

Chapter 8

Asthma Self-Management

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Asthma self-management represents a systematic way of educating patients to control the disease by avoiding it when possible and reducing it when necessary. In its present form, it has been practiced for little more than 30 years. It was encouraged initially by the National Institute of Health (NIH) through support of extramural asthma self-management research, and subsequently, by its inclusion in the first NIH asthma diagnosis and treatment guidelines (NIH 1991). The seminal programs (Clark et al. 1980; Creer et al. 1988; McNabb et al. 1985) developed with the help of NIH were concerned with control of pediatric asthma. Subsequent work has expanded to cover a variety of other populations, both pediatric and adult, as well as individualized programs. This chapter represents an overview of existing self-management programs as well as an evaluation of their effectiveness.

The term ‘self-management’ is not to be confused with ‘self-care.’ While the goal of self-care is to reduce the role of the physician in the treatment of disease, self-management recognizes the importance of the physician and encourages the patient to partner with the physician in the management of the disease. The partnering relationship implies that the physician’s effectiveness in managing asthma increases in direct proportion to the quality of asthma information provided by the patient. To be successful, asthma self-management requires the patient to understand the essential features of asthma including: the physical changes underlying difficult breathing, asthma triggers and symptoms, how to evaluate asthma severity, and how to prevent asthma and reduce its exacerbation.

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These facets of asthma constitute a blueprint for the development of asthma self-management programs, and represent the elements of effective, chronic disease management.

The Elements of Asthma Self-Management Programs

Most asthma self-management programs have two objectives: increasing asthma knowledge; and promoting asthma control (Kotses et al. 1990). Asthma knowledge refers to information about the disease whereas asthma control refers to techniques that effectively limit the disease. There is evidence that patients who simply increase their knowledge of asthma without a systematic effort to control the disease do not necessarily improve their management of asthma (Gibson et al. 2002). The same may be said of patients who attempt control of asthma in the absence of knowledge of the disease (Kotses et al. 2006). Asthma knowledge and asthma control appear to be requisites of successful asthma self-management programs; each must be used in conjunction with the other for effective management of the disease.

Asthma knowledge is associated with such things as the physical changes, causes, and symptoms of asthma. It includes information about the variety and purposes of asthma medications, and about special problems that could be encountered in specific circumstances. Asthma control, on the other hand, is concerned both with the prevention and the reduction of asthma. There is considerable overlap between the two, particularly in providing information about asthma and its treatment. Some procedures, such as techniques for improvement of medication compliance

or avoiding triggers may be thought of primarily as preventative measures, whereas others such as using variations in severity to prompt corrective action are more closely related to asthma reduction. In self-management programs, both prevention and the reduction procedures are commonly executed within the context of a strategy to control asthma in accordance with a series of escalating symptoms. The strategy can include an action plan, a set of instructions that outline adjustments as dictated by variations in either symptom or pulmonary function measures. It is important to note that action plan adjustments may consist of either behavioral (i.e., avoiding known triggers, rest and relaxation, and ingesting fluids) or pharmacological procedures for controlling asthma. Apart from elements concerned strictly with asthma knowledge and control, several less common elements relating to relaxation training and social skills training sometimes are included in self-management programs. An outline of the elements of asthma self-management is provided in Table 8.1.

Asthma self-management programs are both numerous and varied. They differ from one another in the instructional model around which they are organized, in their format, and in their method of delivery. No single standard defines the form of asthma self-management programs; no body of knowledge is uniformly taught, and no form or method of instruction is universally employed. The only guidelines that have reached a broad audience are those offered by NIH (1991). They are broad enough to encompass

programs that differ substantially in instructional model, in format, and in method of delivery. These qualities are described below.

Instructional Model

Asthma self-management programs adhere to one of three basic instructional models: group training (e.g., Creer et al. 1988; Kotses et al. 1995), tailored training (e.g., Kotses et al. 1996; Wilson et al. 1993), and self-administered training (Rubin et al. 1986). Group training programs are those in which training is given simultaneously to a number of patients. The programs are written with an eye toward suitability for a wide range of asthma patients. In most cases, a group consists of no more than 10–12 patients, as larger groups might tend to erode the mutual support that patients can develop for one another. Self-administered training is similar to group training in that the same program is offered to many individuals, but different in that the training is applied one patient at a time. Tailored training, on the other hand, takes into consideration the special circumstances of each patient. This form of training implies a somewhat different program for each patient depending upon the patient's special needs. There are advantages and drawbacks to each instructional model. Group and self-administered programs are desirable because, once developed, they may be offered at a low cost and present few

Table 8.1 Components of asthma self-management: informational elements are shown on left and training elements are on right. Overlapping elements are presented on the same line. Less common elements shown in lower box

Asthma Education (Informational)	Asthma Control (Training)
Physical changes caused by asthma	
The causes of asthma	Identify patient's triggers
Signs and symptoms of asthma	Symptom definition and quantification; identify patient's symptoms
Asthma medications	Distinguish between patient's rescue and control medications Proper use of medication. Improve medication compliance. Asthma monitoring (use of asthma diary and peak flow meter) Action plan: pair diary information with control measures (behavior and/or adjustment)
Self-management outside the home (school, work, travel)	Identify and eliminate or reduce patient's triggers at school or work (e.g., reduce effects of physical activity; eliminate environmental irritants; insure availability of medication)
Relaxation training	Progressive relaxation training; systematic desensitization; breathing exercises; biofeedback
Social skills training	Decision making; self reliance; assertiveness and communication training

organizational problems. However, because they are directed to asthma patients in general, they compel most patients to deal with at least some material that may not be relevant to their disease. From a patient's point of view, tailored programs are preferable to either group or self-administered programs because they can be organized exclusively around those aspects of self-management that are useful to the patient. Material that is irrelevant for a particular patient may be safely dropped. Unfortunately, relatively few programs are tailored, an acknowledgement, no doubt, of both the difficulty and the cost associated with developing a unique program for each patient.

Program Setting

The settings in which programs are conducted vary widely. A program may be given in a hospital (e.g., Chiang et al. 2005), a clinic (e.g., Hilton et al. 1986), a home (e.g., Butz et al. 2005; Brown et al. 2002), or a school (e.g., Bruzzese et al. 2008; Horner and Fouladi 2008; Velsor-Freidrich et al. 2004; Christiansen et al. 1997); and some programs are community-based (e.g., Bryant-Stevens and Li 2004). However, other venues also may be used, including pharmacies (e.g., Smith et al. 2007; Barbanel et al. 2003; Diamond and Chapman 2001) and churches (Ford et al. 1996). The unique qualities of each setting may demand that either a group or an individual approach be used, but some settings may accommodate either. Hospital and clinic staff, for example, may find individual programs more convenient to implement than group programs, but community-based programs may be impractical if they do not adhere to a group format. At the present time, no particular advantage in terms of effectiveness may be attributed to any format and setting combination.

Method of Delivery

Asthma self-management education may be conducted by presentation, by written materials (i.e., Behera et al. 2005), or electronically by computer or related electronic devices. Each method has its strengths. A presentation insures that patients receive program material, and often affords them an opportunity for interaction

with health care providers during which they may clarify questions or receive further guidance about asthma control. On the other hand, written instruction, in the form of pamphlets or books, allows unlimited review of a program, a benefit not to be taken lightly. In most programs, patients are given presentations in addition to written material so as to capitalize on the strengths of both (Clark et al. 1980; Creer et al. 1988). The vast majority of asthma self-management programs have made use of either presentational or written methods of delivery or a combination of the two. However, a newer method of delivery, electronic delivery, combines elements of both and offers unique advantages. Electronic delivery is now in its early stages but has been embraced enthusiastically. It encompasses a wide range of strategies, including innovative computer programs for teaching asthma self-management to children (Rubin et al. 1986) and their parents (Fall et al. 1998), teleconsultation (Ostojic et al. 2005), and even daily adjustment of medication schedules based on transmission of peak flow information from patients to health care providers (Pinnock et al. 2007; Ryan et al. 2005). Although the promise of electronic programs is great, their development is hindered by the enormous investment of time and equipment they require. A positive aspect of these programs, however, is that once they are developed, their subsequent application may prove to be both inexpensive and convenient.

The combinations and permutations of program content, instructional format, and method of presentation have given rise to a large number of asthma self-management programs. Their variety suggests that self-management is adaptable to a wide range of conditions, a positive quality. On the other hand, the multiplicity of programs demonstrates that the essential elements of asthma self-management are not well understood, a failure that precludes clear guidance as to the contents of programs. To say that this has complicated evaluation of asthma self-management effectiveness is an understatement. Because programs vary so much, the demonstrated effectiveness of one asthma self-management program is not predictive either of the effectiveness or the degree of effectiveness of another. This needs to be taken into consideration when interpreting the results of research. It may be the case that inconsistent findings are related to differences between programs in what, where, and how they teach asthma self-management. Additionally, programs cannot always be classified with precision,

and they may be organized without much forethought. As a result, programs are often not clearly described. Group programs, for example, that include some meetings with individual patients may or may not include a tailored training component, and programs employing more than one method of instruction rarely, if ever, clarify the interactions between methods or to tease out the contribution of each asthma control. These departures from the best experimental design practices make it difficult to paint a portrait of the effectiveness of asthma self-management with anything other than the broadest strokes. Experimental refinement may come, however, as more is learned about how the individual elements of self-management contribute to its overall effectiveness. After a brief excursion into the asthma self-management theory, the following sections outline the use and effectiveness of asthma self-management programs in pediatric and adult populations, and deal with the problems of tailoring self-management to individuals.

Asthma Self-Management Theory: Basic Considerations

The self-management theory has not received a great deal of attention, and no single formulation has dominated self-management research. Two competing theories, both concerned with how behavior is controlled have been advocated in efforts to organize self-management findings, and to formulate questions for further research: one has to do strictly with environmental control of behavior, and the other emphasizes control of behavior through its interaction with private events such as cognitions and emotions (Kotses et al. 1990). Both approaches may be described as behavioral, but in the former, the elements controlling behavior are features of the environment, and in the latter, they may additionally reside in the individual.

Environmental theory, most clearly articulated by operant conditioning theory (Skinner 1953), makes extensive use of the concept of reinforcement, defined as any event that increases the frequency or probability of occurrence of some behavior. Essential in this formulation is the temporal relationship between the target behavior and the reinforcing event: reinforcement must follow the behavior. As it applies to asthma self-management, the reinforcement increases the fre-

quency of behaviors capable of controlling asthma. In general terms, reinforcement consists both of events or outcomes that patients ordinarily avoid (i. e., the symptoms and consequences of the disease) and of events that patients seek (i. e., the benefits of good health). The likelihood of avoiding or seeking specific outcomes is facilitated by use of symptom monitoring and asthma attack management, procedures introduced by self-management training. Monitoring provides the patient a series of benchmarks for initiation of behavior intended to avoid asthma, and attack management consists of guidelines to reduce the severity of an attack. Both monitoring and attack management may consist of a series of graded steps that provide explicit behavioral recommendations depending on asthma severity. In this way, the stages of asthma severity serve as cues, discriminative stimuli in technical parlance, for progressively ramping up behavior whose goal is asthma control. Mild symptoms, for example, cue for minimal interventions, whereas more severe symptoms are cues for potent control measures. Successful management of individual asthma episodes for a period of time insures that larger systems of reinforcement come into play, including lowered treatment costs, fewer disruptions of daily activities due to asthma, and positive regard from others for successful control of asthma. Asthma self-management, viewed from this perspective, represents a series of control measures taken in response to specific environmental cues related to the severity of asthma. A chief benefit of the approach is that both the cues that signal the occurrence of asthma and behaviors that reduce asthma are objective, a quality that ensures patients can be given clear and specific guidance as to how the disease may be controlled. Among those with philosophical leanings toward environmental control of behavior, progress in asthma self-management might involve increasing the number or the saliency of environmental cues built into training programs so as to facilitate or improve control of the disease. Critics of environmental theory have argued that the approach is mechanistic and cannot adequately account for the complexity of human behavior. In addition, environmental theory makes no provision for inclusion of important human qualities such as mood, emotion, and thinking. The failure to consider these qualities contributes to resistance to the theory.

Behavior control that includes the influence of private events represents an alternative to environmental

control. Formulations within this tradition are known generally as social learning theory. As a group, they posit an additional level of explanation mediating between environmental stimuli and reactions to them. Various terms have been used to describe the mediators, but mostly they may be considered cognitive factors. In asthma self-management, the most influential of this group of theories is social cognitive theory (Bandura 1986). Consistent with operant theory, it places an emphasis on reinforcement, but in addition, social cognitive theory takes into account the interactions between the person and both the environment and behavior. It is the addition of the person to the mix that gives this and other similar theories their distinctiveness (e.g., Creer 2008). Thinking, for example, a concept that has no place in a strictly behavioral approach, both influences and is influenced by behavior according to the social cognitive theory.

Self-management in the social cognitive theory relies on a form of internal control, rather than exclusively on reinforcement. It is greatly affected by observational learning, meaning learning without behavior, and by self-efficacy (Lavoie et al. 2008), referring to the belief that one can achieve some standard of performance (Bandura 1991a, b). In self-management, observational learning allows for a rapid determination of appropriate control behavior, while self-efficacy provides the motivation to perform appropriately. These abilities and beliefs guide behavior relevant to the control of disease while influencing and being influenced by the environment. Developing a self-management program along these lines might involve increasing opportunities for observational learning and seeking ways to improve self-efficacy. A benefit of this approach is the antithesis of a problem that plagues environmental theory: the acknowledgment that humans are capable of complex behavior in the absence of reinforcement and the recognition that human qualities such as thinking and emotion play a role in controlling behavior. In addition, theories of this sort are compatible with efforts in behavioral neuroscience to identify physiological elements related to cognition. Criticism of the approach often focuses on the use of unobservable quantities. It is important to note that all elements of asthma self-management may be conceptualized in terms of either operant or social cognitive theory, and that reliance on one theory or another is a matter of preference.

Pediatric Asthma Self-Management Programs

By any measure, childhood asthma is a serious disease. It is the most common of the chronic childhood diseases, affecting 4.8 million of those aged 0–18 years (Adams and Marano 1995). Information from 2003 showed that 3.1 million children experienced an asthma episode during the previous 12 months (American Lung Association 2005). These attacks, no doubt, accounted for a major portion of the 14.7 million school days missed in 2002 (Centers for Disease Control and Prevention [CDC], 2004). Unfortunately, not all attacks can be successfully reduced either at home or by a visit to the doctor. Among those 15 years and younger, asthma is the third-ranking reason for hospitalization (Popovic 2001). And some attacks simply cannot be reduced. Although the asthma death rate among the young is not large, 3,850 deaths of individuals up to 24 years of age were reported between 1980 and 1993 (CDC 1996). This level of morbidity and mortality consumes a significant portion of our health care budget. An estimated \$3.2 billion is spent annually treating asthma in those younger than 18 (Weiss et al. 2000). There is little doubt that the early encouragement and support of pediatric self-management by NIH was well considered.

At the outset, and at the risk of stating the obvious, asthma self-management programs for children are not solely for children; they are for children and their families. This is the chief distinction between programs for children and those for adults. The reason that families must be included in pediatric programs is twofold. First, many children do not have the skills needed to conduct the program on their own. The practice of asthma self-management is not especially complex, but it does require symptom monitoring often assisted by use of a peak flow meter, record keeping, data interpretation, decision-making, and discipline to conduct these activities on a regular basis. Each of these skills may be developed with practice, but they are beyond the ability of younger patients and they must be supported, in large measure, by parents until children are capable of dealing with the program demands on their own. Second, a child's asthma cannot help but be affected by the actions of members of the child's family. Parental responsibilities such as controlling allergens and irritants within the home, insuring the

availability of medication, mediating conflicts related to a child's asthma between and among family members, communicating with health care providers, and intervening with school and community officials to neutralize potential asthma hazards must be included in a comprehensive disease management program. These considerations should not be taken to suggest that the families of adult asthma patients are unimportant in asthma self-management, but only to emphasize that in pediatric asthma self-management, cooperation between all members of a child's family is essential for success.

The decade of the 1980s witnessed the rapid development of asthma self-management programs for children; by 1990, several dozen programs had been produced (Wigal et al. 1990). Each of these early programs may be considered a pioneering effort, and each resulted in asthma morbidity improvement. Unfortunately, a number of the studies evaluating the programs were plagued by procedural problems (Creer et al. 1990). In subsequent years, more attention had been paid to research procedure, but problems remained. A meta-analytic review of pediatric asthma self-management studies (Wolf et al. 2003) detected a number of these. Of the 32 programs reviewed, group assignment was biased potentially in 20, confounding was evident in 6, and differential withdrawal was noted in 8. A similar review that included 25 randomized control trials in children (Smith et al. 2005) echoed these concerns. Of the trials, randomization was based on a unit or group rather than the individual in 4; was restricted by matching in 5, by stratification in 4; and was based on inadequate methods in 3. Smith and her colleagues (2005) also reported that only 10 of the 25 programs were blinded in some fashion, that only 9 were free of the potential for selective reporting, that only 7 reported power calculations, and that only 15 featured adequate reporting. Some of these problems could be related to the difficulty of conducting research in pediatric self-management, but that doesn't excuse them. Research difficulty merely underscores the importance of knowledge of common research pitfalls.

In spite of the complexity inherent in pediatric asthma self-management research, the effectiveness of self-management was confirmed by meta-analysis. In their systematic review, Wolf and his colleagues (2003) concluded that self-management programs were associated with improvement in airflow, school absenteeism, restricted activity days, and emergency room visits.

A similar review (Coffman et al. 2008) documented an association between asthma education and improvement both in hospital admissions and emergency visits, and a review that included adult as well as pediatric studies (Smith et al. 2005) concluded that self-management positively affected hospital admission and asthma symptoms in children. Descriptive as these summary statements are, they fail to communicate a flavor of the breadth of self-management effects. Broadly speaking, dependent variables of interest in pediatric self-management studies may be grouped into eight categories: (a) physical condition, (b) activity restriction, (c) cognitive factors, (d) quality-of-life, (e) asthma self-management behavior, (f) use of health care facilities, (g) school attendance, and (h) health care cost. We consider each of these in the following sections.

Physical Condition

Aspects of physical condition may be the most commonly recorded indices of asthma in self-management studies. They include the common asthma symptoms: wheeze, cough, chest tightness, and dyspnea. Because of vast differences both within and between patients in expression of symptoms, it is difficult to detect reliable change in any one symptom. Therefore, symptoms are often measured in the aggregate, as asthma exacerbations or attacks. They may be measured either as occurrences of asthma, as days on which unspecified asthma symptoms occurred, or as ratings of symptoms on some scale of severity. Extreme exacerbations of symptoms are termed asthma attacks or episodes and are frequently compiled independently of symptom episodes; they differ from the occurrence of symptoms only in degree. Symptoms that occur at night have been expressed either as a measure of severity or frequency and are sometimes measured separately from those that occur during the day. They can include awakenings as a separate category. In addition, the category of physical condition includes pulmonary variables, most notably peak flow, but other quantities derived from the forced expiratory volume maneuver also have been studied.

1. *Symptoms.* Two aspects of quantifying asthma symptoms may result in confusion. First, the various ways of measuring asthma symptoms: occurrences,

symptom days, and ratings, are not necessarily consistent with one another. More than one symptom occurrence, for example, may take place on a single day, thereby giving rise to a discrepancy between the number of occurrences and the number of symptom days. And ratings, clearly based on a property other than frequency, may or may not coincide either with the number of symptom occurrences or with the number of symptom days. This is no small matter. When measurement method is not taken into consideration, its implications for findings and conclusions can go unrecognized. It is entirely possible to reach different conclusions from the same data depending on how symptom scores were computed. Second, quantification of asthma attacks is subject to interpretation by the patient. The same degree of symptom exacerbation may be classified as an attack by a patient on one day but not on another, or classified differently by different patients. Efforts to circumvent this are made by specifying objective criteria for identification of asthma attacks, but ultimately, the judgment is made subjectively and is subject to within- as well as between-patient variability.

These cautionary considerations on scoring procedures notwithstanding, improvement in asthma symptoms frequently is associated with self-management. Children who were given self-management training experienced fewer symptom days (Clark et al. 2004; Evans et al. 1987) or more symptom-free days (Brown et al. 2002) than children who were not. Improvement not only in symptom days but also in symptom ratings occurs with administration of asthma self-management. In a study of a home-based education program for low-income families (Brown et al. 2002), caregivers of children aged 1–3, given self-management training assigned lower severity ratings on the symptom subscale of the Paediatric Asthma Quality of Life Questionnaire (Juniper et al. 1996a, b) than did caregivers of children not given training. Consistent with these findings were results reported for hospitalized children who were given training in an effort to reduce readmission (Madge et al. 1997). The improved symptom severity ratings obtained with the Usherwood index (Usherwood et al. 1990) applied to all ages (2–14) and extended to night symptoms, in addition to those noted in the day. Even a 5-item questionnaire consisting of questions relating to symptoms and activity restriction was sensitive

to asthma education (Christiansen et al. 1997). Six months after the start of the study, children who received education had lower symptom ratings than control children. Other measures of asthma symptoms that improved by their association with self-management included: number of children experiencing night symptoms (Deaves 1993); frequency of awakening due to asthma (Colland 1993); and parental reports of symptom frequency (Colland 1993). An indirect measure of symptoms, use of reliever medication, also improved in children taught self-management (Dahl et al. 1990; Glasgow et al. 2003). As for findings concerning specific symptoms, few reports exist, but one (Glasgow et al. 2003) detailed a reduction of speech-limiting wheeze in children who had undergone brief self-management training given by general practitioners.

Reduction of asthma attacks has also been reported in studies of asthma self-management. Both the number of asthma attacks (Creer et al. 1988; Evans et al. 1987; Fireman et al. 1981), and the duration of attacks decreased (Evans et al. 1987) when children were given self-management training. Fireman and his colleagues (1981) compared asthma attacks in self-managed and control patients during their study, whereas the others based their comparisons on improvement from a baseline taken prior to the study. In no case, however, was a standard criterion for asthma given to children, leaving open the possibility that the meaning of an asthma attack varied among studies.

2. *Pulmonary measures.* Peak expiratory flow, another aspect of physical condition, was initially thought to be capable of supplanting reliance on symptoms for the purpose of gauging the severity of asthma. This has not happened, as the relationship between peak flow and symptoms was found to be only moderate and complex (e.g., Apter et al. 1997). Detracting from the relationship are factors that affect the measurement both of peak flow and of symptoms. Peak flow is effort-dependent, and for that reason some of the variability it exhibits is not due to physical condition but other factors under the control of the patient. And a portion of symptom score variability, as noted previously, is due to patient interpretation and independent of physical condition.

Much like asthma symptoms, peak flow may be expressed in a number of different ways. It may be presented as the recorded value, but this is a risky practice as peak flow is affected by the height, age, and sex of

the patient. If adjustment is not made for these factors, the peak flow value may be misleading. Despite this, unadjusted peak flow in one study improved in a self-management group relative to a control group (Weingarten et al. 1985). The averaged peak flow scores observed in the study did not differ between the groups at baseline, but differed after intervention. A more common practice is to express peak flow relative to some standard such as the predicted values for a specific child. Using percent of predicted values, Creer and his colleagues (1988) observed that children in a self-management group were breathing below their predicted values at the start of treatment, but reached their predicted values at follow-up, some 18 months after the beginning of the study. A similar finding was reported for trained children but not for controls in a study of the effects of asthma education provided by nurses in the homes of patients (Carswell et al. 1989). It is also possible to compare asthma patients on the frequency of peak flow scores occurring within a specific range of percent of predicted values. In one such comparison (Charlton et al. 1994), trained children had a lower frequency of peak flow scores below 30% of their predicted value than did untrained children. Pulmonary measures other than peak flow for evaluation of self-management are uncommon, but they are recorded occasionally. Of these, one-second forced expiratory volume (FEV_1) has been used more than others. In a community-based asthma self-management program, higher FEV_1 values were observed in children who received the program as compared with those who did not (Toelle et al. 1993). The program included education and treatment for children and involved parents, doctors, nurses, pharmacists, and teachers.

Activity Restriction

Restriction of activity may be considered a consequence of asthma, placing it in the same category as school attendance, doctor visits, and other variables. Nevertheless, it is useful to consider restriction of activity independently of other consequences because it represents a salient patient complaint. As with any chronic condition, asthma patients complain that they cannot engage in many activities. Activity restriction has been quantified by tabulating asthma diary entries, by interview, and by questionnaire.

A number of investigators have reported evidence of changes in activity restriction as a function of asthma self-management. In a single group study (Hindi-Alexander and Cropp 1984), activity restrictions based on diary entries declined over the course of the study. Activity restrictions referred to such things as participation in Little League, newspaper delivery, and participation in intramural gymnastics. Diary entries also confirmed a differential decline in activity restriction between children given an asthma self-management program and those who were not (Charlton et al. 1994). The change favored the trained group. Information gleaned from interviews has supplemented data from asthma diary entries in support of beneficial self-management effects on activity restriction. In a study of a school-based, general program of asthma self-management (Cicutto et al. 2005), interviews guided by the activities scale of Paediatric Quality of Life Questionnaire (Juniper et al. 1996a, b) revealed that children who received the intervention had higher levels of activity than did control children at 2-month follow-up. The difference in activity level held up a year later when the measurement was taken on a questionnaire that the authors called a tracking sheet. A modified version of an adult asthma quality of life scale (Juniper et al. 1993) also was sensitive to differences in activity level between children who received a teacher-led asthma education program and those that did not (Henry et al. 2004).

Cognitive Factors

Among the most commonly studied variables in asthma self-management research, cognitive factors include measures of knowledge, attitude, and emotion. They represent an important dimension of asthma that is not addressed by traditional morbidity measures. They are important in another way: they interact with traditional measures of morbidity and can thereby influence them.

1. *Knowledge.* Asthma knowledge represents familiarity with materials presented in education sessions of self-management programs. It consists of information about the nature of asthma, its symptoms, and ways to control the disease. It has been evaluated with positive results over a dozen times. Both children (e.g., Holzheimer et al. 1998) and parents

(e.g., Deaves 1993; Parcel et al. 1980) have been tested. Instruments used to evaluate knowledge have included true false items (e.g., Parcel et al. 1980; Christiansen et al. 1997), multiple choice items (e.g. Talabere 1993), and pictorial multiple-choice items (Holzheimer et al. 1998). Knowledge has also been evaluated by interview (Deaves 1993). All efforts to evaluate the effect of asthma education on asthma knowledge have consistently shown that education improves knowledge.

2. *Attitude.* Self-management requires that the patient shoulder much of the burden for control of disease. Accordingly patient attitudes relating to such things as factors responsible for disease, and patient ability to control disease have a bearing on the success of asthma self-management. One concept that captures the essence of these concerns is locus of control, a measure of beliefs or attitudes about the source of control of matters affecting one's life. A patient may believe he or she either can control an asthma attack or cannot control it because it is under the control by factors independent of the patient. A scale that measures the tendency of patients to assign control of health matters either to themselves or to other factors was developed years ago and is known as Health Locus of Control (HLOC) scale (Parcel and Meyer 1978). As might be expected, self-management training is associated with changes in locus of control away from external control and toward internal control. This has been confirmed by changes in locus of control of children undergoing asthma self-management training a number of times (Hindi-Alexander and Cropp 1984; Henry et al. 2004; Kubly and McClellan 1984; Parcel et al. 1980; Robinson 1985; Taggart et al. 1987), and at, least once, in their parents (Hindi-Alexander and Cropp 1984). In related work, children's attitudes toward themselves and their ability to manage asthma changed positively, as documented by the Children's Asthma Attitude Scale in an early program (Creer et al. 1988).

Self-efficacy is a concept that bears some similarity to locus of control. While locus of control is concerned solely with beliefs about the source of control, self-efficacy, as noted previously in the section on theory, is concerned with the degree to which patients are confident they can control important disease factors. This concept has not been used much in pediatric asthma self-management studies, but it promises to have an impact. In one

study (Cicutto et al. 2005), self-efficacy measured from baseline to post-intervention was greater in elementary school children who received an asthma education program than it was in their controls. The children who received the program experienced gains in their confidence to use an inhalation device, control asthma, manage triggers, and prevent asthma from getting worse.

One other attitudinal measure that has been used with some frequency, but with mixed results in evaluations of asthma self-management programs for children, is the Piers-Harris Self-Concept Inventory. The inventory measures how children feel about themselves. Positive increases in self-concept following self-management training have been reported on two occasions (Creer et al. 1988; Weiss and Hermalin 1987), but in two other studies (Parcel et al. 1980; Rubin et al. 1986), changes in self-concept were not observed.

3. *Emotion.* A connection between asthma and emotion has been recognized for over a hundred years. Some of the evidence is drawn from observations of innocuous objects causing asthma. MacKenzie (1886) noted that a paper rose elicited chest tightness and dyspnea in a patient who was being treated for a variety of allergic and asthma-like symptoms that occurred annually between spring and fall. And Dekker and Groen (1956) described patients whose asthma was brought on by picture of a horse, in one case, and a toy goldfish in a bowl in another. In each of these cases, a seemingly harmless stimulus apparently triggered an arousal of emotion, a condition that has the effect of narrowing airways caliber. This consequence of emotion is fairly well known. In healthy individuals, respiratory resistance is increased under conditions of emotion or stress (Kotses et al. 1987a; b; Wigal et al. 1988), an effect most likely due to an elevation in bronchomotor tone. The underlying mechanism, of course, is not related to asthma, but its action in asthma patients may affect breathing and may, at times, combine with inflammation to produce a serious asthma exacerbation. This is recognized in many asthma self-management programs by inclusion of instructions to rest and relax in the face of an attack. An even more effective way of nullifying the deleterious effects of emotion in asthma is by training patients to relax. It is for this reason that relaxation training of one form or another sometimes is included in asthma self-management programs.

Progressive muscle relaxation, a form of relaxation training that involves teaching a patient to distinguish between tension and relaxation by alternately tensing and relaxing each of the major muscle groups of the body while attending to the accompanying sensations has been shown to affect pulmonary function. In two experiments, Alexander and his colleagues (Alexander et al. 1972; Alexander 1972), provided evidence that progressive relaxation training resulted in an increase in the peak flow scores of children with asthma. Biofeedback relaxation, a form of training in which electronic feedback is used to assist the patient to relax specific muscles also is associated with pulmonary improvement in children with asthma (Kotses et al. 1991a, 1978, 1976), and with improvement in attitudes toward asthma and chronic anxiety (Kotses et al. 1991a). Apart from relaxation-induced asthma improvement, there is some evidence that self-management training alone may be responsible for a decrease in anxiety. In particular, self-management resulted in a decrease in trait anxiety for all patients, and asthma-specific anxiety in a subgroup of children who had a high level of asthma anxiety (Colland 1993). In addition, self-management children exhibited more favorable scores than controls on the emotion domain of a quality-of-life index (Cicutto et al. 2005; Henry et al. 2004).

Asthma self-management appears to reduce anxiety in children, even without the inclusion of relaxation training procedures. The case is much stronger, however, when specialized training in relaxation is given. Unfortunately, the time it takes to train children in progressive relaxation or biofeedback is often considered too great for the return it provides. Consequently, few programs today include much training in relaxation.

Quality-Of-Life

Asthma quality-of-life combines measures of asthma symptoms, activity restriction, and emotion (Juniper 1998). It is assessed most frequently with the Paediatric Asthma Quality of Life Questionnaire (Juniper et al. 1996a), an instrument that may be administered in about 10 min. As we described earlier, individual subscales of the questionnaire have been used to document symptoms and activity restriction. The scale has also been used in its entirety in asthma self-management research to obtain a global measure of quality-of-life.

In a school-based program of self-management conducted by asthma educators, quality-of-life scores increased from baseline to post-intervention for children who received the training, but evidenced no change for children who did not (Cicutto et al. 2005). Closer examination revealed that the changes were limited to emotion and activity domains. Similar results for both total and domain scores were reported in another school-based study, this one led by teachers (Henry et al. 2004). Not only is quality-of-life improved by self-management in children with asthma, but benefits of training accrue even to caretakers. A caretaker quality-of-life scale developed by Juniper and her colleagues (Juniper et al. 1996b) was sensitive to caretaker improvement both at 3 months and at a year after children received the intervention. The improvement was limited to caretakers of children who themselves improved after self-management.

Thus far, quality-of-life indices have not been used extensively to evaluate self-management programs, but their potential is great because they ferret out information of several types that may negatively affect asthma patients. They also represent a convenient and economical way of obtaining a great deal of information for a small investment in time. In addition, these instruments may be put to use in diagnostic applications.

Asthma Self-Management Behavior

Changing the way patients respond to asthma is a primary goal of asthma self-management; therefore, determining whether behavior changed as a result of self-management is a key concern. An increase in the ability of self-management children to cope with an asthma exacerbation has been documented a number of times (Charlton et al. 1994; Colland 1993; Evans et al. 1987; Holzheimer et al. 1998; Hughes et al. 1991; Lewis et al. 1984; Rakos et al. 1985; Rubin et al. 1986; Whitman et al. 1985; Wilson-Pessano and McNabb 1985). Usually, the determination is made by questionnaire, but other procedures, including interviews, analyses of diary entries, tabulation of responses to a single item, and observation of targeted skills have been used. Adherence to medication recommendations, an important self-management behavior, also has been found to increase in children given self-management training (Holzheimer et al. 1998; Lewis et al. 1984).

Use of Health Care Facilities

Examination of two variables, emergency treatment and hospital admission frequency, make up the bulk of research on how health care facility use is affected by self-management. Typically, researchers tabulated frequencies in treatment and control groups of patients during lengthy periods of observation before and after the intervention. The before and after measures are needed so as to control for individual variation, especially when the number of patients studied is small. The observation periods are often a year in length so as to control for seasonal variation. Analyses of the frequency of emergency treatment in self-management and control patients for a year before and a year after the intervention have favored self-management (Alexander et al. 1988; Greineder et al. 1999; Lewis et al. 1984; McNabb et al. 1985). Findings consistent with these were reported when observation periods shorter than a year (but still a year apart) were used (Colland 1993), when patients were used as their own controls (Hindi-Alexander and Cropp 1984), and when self-management and control groups were compared only after the intervention was delivered (Fireman et al. 1981).

Evidence indicates that self-management training also improves hospital admission for asthma, but the case is not as strong as it is for emergency visits. The strongest evidence comes from only one study in which improvements in hospital admission were measured from before to after the intervention for a self-management group and a control group (Greineder et al. 1991). In several other studies (Fireman et al. 1981; Madge et al. 1997), hospital admissions were tabulated only during a post-intervention period and may have been subject to individual variation. In addition, frequencies were small, in one case (Fireman et al. 1981), and observations were limited to patients that had been hospitalized for asthma, in another case (Madge et al. 1997).

Two additional variables relating to health care facility use that could be examined for self-management effects: scheduled physician visits and number of hospital days may not be reliable measures for that purpose. Scheduled physician visits are as likely to increase as they are to decrease following self-management training, and therefore, a consistent prediction as to the effects of self-management cannot be made. Hospital days, on the other hand, may be affected by factors other than asthma condition,

including insurance plan provisions and availability of hospital facilities. In addition, hospital rates may be affected by the practices and beliefs of individual physicians who treat asthma. A series of articles a decade or so ago suggested that these were due, in part, to whether or not patients were treated by asthma specialists (e.g., Bartter and Pratter 1996; Mahr and Evans 1993). The consensus was that specialists were significantly better at treating asthma than general practice physicians. More recently, there has been concern as to whether the rate of hospital referrals was due to whether or not physicians followed national and international guidelines for the treatment of asthma (e.g., Vermeire et al. 2002). This debate is ongoing. However, it should be emphasized that there is a spectrum of physician views in deciding whether to refer asthma patients to a hospital. At one end, there are the physicians and medical personal who see the need to refer a patient to a hospital for asthma as unnecessary. At the other end of the continuum, there are physicians and medical personal who actively encourage their patients to seek hospital services in the event of an attack. This breadth of practices makes hospital use a highly problematic outcome variable in comparing data gathered across studies.

School Attendance

School attendance is a difficult variable to measure because it takes a long time to evaluate. Additionally, school records often do not distinguish absences by cause; so missing a day of school for asthma is recorded in the same way as missing a day for some other reason. To the extent possible, investigators have tried to collect school attendance data not only for periods of active self-management investigation, but also for periods prior to the start of the study. Weiss and Hermalin (1987) recorded school attendance for 2 years prior to and for 1 year after introduction of Superstuff, a self-administered asthma self-management program. School attendance in their treatment and control groups before the intervention was not different, but after the intervention the treatment group attended about five more days of school, on average, than did the control group. The difference was statistically reliable. Similar findings for observation periods of only 1 month (Colland 1993; Dahl et al. 1990), for

within-patient comparisons of pre- and post-intervention performance (Creer et al. 1988; Hindi-Alexander and Cropp 1984), and for post-intervention only comparisons of intervention and control group (Cicutto et al. 2005; Clark et al. 2004; Fireman et al. 1981) also have been reported. In addition, the academic grades of self-management patients but not of control patients increased after the intervention was introduced (Clark et al. 2004; Evans et al. 1987). The assumption was that school attendance influences academic performance.

Cost of Healthcare

It is difficult to estimate the cost of treating a child with asthma and easy to understand why. For most families, insurance of one type or another or public assistance keeps the cost of treatment stable from month to month and independent of the condition of the child. Only in a few families does the cost of asthma care accurately reflect the need for medical services. In families such as these, the percentage of net family income devoted to the treatment of the child was 1.79 after self-management training, a drop from 2.71 prior to training (Creer et al. 1988). These data were based on only nine families and may not be representative of asthma costs in a larger segment of the population. A partial measure of asthma care cost, the amount a family spent on the use of facilities not covered by their health care plan, also went down following self-management training (Greineder et al. 1999). The average cost after training was \$471 per family as compared to \$2692 prior to training. The analogous figures in a control condition were \$1638 and \$2266, respectively. The difference between the drop in the trained group and that in the control group was statistically reliable. In one other comparison, the combined hospitalization and emergency treatment costs over the course of a year were estimated at \$35 for 13 patients in self-management group, and \$2955 for 13 patients in a control group (Fireman et al. 1981). Admittedly, a conclusion about the effect of self-management on health care cost is difficult to reach based on these few observations. However, it is not unreasonable to expect self-management to decrease health care costs owing to the reduction it brings about in the need for some medical services.

Adult Asthma Self-Management

Asthma self-management for adults was a natural outgrowth of pediatric programs. The programs began to appear in numbers in the decade of the 1990s. As a group, they are similar to children's programs with the following exceptions. First, and most obviously, adult programs do not require extensive participation of all members of the patient's family. Unlike pediatric programs, adult programs can be restricted to the patient, although this probably does not represent the ideal circumstance. Second, because a certain level of comprehension may be assumed with most adult patients, adult self-management programs may be more complex than those designed only for children. This has promoted use of procedures such as action plans that permit patient adjustment of medication in adult programs as compared with those for children. Finally, developmental considerations may be less a problem with adult than with children's programs. Children at different stages of development may require the use of somewhat different educational and behavioral control procedures, a problem not encountered in adult population. Perhaps partially for these reasons, the effects of adult programs appear to be more robust than those of children's programs. A systematic review of adult programs (Gibson et al. 2002) concluded that use of self-management in adults is correlated with clinically significant reductions in hospital admission, emergency treatment, days lost from work, nocturnal asthma episodes, and costs; and in improved quality-of-life.

As we did in our review of pediatric programs, we grouped outcome variables of adult programs into the following eight categories: (a) physical condition, (b) activity limitation, (c) cognitive factors, (d) quality-of-life, (e) self-management behavior, (f) use of health care facilities, (g) work absenteeism, and (h) cost. We consider only those studies that examined the effects of a comprehensive self-management program, one that included both an education and an asthma control component. We tolerated wide latitude of asthma control procedures including: those in which either symptoms or peak flow was monitored, either with or without a formal action plan; and both those that provided and those that did not provide for medication adjustment. In the studies we examined, self-management training usually was compared with customary care. This is by far

the most common form of comparison, even though it is not entirely trouble-free. We shall return to this point in a subsequent section. To avoid redundancy, we omit extended discussion of outcome variables in studies of adults. Interested readers may refer to analogous coverage of outcome variables in children's programs.

Physical Condition

Self-management is associated with a reduction in either the number or the severity of asthma exacerbations in adult patients. The effect of self-management on exacerbation has been confirmed by both direct and indirect means. In some cases, self-management reduced the frequency of exacerbations (Bailey et al. 1990; Kotses et al. 1995; Snyder et al. 1987); in others, it increased the number of symptom-free days (Cote et al. 2000; Wilson et al. 1993); and in still others, it improved scores on symptom severity scales based either on self-reports of patients (de Oliveira et al. 1999; Levy et al. 2000; Put et al. 2003) or on questionnaires of patient experience that were completed by others (Wilson et al. 1993; Yilmaz and Akkaya 2002). In addition, the symptom dimension of quality-of-life scales indicated improvement following self-management in several studies (Cote et al. 2001; de Oliveira et al. 1999; Put et al. 2003). Other aspects of physical condition that improved with self-management training included peak expiratory flow (Ghosh et al. 1998; Ignacio-Garcia and Gonzalez-Santos 1995; Kotses et al. 1995; Levy et al. 2000; Put et al. 2003), and airway responsiveness to methacholine (Cote et al. 2000). Additionally, a decrease in eosinophils, a biological marker of airway inflammation, was reported in sputum samples (Janson et al. 2003) of patients who received self-management training as compared with patients who did not. In general, findings regarding the effects of self-management on physical condition in adults were consistent with those observed in children. The evidence makes a strong case that self-management training improves physical condition.

Activity Restriction

In contrast to studies of children, there is relatively little support showing that self-management affects activity

level in adults, but some evidence exists. Information about activity limitation was gathered in a multi-site study of 323 adult patients who were given either group or individual self-management training and followed for a year after training (Wilson et al. 1993). A trained nurse administered questionnaires that sampled information about activity limitation at 5 months and at 1 year after the intervention. One year after the intervention, patients who had received group training reported less activity limitation than either patients who received individual training or patients in control groups. A somewhat similar result was reported in a study of patients given self-management training after they had been hospitalized with acute asthma (Osman et al. 2002). One year after the intervention, more patients in the intervention group than in the control group, 60% vs. 52% respectively, reported experiencing no activity limitation. Perhaps the strongest evidence of the effects of self-management on activity restriction comes not from activity reports but from quality-of-life measures. On more than one occasion, the activity domain of quality-of-life indicated improvement following self-management (Cote et al. 2001; de Oliveira et al. 1999; Put et al. 2003). In each case, activity questions on the scale had been individualized according to interests of the patient. It is possible that changes in activity restriction effected by self-management are less apparent in adults than in children because overall level of activity is lower in older patients. A lower level of activity is likely to be associated with lower variability making changes in activity restriction more difficult to demonstrate.

Cognitive Factors

1. *Knowledge.* Ample evidence shows that asthma self-management training improves asthma knowledge in adults. Improvement of knowledge has been reported in a number of controlled studies that included baseline and post-intervention measures (Allen et al. 1995; Cote et al. 1997, 2001; Kotses et al. 1995; Put et al. 2003; Snyder et al. 1987). In each case, knowledge was assessed by questionnaire. The inclusion of a baseline measure is important for control of pre-existing knowledge differences. Studies in which knowledge questionnaires were administered only after the intervention also documented knowledge differences in favor of

the self-management group (Abdulwadud et al. 1999; Brewin and Hughes 1995; Yilmaz and Akkaya 2002; Yoon et al. 1993). In one study (de Oliveira et al. 1999), the dependent variable on which knowledge was evaluated consisted, not of questionnaire score, but of the percentage of patients in self-management and control groups correctly answering questions related to knowledge. Here too, as in all other studies, the comparison favored the self-management group. Considered as a group, these studies strongly support the assertion that self-management increases knowledge of asthma in adult patients.

2. *Attitude.* Work concerning attitudes in studies of adult asthma self-management is largely limited to asthma control, self-efficacy, and asthma health beliefs. The research suggests that self-management training leads to an improvement in: willingness to work within the framework of self-management toward greater asthma control, confidence to manage asthma, and beliefs about asthma drugs. Positive changes in willingness to control asthma (Put et al. 2003) and self-efficacy (Kotses et al. 1995) were observed in adult patients given self-management training but not in waiting-list controls. And beliefs concerning whether asthma drugs are addictive or lose effectiveness with time shifted in an appropriate direction in self-management but not control patients (Yoon et al. 1993). Beliefs concerning asthma drugs, however, were based on responses to only five statements.
3. *Emotion.* Emotional changes associated with self-management in adults have been registered on the Negative Emotionality Scale (NEM) (Tellegen et al. 1988), on the emotion dimension of the McMaster Asthma Quality-of-Life Questionnaire (AQLQ) (Juniper et al. 1992), and on the Beck Depression Inventory (BDI) (Beck 1967). The NEM measures such things as irritability, instability, and nervousness, the AQLQ is a general quality-of-life questionnaire for adult patients, and the BDI is a widely employed test of depression useful for identifying severe depression requiring intervention. Improvement in both in negative emotionality and in emotion measured by a quality-of-life scale was observed in self-management patients throughout a period of 6 months after training, but not in control patients (Put et al. 2003). Similar findings were reported for depression (Kotses et al. 1995),

but the depression scores of both trained and untrained patients were entirely within the normal range of values before and after the intervention. That suggested that depression is not prominent in the majority of patients with asthma. On the other hand, the findings for negative emotionality and emotion measured as a part of quality-of-life are of interest and deserve further study.

Quality-Of-Life

The quality of life of adult asthma patients has been measured by the AQOL (Juniper et al. 1992), and the St. George Respiratory Questionnaire (SGRQ) (Jones et al. 1992). The AQOL has four domains (symptoms, emotions, exposure to environmental stimuli, and activity limitation), and the SGRQ has three (symptoms, activity, and impacts of daily life). Of the two, the AQOL seems to have greater responsiveness (Juniper 1998) and has become the instrument of choice. Following self-management, improvement has been observed in total AQOL score (Cote et al. 2000; Put et al. 2003; Yilmaz and Akkaya 2002), in total SGRQ score (Lahdensuo et al. 1996), and in a total measure that combined aspects of the AQOL and SGRQ (de Oliveira et al. 1999). Positive change in the individual domains of quality-of-life also has been reported for exposure to environmental stimuli (Put et al. 2003), and as noted in earlier sections above, for the domains of symptoms, physical activity, and emotion.

Asthma Self-Management Behavior

As expected, the frequency with which patients practice asthma self-management behavior increases as a result of self-management training. Confirmation of the expectation has come in the form of both: an overall measure of self-management behavior frequency and measurement of specific behavior frequency. Patients who had undergone self-management training reported a higher frequency of self-management behavior than patients in a control group (Kotses et al. 1995). The comparison was made on the basis of the number of self-management behaviors endorsed on the Report of Episode/Attack of Asthma (Creer 1992), a checklist of

behaviors useful for reducing an exacerbation. Specific behaviors reported to have increased after self-management training included improvement in the control of both house dust mites (Cote et al. 2000) and of the bedroom environment (Wilson et al. 1993). The latter referred to such things as elimination of allergenic bedroom furnishings, dust control, and cleaning practices. An improvement in the frequency with which peak flow was checked also has been reported (Knoell et al. 1998), as well as an increase in keeping follow-up appointments after training in self-management (George et al. 1999).

Adherence to medication recommendations has attracted more interest than any other self-management behavior. Taking medication as prescribed can be a problem for asthma patients as many think they have no need for medication during symptom-free periods. Self-management helps the problem. Adherence to inhaled steroid medication, measured in a variety of ways, improved in conjunction with self-management (Berg et al. 1997; Cote et al. 1997; Janson et al. 2003; Levy et al. 2000), as did both self-report measures of medication adherence (Bailey et al. 1990; Put et al. 2003) and rated medication adherence (Bailey et al. 1990). Ability to properly operate a metered dose inhaler also improved with self-management training (Bailey et al. 1990; de Oliveira et al. 1999; Wilson et al. 1993). Assessment of the inhaler technique was made in each case following a standardized procedure (Manzilla et al. 1989).

Use of Health Care Facilities

Self-management reduced unscheduled visits of adult asthma patients to medical facilities. Most studies were concerned with emergency room use. Supporting evidence derived from contrasts of: the number of emergency room visits in self-management and control groups (Cowie et al. 1997); the number of emergency room visits in self-management and control groups before and after the intervention (Cote et al. 2001; George et al. 1999; Ghosh et al. 1998; Yoon et al. 1993); the average number of emergency room visits per patient in the self-management and control groups (Ignacio-Garcia and Gonzalez-Santos 1995); and the percentage of patients making emergency room visits in the self-management and control groups (Gallefoss and Bakke

2000; Lahdensuo et al. 1996). Although these estimates of emergency room use do not necessarily yield identical results, the conclusions in the studies cited were consistent. Similar findings also were reported for a closely related variable: number of unscheduled physician consultations (Moudgil et al. 2000).

Hospital admission rate research has targeted high-risk patients, those who have experienced hospitalization for asthma in the past. Typically, hospitalized individuals are given self-management and their rate of hospital admission is compared with controls for periods before and after training.

Hospital admission rates follow a pattern much like that of emergency room visits. And dependent variables used to measure admission rates are similar to those used to measure emergency visits. These include: hospital admission frequency (George et al. 1999; Yoon et al. 1993); admissions per patient (Mayo et al. 1990); and percentage of patients admitted (Castro et al. 2003; Osman et al. 2002). In each study, a lower rate of hospital admission was associated with self-management training.

Number of hospital days is another variable of health care facility use. As noted previously, it is a difficult quantity to work with because factors other than patient health can affect the length of time one spends in a hospital. Despite this, the number of days spent in the hospital declined for patients who had self-management training. The findings were expressed either as number of hospital days (Ghosh et al. 1998) or as hospital days per patient (Mayo et al. 1990). It is of interest to note that effects of self-management on number of hospital days are limited to these two reports. This may be an indication of influence of other factors on this variable.

Absenteeism

The findings regarding absenteeism in adults are consistent with the results of research on school absenteeism due to asthma in children, but our information regarding the former is less extensive than that of the latter. Comparisons of self-management and control group for a period of a year after training revealed lower rates of absenteeism for self-management patients (Ghosh et al. 1998; Lahdensuo et al. 1996). In each case, absenteeism of patients in the self-management

group was about half that of patients in the control group. A more thorough comparison included information about absenteeism not only after training but also for a period prior to training (Ignacio-Garcia and Gonzalez-Santos 1995). Work days lost were roughly equivalent between groups during a 6-month period before training but dropped sharply in self-management patients during the 6 months after training, a change that did not occur in control patients. Although these outcomes seem straightforward, it should be noted that factors other than asthma severity could contribute to days lost from work. These factors include type of work performed and manner of remuneration.

Cost of Healthcare

Like some other self-management outcome variables, cost of healthcare is difficult to pin down precisely because health care costs in parts of the world and at different times vary greatly. As noted earlier, even within a region, differences between patients in medical insurance coverage adds further variability to costs. These factors make it difficult to compare cost figures between studies, and sometimes even cost figures between individuals within the same study. However, changes in health care costs in self-management training may be examined if these considerations are kept in mind.

Determining changes in the cost of health care for adult patients who receive self-management training has been studied in two ways: by between-group cost comparisons, and by cost-benefit analyses. Average cost estimates per patient for asthma care in India in the early 1990s were \$210.52 and \$270.24 in self-management and control groups, respectively, for a period of a year after training (Ghosh et al. 1998). By contrast, the per patient costs for total health care in St. Louis in the late 1990s were \$5,726.00 and \$12,188.00, respectively, in self-management and control groups (Castro et al. 2003). Both direct and indirect costs were included in each study. Indirect costs were especially difficult to estimate accurately because they included the cost of lost workdays, a figure greatly affected by the patient's rate of pay. A technique that gets around some of the problems of comparability is cost-benefit analysis. It is concerned

not so much with a comparison of cost between those who have had self-management training and those who have not, but the degree to which healthcare cost changes for an individual who is given training. Cost-benefit analyses take into consideration cost of self-management training as well as the cost of asthma care. A cost-benefit analysis of an adult asthma self-management program revealed that self-management reduced asthma care cost by an average of \$475.29 per patient as compared to cost of care prior to training (Taitel et al. 1995). The greatest savings occurred in hospitalization cost and in income lost as a result of lost workdays due to asthma. Comparability between studies remains a problem in cost-benefit studies, but it may be reduced if the savings were expressed as a percentage of asthma care costs.

Tailored Asthma Self-Management

Tailoring of treatment and management recommendations is customary in medicine, but not in asthma self-management. Enthusiasm for it has been hindered by the complexity of asthma self-management programs and by variability between patients in their need for asthma control. The main stumbling block to widespread use of tailoring is the lack of a clear and convenient way to assess a patient's need for a large number of practices that potentially can control asthma. But for the lack of such an assessment, a unique program could be developed for each patient, one that would include only those practices effective for the patient. Asthma self-management has far to go before this ideal is achieved, but some preliminary work has been done.

Tailoring in asthma self-management has proceeded along two lines: tailoring individual elements of self-management, and tailoring entire self-management programs. One other practice, a form of tailoring intended for specific populations rather than for individuals also has received attention, but will not be considered in this section because such programs are directed to groups, not to individual patients. For the interested reader, examples of asthma self-management programs for specific populations include those for inner city children (e.g., Butz et al. 2005; Velsor-Freidrich et al. 2004), preschool children (Mesters et al. 1994 Wilson et al. 1996), and college students (Tehan et al. 1989), to name a few.

Tailoring Elements of Asthma Self-Management

The most readily tailored element of asthma self-management is medication requirement. An early example of this consisted of a children's computer game whose program could be altered for each child to include the child's medication (Rubin et al. 1986). A different approach was used in a study of adult patients who received booklets at monthly intervals that were tailored for medication requirement and for information either requested by the patient or deemed valuable to the patient (Osman et al. 1994). These programs yielded positive results, but the tailored aspects of the programs were not independently evaluated.

A common form of limited tailoring consists of combining medication need with an action plan that includes recommendations for medication use and for seeking assistance. The intent is to establish a series of progressively aggressive measures for controlling asthma. Recommendations for increasing medication use or for initiating other measures to control asthma may be based on the status of asthma as indicated by symptoms or by peak expiratory flow level. Perhaps the first study of this sort of tailoring was conducted in a Maori community, where individuals were given a card that outlined procedures for asthma assessment and intervention based on information about peak expiratory flow, and provided specific instruction for when to seek emergency assistance (D'Souza et al. 1984). Unfortunately, the program could not be evaluated because of the design of the study. More recently, research related to limited tailoring has been done within the context of evaluating home monitoring of asthma. Specifically, action plans that include medication adjustments have been studied. Although a great deal of attention has been focused on this area, the contribution of a tailored action plan to a comprehensive asthma self-management program remains unclear. The reason for this resides in the experimental designs of most studies. What is needed to determine the incremental value of an action plan to self-management is a study of programs with and without an action plan. In studies of home monitoring, the converse has been done: action plans with and without self-management have been compared with traditional medical management. In addition, various action plans have been compared with one another. None of this work addresses

the value of tailoring in self-management, and for that reason will not be reviewed here. These studies, however, are the subject of several reviews (Kotses et al. 2006; Toelle and Ram 2004), and additionally, are discussed in a separate chapter in this volume.

Tailoring Asthma Self-Management Programs

At least two approaches to tailoring of self-management programs have been attempted. They differ in how information for tailoring is collected. Ultimately, all tailoring is based on patient experience. But in some studies, tailoring decisions are made by asking patients about their asthma, and in others, by analyzing data collected by patients. Asking patients about their asthma is the simpler of the two. It has been used on several occasions to tailor self-management programs (e.g., Bailey et al. 1990; Dahl et al. 1990; Fireman et al. 1981; Sockrider et al. 2006; Thoonen et al. 2002; Wilson et al. 1993). Improvements were reported in each study, but tailoring was evaluated independently only in one (Wilson et al. 1993). In the latter study, the effectiveness of tailored self-management programs was compared with that of a small group program. The tailored programs were assembled, on the basis of an interview, from a pool of 18 instructional modules that represented the entire content of the small group self-management program. Patients in both conditions improved in comparison to controls, but the improvement favored the group-trained participants to a slight degree. The investigators also pointed out that group participants benefited from peer support and that group programs were cheaper to conduct than tailored programs.

Tailoring that relies on data collected by patients also has produced positive outcomes. In two studies (Creer et al. 1988; Kotses et al. 1995), patients participating in a group self-management program completed a questionnaire relating to both triggers and control practices for each asthma episode they experienced. Patients reviewed the reports periodically for evidence of consistency in either their triggers or effective controls. The intent of this was to help each patient understand the causes and countermeasures of his or her asthma. These tailoring procedures were not evaluated independently of the self-management programs. But

a closely related procedure (Kotses et al. 1991 b, 1996) was evaluated independently and produced evidence of effective asthma control for tailored programs. Patients were asked to collect information regarding the date and time of their asthma attacks, their daily peak flow scores, and their contact with a number of asthma triggers. The information the patients gathered was analyzed statistically for the relationship of asthma attacks both to triggers and to peak flow. On the basis of these analyses, a unique program was designed for each patient that took into consideration the patient's triggers. Patients who were given these programs did at least as well as patients given a group self-management program.

These studies make it clear that tailored self-management programs can be effective. A major benefit of tailoring is a practical one: tailoring is consistent with medical practice. As in customary medical practice, tailoring concerns the individual, not the group. By contrast, group self-management is more closely associated with education than it is with medicine. It requires teaching competencies and facilities that may not be readily available in some medical settings: complex scheduling arrangements, classroom space, teaching equipment, and supplies. Tailored asthma self-management, therefore, might be feasible where group training is impractical. The benefit is, however, offset by its high cost. Even if the costs for development of the two self-management formats were equivalent, the difference between them in the cost of staff time needed for administration would be greater for tailored than for group programs, a problem that could preclude widespread use of tailored programs. But even this barrier may be surmounted by research, possibly by developing tailored programs that can be self-administered, at least to some extent. This and other challenges of tailoring wait to be taken up.

Asthma Self-Management in Hindsight

Our review of asthma self-management focused almost exclusively on outcome. With the exception of our mention of a few methodological problems, we did not consider procedures. But procedures matter, and some of the results we described may not withstand close scrutiny. One serious problem that plagues asthma self-management research concerns its most common

control procedure: usual care. While usual care may appear to fulfill the requirements for control adequately, there is reason to believe that it does not. All research requires that a control condition be identical to the experimental condition in all relevant ways except for the treatment variable: the intervention, in the case of self-management. The requirement includes amount of time spent with patients, a hard thing to balance between groups, as self-management training almost always involves more time spent with the patient than usual care. If both self-management training and time spent with patients differ between groups, research outcomes cannot be fully attributed to self-management.

The argument is underscored by research showing that subtle factors can affect research outcome. In self-management research, the outcome of training may be affected by both demand characteristics and experimenter bias. The former refers to the tendency of patients to behave in ways expected of them and the latter to the expectations of the experimenter. These influences have not been fully explored for asthma-related variables, but related findings have been reported. Evidence of the influence of demand, consisting of air volume and flow variation resulting from the change of single word in forced expiratory maneuver instructions (Harm et al. 1984, 1985), has been reported in healthy individuals. Research has also shown that the expectancy of the experimenter affects respiratory resistance in healthy subjects despite a total lack of awareness on the part of the experimenter that an expectation was communicated (Wigal et al. 1997). The sensitivity of individuals to experimental conditions, as documented in these studies, suggests the likelihood that interactions with self-management patients during periods of extended contact may give rise to influences that affect outcome independently of training. Failure to control such influences could lead to misleading conclusions.

The possibility of this sort of contamination suggests that some of our conclusions regarding the effects of self-management may be overly optimistic. That we have reached this uneasy understanding after much effort researching self-management is not surprising. Conducting research in a naturalistic setting is a tall order. In the case of asthma self-management, the best medical and research practices are often in conflict, a hurdle that limits research effectiveness. Additionally, neither patients nor their health care providers

necessarily play the roles we ask of them in self-management research, and their interactions may be affected by variables of which we know relatively little. Even our best experimental designs may falter against these obstacles. We are encouraged, however, by volume of evidence of self-management effectiveness, even as we recognize that only more research will resolve questions of its efficacy once and for all.

Some Trends in Asthma Self-Management Research

A recent survey of asthma self-management practice in Canada (Tsuyuki et al. 2005) noted that the records of more than half of the asthma patients contained no evidence that they received any type of self-management training, and that only 2% had been given an action plan. The fact that so many asthma patients do not receive self-management training suggests the presence of significant barriers to training. These may include cost, time and money, and possibly the failure of self-management programs to accommodate the needs of some patients. Fortunately, trends in research suggest remedies for these problems are on the way. Recently, an increasing amount of asthma self-management research has been devoted to special populations and to special settings. Both inner-city populations, in which prevalence of the disease is especially high, and school settings, where children may be reached conveniently and at modest cost, have been studied extensively. These investigations may bring access to self-management to a greater number of people. Augmenting these trends is an increase in short forms of asthma self-management. The length of the early self-management programs was six to eight sessions, but more recently programs requiring a little as a single session have been developed. Short programs increase access to training by reducing both the time needed to complete a program and the financial cost of the program. Additional improvement may result from tailoring programs for individual patients. Among new approaches to tailoring, the use of biomarkers may eventually play a role in developing asthma treatment and management programs for individuals (Szeffler 2008) Tailored programs provide the ultimate degree of flexibility and efficiency for asthma self-management. If they could be conducted inexpen-

sively, they would extend the benefits of asthma self-management to every patient who needs it.

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