

Asthma education, action plans, psychosocial issues and adherence

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This article deals with four separate but not disparate topics. The first section discusses asthma education, reviews the current literature and attempts to challenge some of the dogma that is associated with this area. Knowledge alone does not guarantee appropriate behaviour, due to a variety of adverse socioeconomic and psychological factors that need to be considered for each patient. Action plans and peak flow monitoring have both been disappointing in terms of reducing asthma morbidity; the former needs to be individualized, and the latter may be useful in specific situations. Space precludes an in-depth discussion of psychological issues and adherence, but an attempt has been made to address salient issues, particularly related to the first two topics. Psychological factors, especially anxiety, play an important role in asthma outcome. Adherence to medication prescriptions and other management strategies need to be taken into account when an individual's treatment program is planned.

Key Words: *Asthma Behaviour, Compliance, Education, Knowledge, Self-Management*

ASTHMA EDUCATION

International consensus guidelines have stressed asthma education and patient self-management as integral components of asthma management (1-3). In a recent editorial, Blessing-Moore (4) defined the aims of asthma education as to

provide knowledge and find effective motivational techniques that can assist in the translation of knowledge into (positive action) behavioural practices that

Éducation sur l'asthme, plans d'action, questions psychosociales et fidélité au traitement

RÉSUMÉ : Le présent article traite de quatre sujets différents, mais qui ont un lien entre eux. La première partie porte sur l'éducation sur l'asthme, passe en revue la littérature et tente de défier certaines croyances liées à ce domaine. Les connaissances ne garantissent pas à elles seules un comportement approprié, à cause d'une variété de facteurs psychologiques et socioéconomiques indésirables dont il faut tenir compte pour chaque patient. Les plans d'action et la surveillance des débits expiratoires de pointe (DEP) sont des outils qui donnent des résultats décevants pour ce qui est de réduire la morbidité due à l'asthme; ainsi, les plans d'actions doivent être personnalisés et la surveillance des DEP peut s'avérer utile dans certaines situations. Pour des raisons d'espace, une discussion en profondeur sur les questions psychologiques et de fidélité au traitement est exclue; cependant, on a essayé de traiter les questions saillantes, en particulier celles ayant un rapport avec les deux premiers sujets. Les facteurs psychologiques, en particulier l'anxiété, jouent un rôle important dans l'évolution de l'asthme. On doit tenir compte de la fidélité au traitement et aux autres approches de prise en charge pour la planification du programme de traitement d'un patient.

will improve decision making skills and eventually improve therapeutic outcomes. Such programs will need to address the special cultural, educational, psychological issues as well as health beliefs and attitudes and to provide motivation for a positive action and sense of responsibility.

The importance of asthma education is now regarded as something of a fundamental truth; thus, it is somewhat surprising that the relationship among educational interven-

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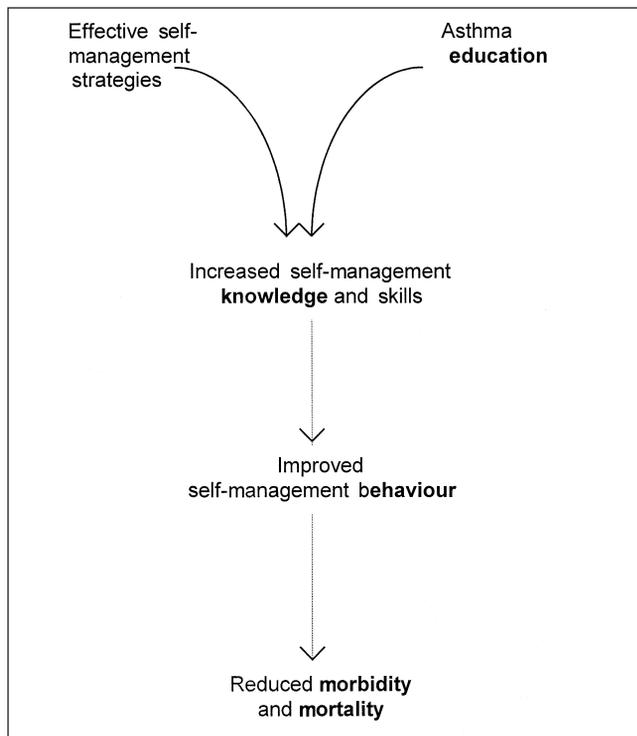


Figure 1) A model of asthma education

tions, self-management knowledge and skills, illness behaviour (particularly during an acute attack), and effect upon morbidity (and mortality) remains unclear and controversial (5,6).

The following discussion of asthma education is based on the paradigm shown in Figure 1. Briefly, there are available, effective management strategies for the on-going treatment of asthma and the management of acute exacerbations. With effective education, patients with asthma can acquire the appropriate knowledge and skills to self-manage asthma appropriately. However, to achieve an improvement in indexes of morbidity (or mortality), a change in self-management behaviour is required; specifically, improved knowledge has to be translated into a change in behaviour.

Asthma education generally includes instruction on the following: avoidance of allergenic and nonallergenic triggers; role of medications; chronic management of asthma; identification of an exacerbation; and the actions to be taken in the event of deterioration in asthma control. The last two are generally incorporated into an action plan and are discussed in more detail under that heading.

Efficacy: Following a meta-analysis of 11 randomized clinical trials of self-management teaching programs, Bernard-Bonnin et al (7) concluded that educational programs improve knowledge but do not reduce morbidity, consistent with the results of the randomized studies conducted by Garrett et al (8) and Coté et al (9). These data, as well as those showing the discrepancy between knowledge and behaviour (10), indicate that relying on an assessment of knowledge as the sole outcome measure may grossly overestimate the effectiveness of an educational strategy.

Assessment of trials of asthma educational interventions are complicated by a variety of factors: the use of selected study populations (so that results are not necessarily generalizable); different baseline levels of self-management knowledge and skills; different types of intervention; presence of confounding factors and different primary outcomes; and variable responses due to psychological, social and economic factors. Other issues are contamination of the control group and what constitutes the control intervention; often a substantial improvement in both the control and intervention groups occurs without a significant intergroup difference (8,9). Given that the majority of patients with asthma have mild symptoms, traditional indexes of morbidity may not be the most appropriate outcome to monitor. Asthma educational programs have been shown to improve asthma-specific quality of life (11), and perhaps this should be a primary outcome variable in intervention studies.

In a recent systematic review on behalf of the Cochrane collaboration, Gibson et al (12) found that interventions that consisted of education only did not bring about improvements in morbidity indexes. Conversely, interventions in which education was combined with self-monitoring and/or regular medical review and/or a written action plan improved a variety of health outcomes. Thus, asthma education should not be provided in isolation but as part of an integrated program of good quality care. Determination of the effects of specific components of educational programs has proved difficult.

Self-management knowledge versus behaviour: No matter how successful the educational strategy, the acquisition of practical asthma knowledge is not sufficient to ensure satisfactory self-management behaviour (10): "To know is not to do"(4). In a cohort of patients admitted to hospital with severe acute asthma, Kolbe et al (10) found that the score for self-management knowledge consistently exceeded the score for self-management of the same situation during an actual attack (behaviour). In other words, even when patients had a reasonable idea of what to do in an acute attack (and only 44% were judged to have such satisfactory knowledge), they were less likely to put those strategies into practice when faced with the real life situation. Of greater concern, the discrepancies were greatest for the strategies most likely to successfully abort an impending attack or be potentially life saving. A variety of psychological, health-care and socio-economic factors had powerful and differential influences on self-management knowledge and behaviour (Figure 2). However, there was encouraging evidence that the factors associated with appropriate educational initiatives and good quality of ongoing medical care were positively associated with both knowledge and behaviour scores, providing support for current asthma educational initiatives.

Self-management errors: Despite the widespread use of asthma education, patients commonly make serious self-management errors during an acute attack, including no or delayed use of oral corticosteroids and/or no or delayed summoning of emergency services (13). Errors are generally made by the patient rather than the doctor, and may be pre-

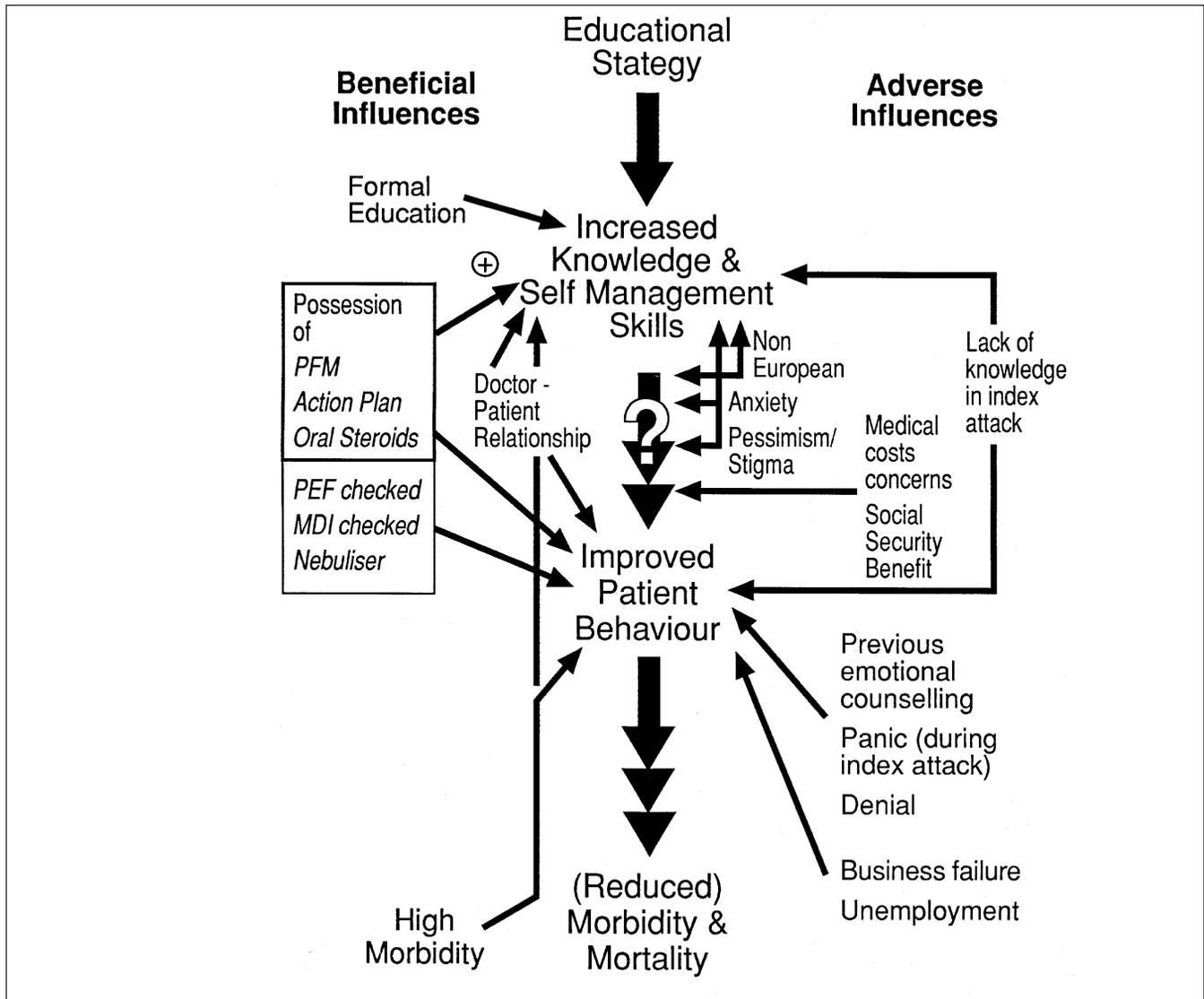


Figure 2) Influences on self-management knowledge and behaviour. MDI Metered dose inhaler; PEF Peak expiratory flow; PFM Peak flow meter. Reproduced with permission from reference 10

dicted by a variety of adverse socioeconomic and psychological factors (13). These factors may so totally dominate and overwhelm the individual so as to nullify the potentially positive influences of asthma education. This is consistent with the hierarchical principle of behaviour change in education, in which there is a natural order in the sequence of factors influencing behaviour (14). Unless the most pressing psychological issues, and financial and practical concerns of patients are addressed, an educational initiative is unlikely to be beneficial. However, errors were not predicted by the level of self-management knowledge (13), suggesting that such errors may not be avoided by conventional asthma self-management education. Because most severe attacks leading to hospitalization are theoretically preventable, the challenge is to change patient behaviour in the face of these adverse socioeconomic and psychological factors.

Timing, setting and form of education: There is insufficient evidence to decide upon the optimal timing, delivery

setting and form of asthma education (15). Initiating the educational strategies while the patient is still in hospital has advantages. The individual has already been identified as being at 'high risk' for severe life-threatening asthma or death (16-18), they are accessible and (arguably) amenable to intervention, and it is possible to initiate a therapeutic relationship involving the patient's physician. However, the hospital environment may not be an ideal setting for educational interventions, and the recently hospitalized patient may not be amenable to educational initiatives.

Alternatively, out-patient interventions may take place in less stressful, more conducive surroundings with a greater likelihood of the patient establishing a meaningful therapeutic relationship and assimilating information. Evidence suggests that only a proportion of eligible patients take part in out-patient educational programs and nonattenders are more likely to be male, single, less well educated and current smokers (19,20). Those who fail to attend out-patient

follow-up are those with the highest subsequent morbidity and mortality (20). To limit an intervention to clinic attendees may exclude those with the greatest contribution to morbidity statistics and health care costs. Offering outpatient appointments at times preferred by the patient (including beyond normal working hours) does not necessarily improve nonattendance (21; J Garrett, personal communication). In reality, the educational initiative is a continuum of care, merely beginning in hospital, and there are different roles for the interventions in the different settings.

On the basis of current evidence, it is not possible to determine the most effective format of patient education. There is some limited evidence that group education may be more effective for some outcomes (22), but a recent meta-analysis failed to provide a conclusive answer (15). Certainly, group education provides social support, allows interaction with others with similar medical problems, and may help to validate the patients' experiences and to solve some self-management problems. Group sessions may be less useful for some patients, particularly if there is disease-related stigma – an issue for a substantial proportion of patients with asthma (6,10,23,24). The contributions to asthma education by lay organizations and pharmacists are not well researched.

An equally cogent argument can be mounted in favour of education being tailored to the needs of the individual. This fits more readily into the model of traditional personal medical services, takes place in the patients' own health care setting and allows greater flexibility in scheduling. Further, the factors associated with poor self-management behaviour (10) and serious self-management errors (13) were many and varied. Individual patient circumstances are of crucial importance, and, in this context, generic or nonspecific interventions are unlikely to be helpful. Finally, the likelihood of a desirable outcome depends on the patient's stage in the continuum of behaviour change (25); different messages are appropriate at different stages and a strong argument in favour of an individualized approach.

However, personal education does not guarantee an individualized approach, especially if the same unmodified information is delivered to every patient in the same manner. Provision of written material does not guarantee comprehensibility because such material is often written for a reading age above the target audience (26). Although educational computer games have been developed, their efficacy has not been demonstrated (27). Simple strategies to increase the recall of information should be used; these include primacy, stressing the importance of certain issues, simplifying and explicitly categorizing information, including hands on practice and feedback, repeating and tailoring advice to the individual, and providing written back-up material. It is important to elicit family support and not to aim for perfection, initially. The patient's own experience and expertise needs to be acknowledged. Asthma education needs to be *relevant* to the individual, have *realistic* goals, be *readily available* and *reinforced* over time to achieve behavioural change – the 4 Rs of asthma education (5).

ACTION PLANS

The specific impact of action plans on asthma morbidity is difficult to determine. Although their introduction has been associated with reduced morbidity indexes, only selected patient groups were studied, and, thus, the results may not be generalizable. Control groups are often lacking, and the extent to which improvements are due to other factors, such as regular or higher doses or more appropriate use of inhaled steroids (28), is difficult to assess. Action plans vary, and no single plan is likely to be suitable for every patient; it must be feasible and applicable to the individual patient. Most include an objective self-assessment of asthma severity, indications for and specifics of management change (usually the use of oral steroids), and indications for the summoning of emergency services.

Serious self-management errors in the use of oral corticosteroids and in summoning emergency services are common (in 54% and 68%, respectively, of those hospitalized) and readily identifiable (11). Nevertheless, such errors are infrequently identified by the clinical team and corrective action is taken even less frequently (14% and 7%, respectively) (unpublished observations). These disturbing results occurred in a medical service which in terms of other quality indications were equal or superior to other published results (29-32). An essential component of management should be a review of the action plan after each acute attack, and reinforcement and modification of the plan as necessary to prevent future errors.

Peak flow monitoring: Measurement of peak expiratory flow (PEF) provides a safe, simple, reliable, available method of quantitatively assessing the degree of airflow obstruction.

The need for such a quantitative assessment was based on earlier studies demonstrating that a significant proportion of patients with asthma poorly perceived worsening airflow obstruction (33,34). However, much of the initial enthusiasm for peak flow monitoring has been dampened by subsequent experience (35).

Symptom observation may provide a guide to asthma control which is more sensitive and just as valid as peak flow monitoring. Boulet et al (36) found that symptoms and PEFs were similar in their ability to predict control in a four week period following recovery from acute asthma. Gibson et al (37) and Chan-Yeung et al (38) found that worsening symptoms preceded decline in peak flows during an exacerbation of asthma and no patient had a decrease of more than 30% in PEF before the onset of symptoms.

Following the study of Malo et al (39), attention has focused on the relative usefulness of PEFs and symptoms in detecting exacerbations of asthma and forming the basis of action plans. There have been five randomized controlled trials of peak-flow based and symptom-based action plans. Four of these demonstrated no advantage of the peak flow-based plans in terms of outcome (9,40-42). On the other hand, in a study based in a university hospital asthma clinic, Cowie et al (43), found that patients with a peak flow-based action plan had less emergency room visits for asthma than

those with a symptom-based action plan or no action plan. The use of either a symptom-based or PEF-based action plan is likely to be equally effective when combined with comprehensive asthma management. However, there is a need for longer term comparisons of PEF and symptom-based action plans because there might be a systematic change of a patient's perception, interpretation and subsequent behaviour over time.

Patient adherence needs to be considered in relation to peak flow monitoring. Selected patients reliably monitor peak flows over a limited period (44). However, these results cannot be generalized to patients with asthma who are based in the community rather than a hospital clinic (45), in whom manual records were markedly deficient compared with electronic records. As well as factitious readings, there were errors in reading and transcribing; the completeness of the record declined from the first to the third week. In a three-month study of PEF monitoring, adherence decreased rapidly after two weeks (46). Côté et al (47) have shown that even after receiving asthma education and with regular reinforcement, compliance with peak flow monitoring (50% of measurements done) fell from 60% in the first three months to 30% at one year. More important, peak flow meter use during an acute exacerbation is also disappointing; only 25% to 50% of patients who have a peak flow meter actually use it in the event of an acute severe attack (48).

If peak flows are to be used as a basis of action, the criterion of a 30% decrease in PEF to define an acute exacerbation needs review. Changes in peak flow are less sensitive than deterioration in symptoms during an acute exacerbation (37,39) and are less sensitive than changes in forced expiratory volume in 1 s (49). In the study of Chan-Yeung et al (38), only 27% of subjects had a decrease in PEF of more than 30% from baseline during an acute exacerbation. Similarly, Charlton et al (41) concluded that patients with a symptom-based action plan implemented higher doses of inhaled corticosteroids earlier in the attack and were, thus, more likely to respond than patients who waited until their peak flow fell to 70% of normal. In a study of back titration of inhaled corticosteroids in patients with moderate or severe asthma, it was found that when peak flow had fallen by 20% or more, patients had a moderately severe attack requiring more than one week of oral corticosteroids (unpublished data). Gibson et al (50) have recommended using individualized PEF action thresholds because they were more sensitive in identifying exacerbations and had fewer false positives than previous recommendations.

On the other hand, an objective measure of airflow obstruction is crucial if there is concern that the deterioration in symptoms is due to conditions other than asthma, such as disordered breathing or hyperventilation. Some physicians may be more comfortable basing decisions regarding use of oral steroids on a quantitative measure rather than on symptoms alone.

Routine daily monitoring of peak flow cannot generally be recommended. Use of peak flow monitoring should be discretionary, and limited to two- to four-week periods of monitoring for the purposes of diagnosis, education, assess-

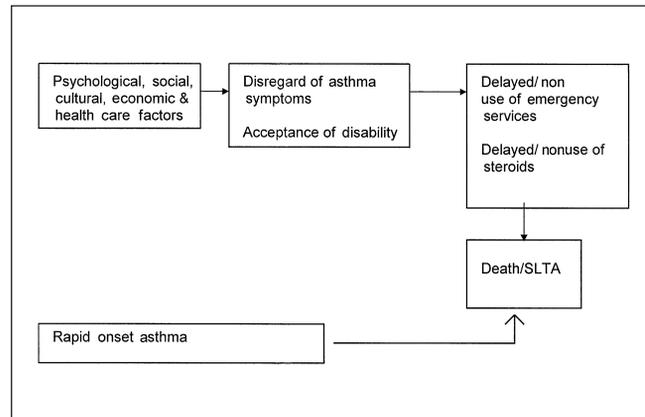


Figure 3 Scenarios of asthma death and severe life-threatening asthma (SLTA). Adapted from reference 51

ment of control, determination of best PEF and assessment of response to therapy or another intervention. There may be a role for the use of peak flow monitoring in conjunction with a written action plan in the context of an exacerbation in some patients. Lending patients a peak flow meter for a few weeks may be a satisfactory way of teaching the importance and relevance of their symptoms that can subsequently form the basis of the self-management plan. As the patients' perception and interpretation of symptoms improve, the value of peak flow monitoring probably declines.

Rapid onset asthma: Published evidence suggests that the vast majority of attacks causing death, severe life-threatening asthma (SLTA) or hospital admission develop over a number of hours, are thus theoretically identifiable and preventable by strategies contained within the action plan (Figure 3 [51]). However, a small proportion of patients (less than 10%) presents with acute severe asthma of rapid onset (less than 6 h). Such patients were more likely to be male, to present with SLTA and to have had a past history of intensive care unit admission for asthma (52). Rapid onset attacks were not associated with conventional risk factors for SLTA and death (52). Such patients need to be identified and different self-management strategies (from those contained within the usual action plan) employed.

PSYCHOLOGICAL FACTORS:

Previous studies have shown high levels of psychological morbidity in patients who had SLTA (53-57) or who died of asthma (58-60); these findings have now been extended to include those admitted with acute asthma (57). However, in a case control study, no differences were found in any specific psychological parameters between those with SLTA and those admitted to hospital with acute asthma (57), similar to the results of Boulet et al (56). While individual psychological factors may not be risk factors, a gestalt assessment of psychosocial dysfunction, as used by Rea et al (58), has been shown to be a risk factor for asthma death. Nevertheless, psychological morbidity (anxiety, depression, and total and certain life events) was significantly higher in those admitted to hospital in comparison with community-based patients with

asthma (57) or asthma clinic attendees (61). Thus high levels of psychological morbidity exist, particularly in patients with asthma with severe disease and/or high morbidity.

Breathing is threatened in asthma. It is, therefore, not surprising that the most common form of psychological morbidity was anxiety (53,54,57,61,62); anxiety at the level of psychiatric diagnosis was found in up to one-third of hospitalized patients and 25% in the community. Post-traumatic stress disorder may follow an acute severe attack; the intensity and severity of anxiety may not disappear readily. While states of mild fear are common in all who have asthma, clinically significant anxiety is a much greater problem in those with clinically more serious disease (57,61), underlining the need to address anxiety as part of comprehensive asthma management. Asthma is an illness that demands constant monitoring for the early signs of a serious attack. Limited anxiety occurring only during an attack may lead to more appropriate management decisions, but suppression or denial of this 'signal' anxiety, while protective in terms of unpleasant emotion, may itself be life-threatening (54).

On the other hand, clinically significant depression is not a prevalent problem in adult patients with asthma (57,61,63), although this may not be the case in children (64). Good family support may be protective particularly against the adverse effects of life events (65), while poor family support (66) and abnormal family function (60,67) have been suggested as risk factors for morbidity and mortality. Forty per cent of patients with asthma with SLTA or hospital admission had inadequate disease-specific social support despite otherwise adequate support for more general matters (in more than 90% of cases) (57). Total life events in the previous 12 months were high, and certain specific life events were more frequent in those hospitalized (57). To what extent these differences may reflect differences in severity of disease or differences in socioeconomic or demographic features is unknown, but these patients are not only more likely to come from a difficult environment but also to have challenging stresses with which to deal.

Psychological factors may affect the course of a chronic illness in a number of ways. First, there may be psychoneuro-immunological or psychophysiological (parasympathetic or alpha-adrenergic) mechanisms, including the effects of psychological factors on lung function (68). Psychological variables may affect the patient's awareness of symptoms, either exaggerating or repressing the symptom's intensity and significance, while stress may be one of a number of factors triggering a relapse in vulnerable subjects. Certain psychological factors may have specific effects. Anxiety or panic-fear may cause dysfunctional breathing patterns that are difficult to distinguish from airflow obstruction, high levels of anxiety may impair the ability to make correct self-management decisions (10,69), and doctors may be influenced by excessive anxiety and alter medical regimens inappropriately (70). Asthma medications may also have a negative influence by enhancing the physiological effects of anxiety. It may be the sum total of all influences rather than specific factors which is important; the total psychological

burden may so overwhelm an individual that there is no room left to cope with managing day-to-day asthma, and to recognize and treat an acute exacerbation appropriately.

Psychological factors may have a significant impact on attitudes to disease and medications, on the ability to work with health professionals and to comply with management regimens (71). Psychological status is also associated with reported respiratory symptoms, independent of pulmonary function (63). However, the impact of adverse psychological factors may be more subtle and insidious. Such factors have a negative impact on the acquisition of self-management knowledge and on self-management behaviour (10) as well as being associated with serious self-management errors (13). For educational initiatives to be maximally effective, these factors need to be identified and acknowledged, and management strategies need to be adjusted accordingly.

ADHERENCE

A detailed discussion of adherence in asthma is beyond the scope of this article. It is intuitively obvious that adherence (defined as the extent to which a patient's behaviour coincides with medical advice) is of paramount importance to the effectiveness of any form of intervention. Evidence suggests that nonadherence with asthma medication is endemic, with approximately 50% of subjects being nonadherent (72), and that physicians are poor and biased at predicting adherence. No predictable association exists between personality factors and adherence, and there is no single set of characteristics to assist clinicians in recognizing those individuals at risk of nonadherence. The reliability of patient self-reported adherence depends on the type of response; low self-reported compliance is highly reliable, while high self-reported compliance is unreliable.

In chronic disease, it is generally accepted that compliance is independent of age (excluding adolescence), sex, level of education, socioeconomic grouping and experience of symptoms and treatment side effects. Factors shown to be associated with nonadherence are a variety of psychopathologies (particularly depression [73]) and cognitive impairment. In the Lung Health Study, factors associated with long term metered dose inhaler adherence included being married, greater age, and having greater airway responsiveness, severe airflow obstruction and fewer hospitalizations (72). Medication regimens in asthma are particularly vulnerable to adherence problems because of the complexity of regimens with multiple medications, different methods of delivery and frequency of use, periods of symptom remission, long duration of use of medications, impact of disease on lifestyle, sometimes distressing side-effects, and the fact that the treatment regimen is preventive rather than curative (74,75). Lack of consistency in physician advice, heightened by medical disputes, contradictions and reverses, may also inadvertently contribute by reducing the patient's willingness to accept medical recommendations. Nonadherence may also reflect dissatisfaction with care. For many, adherence represents a daily reminder of a condition that many would rather forget.

However, self-management of asthma is considerably more difficult for the patient than the mere taking of medications. The patient is expected to avoid precipitants, monitor the course of the disease, detect changes, assess them accurately and alter treatment accordingly, at times having to shift rapidly from regular treatment into emergency mode. As already stated, serious errors of self-management are frequent and influenced by a variety of social, economic and psychological factors (13). Thus, the comprehensive assessment of adherence in asthma should focus not only on the use of medications but also on the behavioural aspects of self-management. Each patient has a unique set of beliefs and attitudes towards their illness, its treatment and accompanying adverse effects, and to their family and their doctor as well as to many social, economic and psychological issues. Insight into these should allow the development of more effective adherence interventions (76).

Few strategies to improve adherence in asthma have been

subjected to adequate trial. Such strategies have been summarized by Milgram and Bender (77) as educate, communicate, negotiate treatment goals, streamline, remove barriers and individualize. Education alone is insufficient to ensure high levels of adherence, and such initiatives have been shown to have limited influence on patient behaviour (10,13). From other chronic conditions, it is known that the doctor-patient relationship is critical; strategies, such as a nonjudgemental environment (in which a degree of nonadherence is assumed), an empathetic and nonpunitive approach, the use of open-ended statements and the establishment of a partnership with shared responsibilities (76-78) using clear language to explain recommendations, help to reduce nonadherence.

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