthma surveyed in the five European countries reported that they had been to their general practitioner for review of their asthma. However, the frequency of attending was a median of every 13.4 months and patient recall of the average duration of each consultation was 12 minutes. If we recalculate these data, we can see that for 364 days, 23 hours and 49 minutes of each year, the person with asthma looks after their own condition themselves. This is thus the reality as to why self-management support is so important, because patients are self-managing their condition for the vast majority of the time. As international guidelines so clearly stress, it is thus our responsibility as health professionals to provide those with asthma with the tools, skills, and knowledge which they need to enable them to look after themselves appropriately for all but the 12 or 13 minutes a year when they are sitting alongside us in our consulting rooms.

In the same study, those with asthma regarded the most important aspects of their relationship with their doctor as having doctors who did the following:

- listened carefully when I talked about my symptoms and problems
- understood what I was trying to express
- explained clearly what my condition is and the problems it can cause
- devoted an appropriate amount of time to the visit
- explained clearly how to use the inhaler
- explained clearly the possible side effects of medication
- understood clearly what concerns me
- offered me support to help me manage my own condition
- consulted me regarding the choice of inhaler

The concept of self-management support is not new. In the Guidelines for Management of Asthma in Adults (section 1: Chronic Persistent Asthma), pub-

lished in the British Medical Journal in 1990 (2), it is clearly stated that “as far as possible patients should be trained to manage their own treatment rather than be required to consult their doctor before making changes”. However, if we fast forward a decade or two, from 1990 to 2007, we can find studies (3) that look at whether practices comply with key recommendations of the British Asthma Guidelines and find that the major recommendations such as those concerning self-management are still not being implemented. If receipt of a written action plan is used as a marker of whether the patient received self-management support, only 23% of patients surveyed had had this recommendation applied to their care.

When health professionals were questioned as to what the barriers to offering self-management support were, they reported the following:

- doubt about whether the evidence applied to them in primary care
- that they lacked the knowledge and skills to implement this recommendation
- misconceptions about what it involved
- perceived lack of time
- non-availability of resources, such as templates upon which advice is written
- poor teamwork (a doctor thinking that a nurse had offered such support and the nurse in question thinking the opposite)

We therefore need to think about ways in which we can help busy health professionals give advice. That is an issue that was addressed in studies by Roberts et al. (4,5), who devised a simple computer programme that permitted the doctor and patient sitting together to construct a pictorial asthma action plan (Figure 1), which permitted the patient to receive advice about their usual therapy, when they should increase their therapy, when they should start a course of steroid tablets for asthma (or antibiotics or steroids, or both, for COPD: Figure 2) and when they should seek urgent medical attention. These simple programmes can be downloaded for free (<http://www1.imperial.ac.uk/medicine/people/m.partridge/>) and address the barriers outlined in the earlier survey, in that they provide an easily available template upon which advice can be given and they prompt the health professional as to the correct information to give the patient.

These plans include pictorial representations of a patient’s usual medication and pictorial depictions of features suggesting deteriorating asthma and the action one should take. Such pictorial representations help to overcome the problems associated with impaired health literacy. Those with limited literacy skills present with the following (6):

- poorer overall health
- a lower likelihood to make use of screening
- later stages of disease

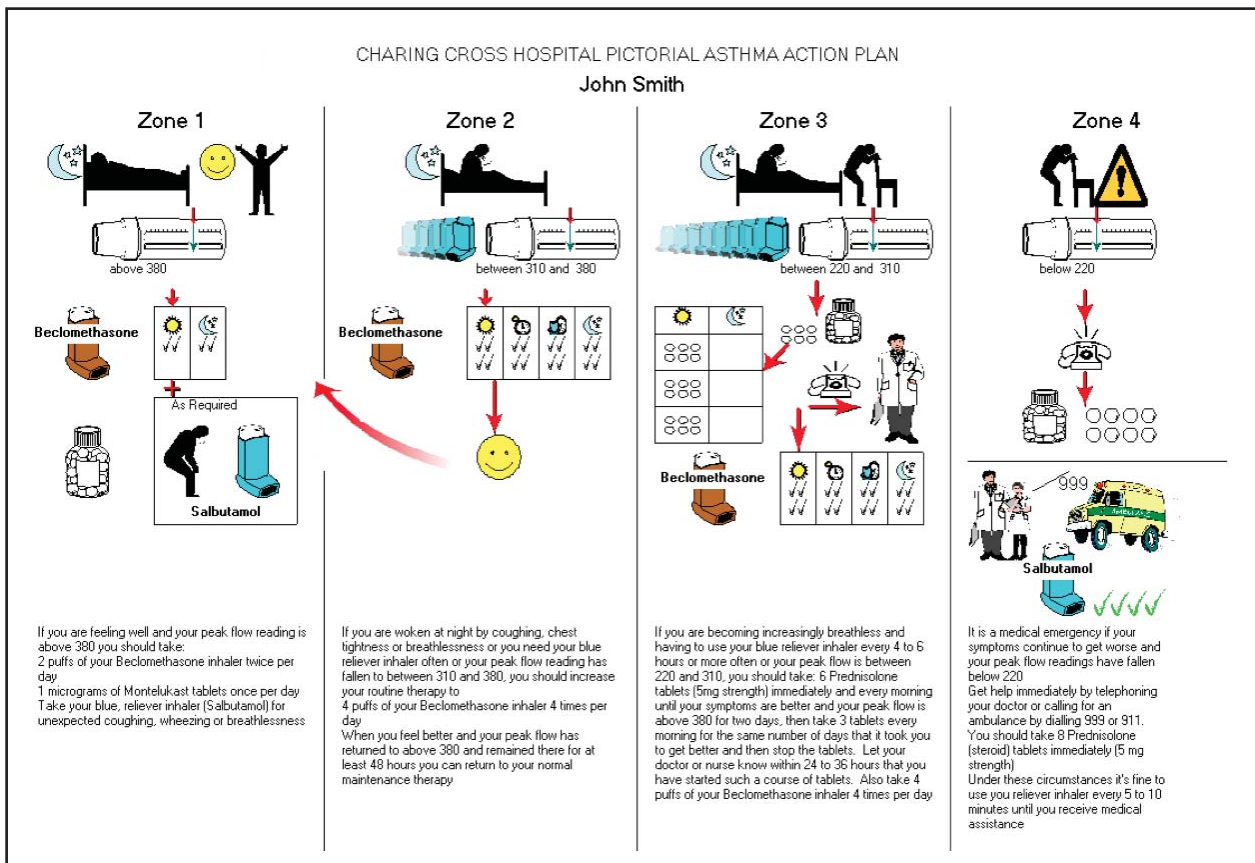


Figure 1 - The Electronic Asthma Action Plan.

Source: <http://www1.imperial.ac.uk/medicine/people/m.partridge/>

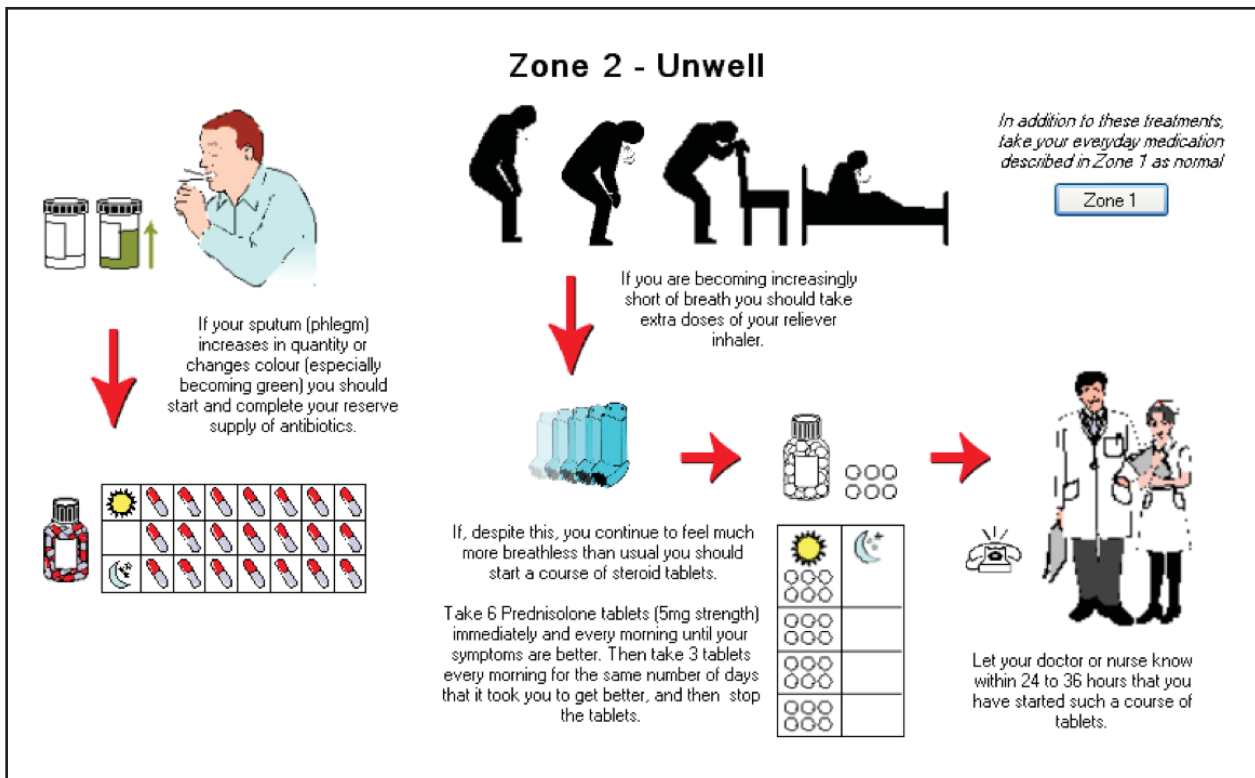


Figure 2 - Part of the Electronic COPD Action Plan.

Source: <http://www1.imperial.ac.uk/medicine/people/m.partridge/>

- a greater likelihood of being hospitalised
- a poor understanding of treatment
- lower adherence to medical regimens

Others have also described quite detailed pictorial prescription charts for those with limited literacy, including examples where pictorial advice is given not only about when to take the medication but also about what each pill is for (7). More recently, Ghiassi et al. published a pictorial Epworth Sleepiness Scale, which gets round the problems encountered in sleep clinics when patients cannot satisfactorily complete the more traditional written Epworth Sleepiness Scale (8). This use of pictorial representations to give advice to patients for both self-management and other reasons has been shown conclusively to improve patient comprehension and compliance (9).

Is all of this effort appropriate for those with impaired literacy and does it improve their self-management skills? That is a question that was tackled in a large study conducted by Paasche-Orlow et al. (10), who found that 22% of patients hospitalised for severe asthma exacerbations had limited health literacy. They offered those patients advice in a more easily assimilated manner and found that the results were equally as good as those achieved in the fully literate. Health professionals thus have a responsibility to ensure that they offer, to all patients, information about self-management in a useful manner.

Are other sources of information used? In the European study cited earlier (1), the patients were also asked from whom they sought certain information about asthma. Of the asthma patients evaluated, 58% reported that their first source of information was the doctor who was treating their lung condition, although 65% reported that they sought information from the Internet. However, less than 5% of the patients reported having had any website recommended to them by a doctor or a nurse. We should therefore consider recommending respected websites as a source of confirmatory information for our patients.

Are there other interventions we should be promoting in addition to self-management support? Self-management support for those with asthma carries Grade A evidence in all international guidelines, and we have so far considered ways in which we might enhance its implementation. However in addition to self-management support, the evidence is now increasingly strong that *shared decision-making* is important. In one large study, patient desire to be involved in choosing the inhaler they used was prominent (1). Wilson et al. (11) looked in great detail at whether such shared treatment decision-making improves adherence and outcomes in poorly controlled asthma. In a study of 612 patients with poor-

ly controlled asthma, the patients were randomised to usual care or shared decision-making. The latter involved the doctor very carefully eliciting patient goals for treatment and their relative priorities regarding symptom control. They discussed with the patient their desires regarding how convenient the therapeutic regimen should be and the amount of concern they had about the costs of any medications. The health professional then showed the patient a list of all available treatments, both devices and dosing, and, using a work sheet, the clinician and patient together worked out the pros and cons of each treatment regimen before a decision was made. The main outcome measure of that study was adherence to treatment. The results were better for all classes of medication, the need for unscheduled healthcare was less, and quality of life was improved. In addition, this had a long-lasting effect on patient behaviour, because, at two years out, short-acting beta agonist use was still significantly less in the intervention group than in the control group.

If self-management support is to be effective, it is not a delegation of responsibilities to the patient, and health professionals need to make themselves easily available for further advice by the patient when needed. However, we do need to make that convenient for patients. Nevertheless, studies of the reason why patients with lung disease do not return for follow up, such as that conducted by Van Baar et al. (12), show that patients do not return to follow up, sometimes because they forget, sometimes because they did not see the same doctor each time, but note the one further important cause why patients did not come for specialist review was that they were "kept waiting last time". We therefore need to make follow up convenient and remind ourselves that many of these patients have had asthma for ten, twenty, forty or more years, and keeping them waiting and seeing them at inconvenient times is not conducive to patients wanting to come back for review of their condition.

There is very good evidence now that telephone consultations can be equally effective and satisfactory for patients, as well as being much more convenient (13). We need to offer that form of follow up much more often to our patients with these common lung disorders.

The evidence is now of such strength that all respiratory physicians need to move on from the making of a diagnosis and the writing of a prescription alone to accepting the wider responsibilities for these issues such as the way in which we organise care, the methods by which we offer patients specialists review, and, of greatest importance, the way in which we address and implement shared decision-making and meaningful self-management support.

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