Leading Article

Educating patients with asthma

Martyn R. Partridge

Whipps Cross Hospital, London E11 1NR, UK

Nearly 3 million people in the United Kingdom have asthma, and each year 100,000 of those are admitted to hospital because of their asthma and over 1,900 die.¹ This suffering continues despite excellent therapies for asthma being available. This paradox may be explained by there being delays in diagnosis of the condition, for until a patient is diagnosed as having a disease they are unlikely to receive treatment for it. It may also be explained by the severity of the condition being underestimated by either patient or doctor, or because the doctor prescribes suboptimal treatment, or the correct treatment is prescribed but for whatever reason the patient fails to take it. All of these explanations are possible and asthma diagnosis is often delayed because symptoms of asthma are attributed to infections in the young,² or symptoms are wrongly ascribed to heart disease or chronic obstructive pulmonary disease in the elderly.³ Two general practice audits^{4,5} and a study of those admitted to hospital with severe asthma⁶ have shown evidence of underuse of preventative anti-inflammatory treatments, underestimation of severity, and an over-reliance on relieving drugs which do not modify the basic problem. Finally, we need to recognize that even when the correct therapy is prescribed there is a high incidence of non-compliance, and this may be as high as 50% of patients on preventative therapy not taking medication as previously discussed with the clinician.^{7,8}

Guidelines on asthma management have now been introduced in a number of countries.^{9–12} These are useful for setting standards and as a basis for audit, and they are also useful as a starting point for the education of both health professionals and patients. Indeed, all of the published guidelines on asthma management have stressed the importance of patient education, but we have to consider what this means and what is involved. Whilst patient education certainly involves the giving of information to patients, it also involves them acquiring certain skills, in using inhalers, learning how to

monitor their condition and in understanding the basics of self-management. Many years ago it was realized that the acquisition of knowledge alone was not enough to reduce morbidity,¹³ and the challenge is to empower, motivate and direct our patients (and their loved ones), in a way that leads to them altering their behaviour in a beneficial manner as a result of the knowledge that they have acquired. To make this likely to happen involves us thinking about three key but interlinked issues:

1. Communication;
2. Patient education; and
3. Organization of care.

Good communication is an integral part of good medicine but may be of even greater importance in the management of those with a long-term condition. It involves the health professional being a good listener¹⁴ and involves him or her giving the patient the agenda during the consultation. It involves us realizing that, whilst the health professional may believe that they know what the patient 'needs' to know, this may not be what the patient 'wants' to know. Unless the patient is permitted to voice their major concerns then they are unlikely to hear what the health professional has to say, and this has been clearly shown to have a significantly adverse effect upon the likelihood of the patient complying with the taking of prescribed medication.¹⁵

The patient needs to be reminded that the consultation is for them. This may involve asking the patient to write down in advance any fears or concerns that they have and to write down any questions that they wish to ask the doctor or nurse.

The consultation should be conducted in a way that reminds the patient (or parent) that the time with the doctor is theirs. By the liberal use of open-ended questions, the patient should be encouraged to outline issues that are concerning them and which if not expressed may act as a barrier to subsequent educational efforts. These issues will be varied in type and are obviously often specific to the individual patient. However, some topics concern those with asthma often enough that they should be sought if they are not specifically mentioned. Some of these are specific issues such as those associated with 'steroid

phobia', others are questions such as 'What do I do with the peak flow meter that I've been given?' 'Do the inhalers lose their effect with time?', 'Will I become dependent on them?', 'Will he grow out of asthma as he gets older?'. These can be raised in conversation by the use of appropriate questions, for example: 'Some people think steroids are harmful, what do you think?'⁹ Questions and concerns can then be tackled by the provision of specific information both verbal and written. Other issues concern a patient's attitude to their illness and here the intention of airing the subject is to elicit its severity and to enable the doctor to express empathy: 'I expect that you feel pretty fed up having to take medicine all the time?' Allowing the patient to talk about how they feel about their condition is also important in enabling us to assess perception of severity accurately, for during such conversations the health professional can often gain an impression as to whether the patient is the type to put up with symptoms rather than to mention them. Once such a state is elicited, educational efforts can be directed at helping the patient expect more from both their treatment and from the doctor.

In considering communication with those with asthma, physicians who care for adults should perhaps be as alert as paediatricians and primary care physicians to the impact upon others, of a family member having asthma. Several studies¹⁶ have shown that having a child or loved one with asthma impacts in a significant way upon parents and partners. This should be acknowledged in conversation and these other carers involved, when appropriate, when partnerships are being built between health professionals and patients.

Good communication is thus a fundamental part of the approach to the management of asthma and it is a fundamental part of patient education. Education of those with asthma involves the patient acquiring knowledge and acquiring certain skills, and then as a result altering their behaviour. The aim is to minimize the impact of their having asthma upon the quality of their lives (and that of those around them), and minimizing its impact upon their future health and on their use of health services. Whilst the prescription of good treatment for asthma may cost more than prescriptions of less good therapy, the benefits are likely to be those of reduced in-patient hospital costs, less time off work and school, and less likelihood of permanent lung damage.

Education of the patient therefore involves them receiving information about the diagnosis, their treatments (with adequate explanation as to which are their relievers and which their preventer therapies), and all patients then require training in how to use their inhalers. All patients and all

parents of children with asthma require information about signs that suggest their asthma is worsening (for example, advice about the significance of nighttime symptoms and an increased need for bronchodilators), and clear advice about what to do under those circumstances. Many adults and some children will also need training in how to monitor their own condition by use of peak flow monitoring. The goal for many of those with asthma will be for them to receive a guided self-management plan. What is meant by this term requires some clarification. To some extent everyone with asthma self-manages their own condition, for they are self-managing themselves every time they use a relieving bronchodilator. However, for some others it is appropriate to give them a detailed plan so that they alter treatment in a number of different ways according to either their symptoms or peak flow, or both. Whilst one study¹⁷ suggested that these self-management plans could be based upon symptoms alone, more recent work¹⁸ has shown that many adults with asthma are actually poor subjective discriminators of severity, and most guidelines have suggested that such plans should be based upon both symptoms and objective peak flow monitoring.

The patient therefore undergoes a period of home peak flow monitoring, often on maximal treatment, so that their target, or optimal, peak flow is determined. They are then given a plan, which would suggest that, if their peak flow is above 70–80% of their target figure and if they are free of significant symptoms, then they should continue their usual medication. If their peak flow falls, they may be advised to double their usual anti-inflammatory preventer therapy, and if it falls further or if other symptoms develop, they are advised to take other treatments or a course of steroid tablets, all in a way that has been predetermined for that individual by their doctor. All patients are also given a medical alert action level and, if they develop symptoms and if peak flow falls below a certain level (for example, less than 40–50% of their target level), they are advised to seek urgent medical attention in a way that is outlined for that individual. These action plans are written out for the individual patient or filled in on partially preprinted forms such as those that are available free from the National Asthma Campaign (Providence House, Providence Place, London N1 0NT) (booklet number 7).

Self-management plans have now been studied extensively^{19–21} but several questions remain.²² Whilst some studies suggest that their use can reduce symptoms, optimize peak flow and probably reduce hospitalization, they may not be suitable or necessary for everyone. Indeed one study suggested that benefit was only likely for those with more severe asthma.²³ Further studies

are necessary to define better who needs such self-management plans and what form these should take. However, academic debate about who needs the more detailed plans should not deflect us from the need for all patients to be given some personalized advice about their own treatment and about signs that suggest worsening asthma. There seems little doubt that this sort of personalized educational material does improve outcome.²⁴

Fifty per cent of all that is discussed during a consultation is forgotten within 5 minutes of it ending and patients therefore need to receive information to reinforce that which they have received verbally from the health professional. By itself this may not alter patient behaviour but it is an essential prerequisite for subsequent educational initiatives, and it is also part of the process of empowering of patients—often it is by having read a leaflet or watched a video that the patient knows what to ask the health professional. Having played videos in the waiting room of our clinic for many years it has become commonplace for patients to attend for a costly secondary care consultation regarding poorly controlled asthma, and for them to walk into the consulting room and announce 'Do you know doctor, watching that video has made me realise that I've been using the inhaler wrongly all these years.'

Giving information to patients and parents is designed to give the patients knowledge and satisfaction, and to enable them to be in a position to ask further questions. It may also be necessary to supplement the spoken word specifically on certain key issues such as on the safety of steroid therapy so that the patient is in a position to make an informed decision themselves on the advantages versus disadvantages of such treatment, and this is likely to enhance compliance. It has also been shown that compliance with a complicated series of instructions is enhanced by supplementing oral advice with the written word.²⁵

Written information leaflets are given more commonly to those with asthma than to those with diabetes, heart disease, cancer or epilepsy (1994 National Asthma Campaign Health Professional poll: personal communication) but a National Asthma Campaign poll of 1,631 patients with asthma showed that it was still unusual for patients to actually receive leaflets (1994 National Asthma Campaign Poll of Members: personal communication). Whilst 63% of those patients had received a demonstration of inhalers, only 47% had had advice regarding worsening asthma and only 27% had had written advice regarding their medicines. A total of 635 (39%) had been given information booklets. Particularly disappointing was the fact that only 61 (4%) had been able to see a video about asthma, and yet this has been shown²⁶ to be a popular choice of patients as a method of receiving

information and it is particularly appropriate for those with poor literacy skills. It is also a good method for demonstrating practical procedures, such as the use of inhalers.²⁷ However, no method of giving information is necessarily superior to another and it is preferable to have a range of materials available (booklets, audiotapes, videos and posters), and to use these to supplement oral advice, whether given by doctor, nurse or other health professional.

Educating patients is not a static process. Information needs to be given in a graded manner on more than one occasion with each consultation involving a period of revision and reinforcement of previously given messages, with there being plenty of opportunity for the asking and answering of questions. Patients who have self-management plans need to have these checked from time to time and they need to be rewarded when self-management which they have undertaken has been successful and correctly executed.

Most of this education should be given in an individual manner and personalized to the individual by the health professional. Such education and supervision has been associated in several studies with improved outcomes.^{19,20,28,29} In the USA and in Germany, particularly, there have been studies of the possible advantages of giving some of this education in group sessions. This may have the advantage of providing support and in reducing feelings of isolation. One study at least has shown that group education is more effective than individual education.³⁰ However, some of these studies have had to attempt to enlist very large numbers of subjects in order to find sufficient willing to be allocated to intervention and control groups. Others have involved very lengthy programmes of instruction or have involved prolonged periods of hospitalization for the purposes of education. Not all of the published studies therefore contain conclusions which can easily be extrapolated from one individual to another or from one health care system to another.

The organization of care for those with asthma is thus inextricably linked to the question of patient education. In the United Kingdom hospital care for those with asthma is often provided by general medical services. This actually means that it is provided by physicians, for example, with an interest in diabetes who happen to also have responsibility for general medical admissions. Such non-specialist care may have significant effects upon outcome (as indeed it may if the general physician with an interest in asthma looks after somebody with diabetes). One study³¹ suggested that, if a patient's first admission was not under the care of a respiratory interest firm, then they would be less likely to receive steroid tablets, less likely to have their peak flow monitored, be less likely to be

followed up and be less likely to have their preventative treatment increased.

The effect of this was that they were ten times more likely to be readmitted in the subsequent year than if their first admission was under a respiratory team. This result has been shown again in a more recent study³² which showed that 6% of those whose first admission was under the respiratory firm were readmitted again within 3 months whereas 14% of those admitted under general physicians were readmitted in the same time. The result of such studies may not be to decree automatically that there should be specialist care for all, but instead we should subject different methods of delivering care to scientific scrutiny. We thus need to compare specialist versus generalist care with the alternatives of generalist care according to guidelines, or generalist care plus a visit to the patient by a respiratory nurse specialist, or generalist in-patient care plus follow-up by a respiratory physician in outpatients. By such study we can determine the most cost-effective method of organizing care for the 100,000 asthmatics who are admitted to hospital each year. However, the opportunity of admission must be taken to educate those with asthma about their condition, for whilst for many this admission may be an isolated event, for others hospitalization represents general poor control of asthma and it is from this pool of patients that deaths occur. Similar attention needs to be addressed to patients attending accident and emergency departments with asthma. They may do so for reasons that vary from 'running out of an inhaler' to life-threatening disease, but adequate arrangements should be in place to ensure that A & E attenders are appropriately referred for follow-up. Local asthma task forces should be established

to adapt national guidelines, and to ensure that they cover local issues and induce a sense of relevance and ownership.

Similar organizational issues occur in primary care. The Government's 1993 chronic disease management scheme correctly encouraged the setting up of systems for the regular review and follow-up of those with asthma, often within the setting of primary care asthma clinics where care is often delegated to, or shared with, practice nurses. Whilst such clinics have been shown to work well,³³ not all nurses have necessarily undertaken appropriate training for the tasks that they are undertaking. Similarly we do not know whether those patients who are willing to attend asthma clinics run by nurses on a regular basis are necessarily those who represent the highest risk or are those suffering most morbidity or causing most cost. These organizational issues merit much more study.

In summary, the past 10 years have been an exciting period of research and this has led to us having a much greater understanding of how to use currently available drugs to maximal advantage. However, not all patients are benefiting from this knowledge.

The goal now must be to ensure that the available and effective treatments reach the patient and are taken. This requires:

1. Well-educated health professionals.
2. Well-organized health professionals.
3. Adequate personal/Government finance.
4. Drugs that are easy to take with a good risk versus benefit profile.
5. Attention being paid to clear communication and patient education.

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