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# EFFECTS OF FAMILY ADAPTATION AND ASTHMA SELF-MANAGEMENT TRAINING ON ADHERENCE IN CHILDREN WITH ASTHMA

by

Lara M. Runger

A Thesis Presented in Partial Fulfillment
of the Requirements for the Degree
Master of Science

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## ABSTRACT

The purpose of this study was to examine the adaptation and adherence levels of children with asthma and their families, and to determine if these could be influenced in a positive way by attending an asthma self-management program. The study participants were a convenience sample recruited from a military hospital in the Southwest. Five children and their parent(s) participated in the asthma self-management program AIR POWER, which is published and distributed by the National Heart Lung and Blood Institute (NHLBI). Because of the small sample size, only descriptive statistics were applied to the data. However, the small size of the group was conducive to an informal atmosphere that facilitated the sharing of anecdotal information, coping strategies, and techniques for environmental control and avoidance of asthma triggers. Subsequent to participation in the program, improvements were noted in the areas of asthma knowledge, in asthma self-management behaviors and improved peak expiratory flow rate (PEFR) readings. Chart review three months after the program revealed a decrease in Emergency Room (ER) visits for acute management of asthma. A slight change for the worse was observed in the children's attitude toward having asthma, parents' report of child's behavior in the areas of medication concepts, and in the parents' report of Impact on the Family. Due to the small sample size, it is not possible to discuss whether these findings have any significance.

For my mother

Norma B.

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# CHAPTER 1

## Introduction

### Background and Significance of the Problem

Asthma in children is a chronic medical condition resulting in significant morbidity and mortality. As the most common chronic disorder in children (Gortmaker & Sappenfield, 1984; Newacheck, Budetti, & Halfon, 1986), it has the potential for significant duration and potential long-term adverse impact on the daily lives of children and their families (Varni & Wallender, 1986). Asthma, together with other respiratory diseases, accounts for a staggering 25% of all limitations of children's activities (Newacheck, Halfon, & Budetti, 1986). Asthma-related morbidity results in frequent absences from school, an estimated 10 million school days a year (Taylor & Newacheck, 1992; Weiss, Gergen, & Hodgson, 1992), approximately 12.0 million contacts with medical doctors, and 200,000 hospitalizations per year resulting in 1.9 million days of hospitalization in the United States (Taylor & Newacheck, 1992).

Consequences to physical and psychosocial development can be staggering. Reporting on the 1988 National Health Interview Survey (NHIS), Taylor and Newacheck (1992) found that 35% of children with asthma were reported to have experienced a great deal of pain or bother related to their condition. Asthma in children is responsible for reduced exercise tolerance, loss of sleep at night, frequent clinic and Emergency Department visits, family disruptions, hospitalization, and even death (National Asthma Education Program [NAEP], 1991). Taylor and Newacheck (1992) further reported that compared with the 5% of children without asthma who experience some limitation of their activities, almost 30% of children with asthma have some limitation of their activities. Results of the survey also revealed the asthma prevalence rate among boys to be 50% greater than among girls, and the prevalence rate among black children to be 26% higher than among white children, while black children with asthma experience more functional disability and more frequent hospitalizations than

white children (Taylor & Newacheck, 1992). The number of children under 18 in the United States diagnosed with asthma increased 52 percent from 1982 to 1989 (Rachelefsky, Fitzgerald, Page, & SantaMaria, 1993). From 1980 to 1987 the incidence of asthma increased 29%, hospitalizations increased 6%, and the death rate from asthma rose 31% (NAEP, 1991). In reporting on determinants of near fatality in 81 patients with severe asthma, Kallenbach et al. (1993) reported considerable evidence of undertreatment in the asthmatic population as a whole, particularly as regards the use of steroids.

Current statistics demonstrate the tremendous impact that inadequate control of this disease has on the child, the family, and the health care system. The annual cost of asthma in the United States in 1990 was estimated to be 6.2 billion dollars (Weiss, Gergen, & Hodgson, 1992). Although many consider asthma to be a mild illness easily managed with ambulatory care, the study conducted by Weiss et al. (1992), found that as much as 43% of the costs associated with asthma treatment were related to emergency room visits, hospitalizations, and death. The NHIS produced figures indicating that the 10% of children whose asthma was classified as severe accounted for 41% of the days restricted to bed, 27% of the missed school days, 20% of the doctor contacts, 35% of the hospitalizations, and 77% of the hospital days (Taylor & Newacheck, 1992). These figures would seem to indicate lack of adequate treatment, with resultant dangerous and expensive exacerbations. Furthermore, many people, though receiving adequate treatment, are not functioning at their optimum level (Rachelefsky, 1987).

Improved understanding of the pathophysiology of this disease, as well as advancements in drug therapies should have resulted in a decrease in morbidity and mortality related to asthma. Surprisingly, that has not been found to be true. Rachelefsky (1987) lists lack of patient compliance, and inadequate recognition of the adjustment problems and impact on family dynamics caused by asthma as important

factors contributing to morbidity and mortality. A review of studies of asthma mortality in an editorial by Sears (1988) revealed that the predominant cause of asthma mortality in children was a lack of recognition of the severity of the condition, and insufficient or inappropriate medical treatment. Although there are some cases where death occurs as a result of a sudden, unexpected, severe attack of asthma, most deaths are believed to be preventable (Bloomberg & Strunk, 1992).

Asthma is a disease of the lung characterized by reversible (in most cases) airway obstruction, inflammation, and increased responsiveness of the airways to various stimuli (NAEP, 1991). In people with asthma, the airways tend to be "twitchy", or hyperresponsive, and easily become constricted and narrowed, resulting in diminished air flow. This is particularly problematic in children because their airways are narrower, and the elastic recoil ability of their lungs is less (NAEP, 1991). Obstructive changes taking place in asthmatic airways result in progressively worsening shortness of breath (hypoxemia), cough, wheezing, tight chest, CO2 retention, and may ultimately lead to respiratory arrest (NAEP, 1991).

No medical regimen can succeed in the absence of the patient and family's ability to assume responsibility for self-care and adherence to the therapeutic regimen (McNabb, Wilson-Pessano, & Jacobs, 1986). Consequently, the focus of treatment is currently on home, or self-management of asthma. Patient education, environmental control, and comprehensive pharmacologic therapy all play a major role in modern asthma care (NAEP, 1991). Successful management of asthma is based on pharmacological interventions and behavioral modifications such as avoidance of asthma "triggers", reasonable efforts to avoid infection with upper respiratory viruses, and moderate exercise, prescribed to both prevent and control attacks (NAEP, 1991).

Lack of adherence to these prescribed medical regimens has been identified as a significant contributor to the alarming increase in morbidity and mortality (Birkhead, Attaway, Strunk, Townsend, and Teutsch, 1989; Howell, Flaim, and Lum Lung, 1992;

Lemanek, 1990; Strunk, 1987). Lemanek (1990), in a review of selected literature, revealed that adherence to prescribed medical regimens varied between 17 and 90% in children and adolescents with asthma. Spector et al. (1986) reported that an estimated 10 to 46% of patients with asthma were compliant, depending on which medications were studied and whether the patients felt the medications to be beneficial. Studies cited by Deaton (1985) support the widely-accepted supposition that lack of adherence is a fairly common occurence, with an estimated one-third to one-half of prescribed medical regimens not being adhered to. For the purposes of this study, adherence is defined as the process of following medical advice concerning drug regimens, and practicing the necessary behavioral modifications required in management of the disease process.

Varni (1983) suggested that the improvement of adherence to therapeutic regimens could have at least as great an effect on adverse consequences of chronic medical conditions as advances in biomedical technologies. The importance of adherence is underscored by the negative consequences of nonadherence. Lack of adherence to therapeutic regimens seriously undermines the success of medical treatment in prevention, management, and curative situations, and results in unnecessary morbidity, mortality, and health care costs (Varni & Wallender, 1986).

Lack of adherence may also result in the efficacy of the prescribed treatment being misjudged, with resultant increased expenses from clinic visits, diagnostic tests and unused medications (Varni & Wallender, 1986). Frequent school absences and disruptions in family activities and economic status also may result from poor adherence (Lemanek, 1990). Lack of adherence has even been linked to asthma-related deaths through such mechanisms as improper or overuse of inhalant medications, family difficulties which preclude seeking necessary medical help appropriately, and failure to maintain therapeutic levels of medications such as theophylline (Birkhead et al., 1992) .

Children with asthma may be at twice the risk of suffering emotional consequences adversely affecting development as are other children (Pless & Nolan, 1991). A complex relationship exists between severity of illness and adjustment (Perrin, MacLean, & Perrin, 1989). Even people with mild asthma with no overt symptoms have inflamed airways, which contribute both to airway inflammation and hyperresponsiveness. Thus, asthma tends to be an episodic illness, with periods of wellness and exacerbations (Rachelefsky, 1995). As a result, asthma sufferers are subjected to ups and downs, which may be more stressful than the course of an illness that is relatively stable over time, even if more severe (Pless, 1984). Perrin et al. (1989), in a study of children with asthma, found that parent assessments of severity affected adjustment scores on the Health Resources Inventory in both the most and the least affected groups, while no relationship was correlated with clinician judgement of severity. They recommend, therefore, that resources designed to help children with chronic illness not be limited only to those with severe disease, as difficulty in coping and adjustment may be found among children with asthma at varying levels of severity.

Coping and adjustment are complex processes that are influenced by many factors (Perrin et al., 1989). These include characteristics of the child such as self-esteem, intelligence, understanding of the disease process, and family characteristics such as available support system, usual coping practices, and communication style (Perrin et al., 1989). Pless & Nolan (1991) point out that research is needed to validate the role of education and other interventions in reducing the uncertainty associated with chronic illness, and to facilitate adaptation to such conditions.

Justification of the Study

There is ample evidence that the costs of asthma to the patient, family, and health care system are high. Major support for asthma self-management programs exists at both the governmental level and among physician organizations (Parker, 1987;

Howell, et al., 1992). This study hopes to demonstrate the value of implementing such a program.

Validation of an existing asthma self-management program in the setting of a U.S. Air Force Pediatric Clinic will result in greater recognition by U.S. Air Force health care providers of the benefits to be derived from using a program of this nature to educate their patients with asthma and their families. It should be emphasized that self-management does not imply self-treatment. Howell et al. (1992) report that no researchers have noted an increase in morbidity related to self-management courses, and there has been no tendency to assume an inappropriate degree of responsibility in decision making, or delay in seeking definitive care when necessary. Patients and families should benefit from their increased knowledge of asthma, and the recognition that they can successfully manage the disease. Better management should lead to less stress in their lives, fewer missed days of school, less time spent in hospital, and enhanced quality of life for the affected child, and the entire family (Lewis & Lewis, 1987).

Purpose of the Study

The purpose of this study was to investigate the adherence and adaptation levels of children with asthma and their families, and to determine if these could be influenced in a positive way through participation in an asthma self-management course.

Research Questions

1) What are the adaptation patterns of children with asthma and their families?

2) What is the level of adherence to therapeutic regimens of children with asthma and their families?

3) What is the relationship between child and family coping (adaptation) to asthma, and adherence to therapeutic regimens?

4) What is the relationship between participation by child and parents in an asthma self-management education course and adherence to therapeutic regimens?

5) What is the interaction between child and family adaptation, participation in an asthma self-care training course, and adherence to therapeutic regimens?

Operational Definitions

1. Asthma is a disease of the lung characterized by reversible (in most cases) airway obstruction, inflammation, and increased responsiveness of the airways to various stimuli (NAEP, 1991).

2. Chronic illness is defined as "a physical, usually non-fatal condition which lasts longer than three months in a given year or necessitates a period of continuous hospitalization of more than one month" (Pless & Douglas, 1971, p. 406).

3. Adherence is defined as the process of following medical advice concerning drug regimens, and practicing the necessary behavioral modifications required in management of the disease process (Creer, 1987), and is used synonymously with, but in preference to, compliance.

4. Asthma self-management programs were defined by Clark (1983) as "those organized methods of encouraging the child and his parents to manage the health condition by preventing asthma attacks and managing attacks once they occur, while encouraging the child to live as normal a life as possible" (Clark, 1983, p. 578).

5. Adaptation to chronic illness is defined as the degree to which an individual adjusts both psychologically and physiologically to the stress of long term illness, and includes such concepts as compliance (adherence) and coping measures employed (Grey & Thurber, 1991). For the purpose of this study, adjustment areas include knowledge, behavior, attitude, and imapct on the family.

6. Coping, as referred to throughout this study, will be defined as the family's ability " to demonstrate flexibility to manage and deal with challenges from the environment" (Lipman, 1989, p. 188).

Assumptions

The assumption was that the study sample is representative of the population being studied. It was further assumed that study participants would understand the questions, and would respond to the instruments honestly.

# CHAPTER 2

## Review of the Literature

This chapter will present factors believed to influence adherence to medical regimens, both negative and positive. Several existing asthma self-management programs will be reviewed in some depth, including pertinent findings and study limitations. A conceptual framework illustrating the relationship of self-management behaviors to adherence and improved outcomes is described. How family adaptation influences, and is influenced by adherence to medical regimens will be reviewed, as well as the importance of adequate adaptation to the education process.

### Factors That Influence Adherence

Several factors have been identified through clinical experience and research as influencing adherence in pediatric asthma patients. Complexity of the treatment regimen has been well-documented as a factor contributing to nonadherence to the medical regimen (Creer, 1991; Lemanek, 1990; Smith et al., 1986; Spector, 1985; Weinstein & Cuskey, 1985). Creer (1991) states that medication adherence is a major component in the prevention of asthma attacks. Two kinds of medications are often prescribed for children with asthma: (1) maintenance, or prophylactic medications taken even when the patient is symptom-free in order to prevent attacks, and (2) medications taken as needed when symptoms are recognized. Both types have been associated with adherence issues. For the first type, it is necessary to teach the patient the importance of the medication in managing the disease and preventing symptoms. Recognition of asthma "triggers" and signs that an attack is imminent must be learned by the patient in order to take the second type, the "as needed" medications correctly to alleviate an attack (Creer, 1991).

Studies cited by Spector et al. (1986) have variously reported that adherence to medical regimens is not predictable by the patients' age, sex, race, economic status, marital status, religious preference, educational level, or tendency to keep appointments.

They further described compliance, or adherence, as classifiable in one of four of the following categories: (1) The patient uses the medication appropriately, as it was prescribed; (2) the patient persistently underuses the medication; (3) the patient overuses the medication; and (4) erratic usage, in which case the patient sometimes undermedicates, and at other times, overuses the prescribed medication(s).

Intolerable or annoying side-effects of some medications (Spector, 1985), and fears about long-term consequences, particularly involving corticosteroid use (NAEP, 1991), may adversely affect adherence. Christiaanse, Lavigne, and Lerner (1989), found that greater adjustment problems were associated with nonadherent theophylline levels, and that adjustment and family climate (cohesiveness vs. conflict), and the interaction of the two, were predictive of the percentage of mean adherent theophylline levels. Kapotes (1977), in a descriptive study of 39 children and parents, found inhibited behavior and parental indifference related to nonadherence.

Increased adherence has been found to be positively associated with satisfaction with the care provided, the perception that the physician is approachable and interested, and close supervision of home management (Smith et al., 1986; Spector, 1985). Spector et al. (1986) further recognized the importance of clear verbal instructions, backed up with written materials, cues and reminders to simplify the regimen for the patient, and the support and encouragement of family and friends. He also emphasized the importance of encouraging the involvement of family members in treatment programs, rewards and positive reinforcement of adherent behaviors, and participation in self-management programs.

One of the many positive outcomes of self-management training has been found to be an improvement in the relationship between parents and physicians (Howell et al., 1992). Creer (1991) recommends the behavioral techniques of negotiating and contracting as helpful tools in promoting medication adherence and successful self-management of asthma by children. He attributes the development of contracts

between physicians and patients at one residential treatment facility with not only promoting adherence to medication regimens, but in maintaining the behavior after they returned home. Patient and family education in self-management techniques appears to be a powerful tool for clinicians concerned with increasing adherence in pediatric asthma patients (Clark, 1991; Creer, 1991; Howell et al., 1992; Spector et al., 1986; Wilson-Pessano & Mellins, 1987).

Asthma Self-Management Programs

Successful management of asthma requires a comprehensive approach in which parents and children play an active role as part of the health care team. With the recognition of the importance of self-management techniques in successful management of pediatric asthma, over the past two decades nearly two dozen programs have been developed to assist families and children in becoming effective day-to-day managers of their asthma (Creer, Wigal, Kotses, & Lewis, 1990). Parker (1987) reports that research on asthma self-management courses indicates that these programs improve asthma knowledge and attitudes toward asthma in parents and children, increase self-management behaviors, and decrease health resource utilization among children with all degrees of asthma severity, but particularly among those with asthma categorized as "severe" or difficult to manage. Rachelefsky (1987) concludes that effectively teaching people self-management of their asthma could prove to be as important to their state of health as improving the quality of physician care received.

Tehan, Sloane, Walsh-Robart, & Chamberlain (1989) developed and tested the Dartmouth College "Breathe Free" Program in an effort to assess the impact of self-management education on the health behaviors of a group of college students. They found that use of the college health center for acute exacerbations was decreased among the study population, and that the students felt increased satisfaction with their activity level and asthma control. They demonstrated improved knowledge about asthma based on pre and post-test data from the Asthma Knowledge Test. A chart review four years

later indicated improved use of early intervention strategies as well as improved adherence to treatment recommendations.

Programs developed by the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health (NIH) such as Open Airways, AIR POWER, Living with Asthma, and Airwise, have generally been demonstrated to be effective in increasing self-management skills (Wilson-Pessano & Mellins, 1987). In an implementation of Open Airways in an HMO setting, Moe, Eisenberg, Vollmer, Wall, Stevens, & Hollis (1992) found that parents intervened earlier with medications when they noticed symptoms, felt more awareness about their child's asthma, were more knowledgable, and felt more confident when dealing with their child's asthma. They point out that in order for a program to succeed, it must be tailored to fit the population being served.

In 1984, Lewis, Rachelefsky, Lewis, de la Sota, and Kaplan conducted a randomized trial of a curriculum, Asthma Care Training (A.C.T.) for Kids. In this study of members of the Los Angeles Kaiser-Permanente Health Care System, seventy-six children aged 8 to 12 years were randomly assigned to experimental and control groups. Families were enrolled into the study in groups. The control group consisted of 28 children and their families, who then received 4 1/2 hours of lecture presentation on asthma management. The 48 children and parents in the experimental groups (comprised of four to seven children and their parents) received five 1-hour sessions constituting the treatment.

Findings included equivalent increases in knowledge and change in beliefs about asthma in both groups; and significant changes in the self-reported compliance behaviors in the experimental group only. Significant reductions in emergency room visits and hospitalizations were also noted among those receiving the training. Qualitative data obtained from this study suggests that those in the experimental group experienced improvement in family communication skills, and improved father-child

relationships. A significant association was noted between improved behavioral outcomes and attendance of both the mother and father at the class sessions.

Howell et al. (1992) note that a feature common in successful programs is attention to the children's developmental age and cognitive abilities. A.C.T. for Kids was created based on the following premises:

the information would be in a format easily understood by the children; games, simulation, and modeling would be used whenever possible; parents and children would be treated as equals in the learning and caring process; the child must actively participate in the preventing, controlling, and recognition of symptoms and in carrying out the treatment plan; the child would be taught basic decision making skills, relaxation techniques, and other skills actively contributing to a sense of mastery over asthma; and the parents would be taught skills designed to enhance their nurturing skills and enabling them to provide an environment conducive for the child to successfully practice self-management skills (Lewis et al., 1984).

A.C.T. for Kids uses a traffic light analogy to put children "in the driver's seat" to help them categorize the severity of their symptoms and take the appropriate actions. The program emphasizes that children can take charge of their disease, instead of being controlled by it. Because most children readily recognize that green stands for "go", yellow for "caution", and red for "stop", participants learn to categorize their symptoms appropriately, and then use green-coded medications for prevention, yellow-coded medications for mild attacks or early symptoms, and red-coded medications to stop the attack. Similarly, the color scheme is used as well to identify those actions that the child can self-manage, and those that require parental or professional intervention (Lewis et al., 1984).

Factors Influencing Lack of Dissemination

Parker (1987) states that given the availability of proven health education programs for families and children with asthma, they should be made a part of the

medical care system. Although these programs have generally been shown to be effective in improving asthma self-management and reducing morbidity and medical costs (Wigal et al., 1990), dissemination has been poor. The vast majority of patients have not received the benefits of an educational program (Wilson-Pessano & Mellins, 1987). It may be that many providers are unaware of the availability and success of these programs, and how to use them as a resource for taking care of their patients with asthma (Wilson-Pessano & Mellins, 1987). Over the past decade many asthma self-management programs have been developed and tested. Parker (1987) concludes that available research demonstrates that these types of programs are effective in increasing asthma knowledge and attitudes toward asthma, increasing self-management behaviors taken by the child and family, and reducing morbidity and resultant health care costs.

In 1983, Dr. Edward N. Brandt, at the time Assistant Secretary for Health, United States Department of Health and Human Services, expressed the hope that answers arising from deliberations undertaken at a Workshop on Self-Management of Childhood Asthma would result in helping all citizens cope with chronic illness and enjoy better quality of life. Yet, incorporation of programs teaching self-management skills in the care of children with asthma has not become routine.

Wilson-Pessano & Mullins (1987) note that the vast majority of children with asthma have not had the benefit of participating in a self-management program, and that most providers (specialists and non-specialists) are unaware of the programs, their methodologies, the testing they have undergone, and how to incorporate the content and behavior change principles into their care of children with asthma. They believe that a central barrier to the dissemination of these programs is the difficulty in assimilating such programs into the existing health care system in this country. They cite the lack of behavioral sciences education in most medical school curriculums and house officer training programs as a barrier to widespread utilization of self-management training.

There exists an absence of mechanisms to train and support the personnel necessary to administer these programs to the children who need them. It is also noted that the use of education programs run by others is not common practice for many physicians. Lewis & Lewis (1987), reported that developers of self-management programs have had difficulty in obtaining adequate numbers of subjects for their research. Lack of physician support is cited as a major obstacle. Lewis & Lewis (1987) believe that it will be necessary to overcome the considerable distrust that many physicians have for this sort of program. Some may be concerned about the exposure of their practice-management skills to others. They also believe that programs must address the physicians' fear of loss of patients and increase their comfort in dealing directly with the children themselves. Third-party payers have been unwilling to provide reimbursement for these programs, even those that have documented savings of health-care dollars (Lewis & Lewis, 1987). Until reimbursement issues are rectified, the only groups with a financial motive to provide the programs are health maintenance organizations (HMOs), or practice settings in which health care providers are at risk for the total amount of services used by their patients.

Asthma self-management programs may require behavior modifications that affect youngsters' peer relations (LaGreca, 1990). They are taught to avoid or escape allergens or irritants that act as asthma "triggers" (Creer et al., 1990; Lewis et al., 1984), behavior that may be problematic when it occurs in the course of activities with their peers, as it inevitably causes attention to be drawn to them. LaGreca (1990) points out that youngsters must feel comfortable being assertive with their peers for self-management strategies to be effective.

Some Problems With These Studies

Some weaknesses in previous works cited in Taggart et al. (1991) include such problems as nearly all participants coming from middle to upper socioeconomic groups, difficulties with attendance by child and parents, and number of staff required to

implement such programs. The program they developed, "You Can Control Asthma" (YCCA) is designed to be used in an emergency room or inpatient setting. Their study of 40 children 6-12 years old found an increase in asthma knowledge and greater internal Health Locus of Control after participation in their program. Parents reported improved self-management techniques, and chart review 15 months later showed a decrease in emergency room visits for the study participants.

Other problems found in evaluations of these programs include small sample size and lack of control group, as in the Dartmouth "Breathe Free" Study. The A.C.T. study population reflected a lack of cultural and economic diversity in the sample studied, and recruitment was from a population with no problems in gaining access to health care (HMO users) (Lewis et al., 1984). Rachelefsky (1987) cites differences in treatment and control groups, bias present in subject selection, no suitable controls, and lack of reliable outcome measures, as problems impacting evaluation of asthma self-management programs.

Research conducted by Shields, Griffin, & McNabb (1990) provided self-management training in the setting of an urban HMO to members 18 years of age or less with asthma, with the goal of reducing Emergency Room use. The program consisted of classes conducted in a group setting for patients and their families, and telephone contacts to provide additional reinforcement and instruction. The program did not accomplish the goal of decreasing Emergency Room use for asthma treatment by this group of subjects. The researchers believe this poor outcome was due mainly to failures of implementation and program effectiveness. They postulate that the program was inadequately designed to address the needs of the target population, due to the socioeconomic, educational, and racial profile of the clients of this particular HMO. Although the educational program they used is not mentioned by name, the researchers felt that the behavioral component of this program was not as strong as some others which enjoyed greater success (Shields et al., 1990).

Another problem faced by the developers of these programs has been the lack of standardized, validated instruments assessing knowledge and health beliefs (Proceedings of a Workshop on the Self-Management of Asthma, 1983, cited in Lewis et al., 1984). Questions about the generalizability of the findings can only be answered through replication of the efforts made by past researchers.

Conceptual Framework

A study conducted by McNabb, Wilson-Pessano, & Jacobs (1986), carried out as part of the research and development process of the educational programs AIR WISE and AIR POWER suggested that successful self-management of asthma requires more than simple adherence to therapeutic regimens. They emphasize the importance of basing a health education intervention on the linkage between a person's health-related behaviors and their health status. Recognizing the importance of clearly understanding the skills one is trying to teach when educating children, 66 behaviors were identified as critical to the self-management of asthma using the critical incident technique. The general self-management areas they describe provide a useful conceptual framework for considering asthma self-management training. The classified incidents provide a very specific description, in behavioral terms, of what it means for a child to be able to cope with asthma. The behaviors were found to fall into four general competency areas: (a) prevention; (b) intervention; (c) compensatory behaviors; and (d) external controlling factors.

Prevention behaviors are those the child takes to avoid or prevent the occurrence of symptoms. Eight major categories of preventive behaviors important to self-management were identified. These behaviors include: 1) avoiding allergens such as foods, pollens, animal danders, etc.; 2) avoiding irritants and other precipitants such as extreme temperature changes, fumes, and exercise; 3) controlling or avoiding emotions that act to trigger attacks such as fear, anger, stress, and excessive excitement; 4) taking appropriate action when exposure has occurred to minimize effects; 5) taking

preventative medication routinely or in anticipation of exposure to a trigger; 6) ensuring that there is access to medications for relief of symptoms; 7) using some form of mental imagery or relaxation to control attacks; and 8) cooperating in the treatment of upper respiratory infections.

Intervention refers to those behaviors employed by the child after symptoms have begun. Intervention behaviors fall into four categories and include: 1) taking appropriate action to minimize or control symptoms; 2) utilizing a variety of interventions depending on the progression or severity of the attack; 3) developing or requesting individualized response plans; and 4) correct use of medications. Compensatory behaviors are those actions demonstrating the child's adjustment or adaptation to the condition. They include: 1) discussing asthma with peers and seeking their support; 2) accepting responsibility for self-management; 3) showing determination to overcome limitations imposed by the disease; 4) cooperating with the medical regimen, to include those aspects which are frightening, painful, or restrictive; 5) avoiding denial of the condition and self-blame; and, 6) avoiding manipulative behavior.

The fourth category, external controlling factors, refers to those factors beyond the child's control such as authority figures who are unhelpful to the child, or use the the condition to manipulate the child's behavior; and family problems that interfere with the child's ability to self-manage attacks (McNabb et al., 1985). It seems clear that successful management of asthma requires multiple components to be addressed. The framework guiding this study is adapted from those of McNabb et al. (1986), and Lewis et al. (1984).

Improved knowledge of causes, symptoms, treatments and medications, and learned skills should enhance behaviors in the areas of prevention, intervention, and compensatory behaviors. Learning self-management skills may allow the child to develop more positive beliefs about having asthma, and the ability to manage it.

Learning communication skills, including acknowledgement of the condition, shared responsibility for management, and avoidance of manipulation by the child and the parents will hopefully lead to improved family dynamics, and assist the child in management of external controlling factiors. Mastery in these areas should result in improved adherence and the desired outcomes of improved quality of life, reduced ER use, and fewer bed days. It should be noted that there is considerable overlap among and between the self-management areas. The Conceptual Framework for this study is depicted in Figure 1.

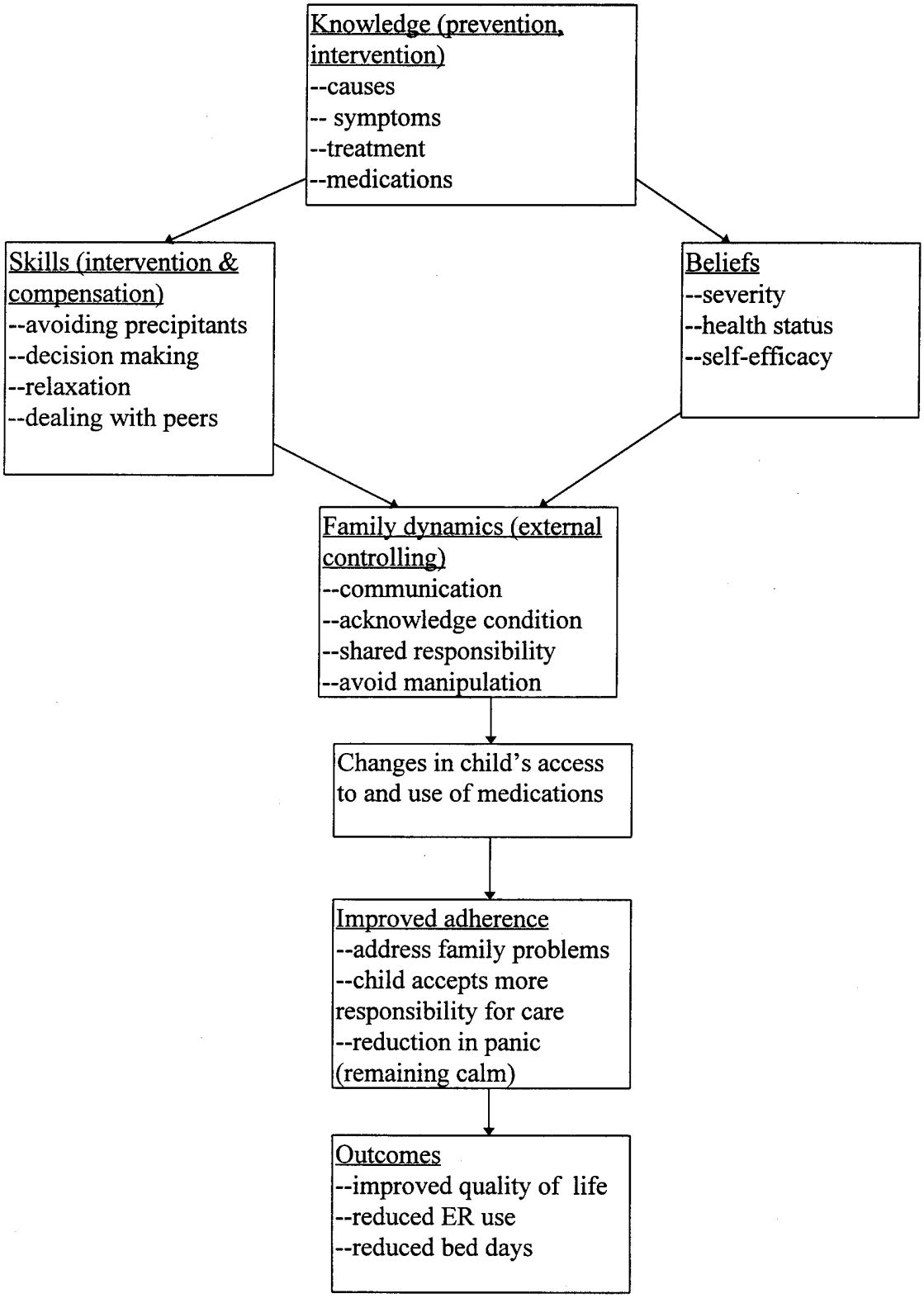


Figure 1
Conceptual framework

Adaptation and Family Adjustment

It is well-accepted that a child's chronic illness adversely affects all members of the family (Sabbeth, 1984). Adherence to therapeutic regimens may be viewed as one aspect of adaptation, to, or coping with a disease (Christaanse et al., 1989). Their study of 38 children and adolescents (ages 7-17 years) showed that a combination of psychological adjustment, degree of family conflict versus cohesiveness, and the interaction of the two was predictive of adherence as measured by mean theophylline levels (Christaanse et al., 1989). Deaton (1985) reported that adaptiveness, or coping, rather than compliance, was associated with better outcomes for children with asthma. Rubin, Bauman, & Lauby (1989) reported that asthma management behavior was related to knowledge, particularly in the less well-adjusted subjects, and in those from lower SES. They also found that beyond a certain threshold level, increased knowledge did not seem to positively influence asthma management behavior.

Coping is frequently assumed to increase with knowledge and education (Howell et al., 1992). An analysis of the coping mechanisms of the child and family is required in order to assess readiness to engage in the learning process, the degree of responsibility the family members are able to handle, and the degree of support needed (Howell et al., 1992). In spite of recognition of the tremendous toll that chronic disease inflicts on families, how self-managment training influences family adaptation has seldom been specified or evaluated (Lewis & Lewis, 1987). Although self-management training may not heal family disruption, it should reduce stress due to anxiety about the disease, sleepless nights due to exacerbations, and medical expenses (Lewis & Lewis, 1987). Fears may also interfere with optimal family adaptation. Korsch, Gozzi, & Francis (1968) demonstrated that parents were unable to focus on educational material presented when their fears and concerns had not been addressed beforehand. Assessment of where the child and family are in terms of their adaptation to, or coping with the disease, is thus an essential step in the education process (Howell et al., 1992).

It is clear that poor adherence to therapeutic regimens in children with asthma is a serious problem. Investigation of factors influencing adherence in children with asthma has been increasing (Lemanek, 1990). Some difficulties identified as resulting in inconclusive results were identified by Lemanek (1990), and include the variability of symptomatology, effectiveness of treatment, problems in individual assessment methods, and nonstandardized interventions. Little has been done to examine the relationship of child and family adaptation to adherence to therapeutic regimens.

Summary

Asthma is clearly a disease that causes significant problems for children with asthma and their families. Lack of adherence to prescribed medical regimens is widely acknowledged to be a major contributing factor to the continued morbidity and mortality due to asthma. With the goal of increasing adherence, numerous education programs with the purpose of teaching children and their families asthma self-management skills have been developed, tested, and found effective in increasing knowledge of asthma, improving asthma attitudes, and decreasing use of health care resources. The problem remains of achieving widespread dissemination and use of these programs to help children and their families better manage their disease, and enjoy improved quality of life, free of unnecessary disability.

# CHAPTER 3

## Methods

### Introduction

The purpose of this study was to examine the levels of adaptation and adherence in children and their families with asthma, and determine if they could be influenced in a positive was through participation in an asthma self-management program. In this chapter the design of the study is presented. The methods, to include the setting, characteristics of the sample, sampling plan, and instruments that were used to measure the desired concepts will be described. The asthma self-management program AIR POWER, and how it was implemented will be discussed.

### Research Design

The design chosen for this study was a pre-experimental one-group design with a pretest and posttest. Although this design is one of the most frequently used, it is recognized that it has some rather serious shortcomings (Burns & Grove, 1993). Efforts were made to minimize the potential alterations in posttest results which may be caused by the following factors: 1) maturation processes; 2) administration of the pretest; and 3) changes in instrumentation (Burns & Grove, 1993).

### Overview of the Procedure

Once approval of the IRB at Arizona State University and the Luke Air Force Base (AFB) Hospital was obtained, letters were distributed to the parents of children with asthma by Luke AFB Hospital Pediatric Clinic, Allergy Clinic, Family Practice Clinic, and Emergency Room Personnel, explaining the program, and offering the opportunity to participate (Appendix D). Flyers (Appendix C) were posted around the hospital, and were provided to the various hospital clinics and to the Emergency Room personnel to distribute to children presenting with asthma, or with history of asthma. Numerous follow-up visits were made to the various clinics to see how the distribution process was going, and answer any questions. These same letters and flyers were also

provided to the school nurses at the Luke AFB Elementary School and Garden Lakes Elementary School, which is attended by many children with parent(s) stationed at Luke AFB. It was also made clear that it was not necessary to be a military member to attend. The school nurses were thoroughly briefed on the program and asked to send the flyers home with the students that they knew to have asthma. A follow-up visit was made to the school nurses to replenish their supply of handouts, answer any questions they might have, and to ascertain if there had been any response to the materials sent home with the children. Those responding were contacted by telephone and invited to participate with their child in the Asthma Self-Management Training Program AIR POWER.

AIR POWER was developed by Wilson-Pessano, McNabb, and associates with the purpose of helping children and parents learn asthma self-management skills. The program is designed to assist them in the acquisition of the necessary knowledge, attitudes, and motivations, and then provide them the opportunity to practice the asthma self-management competencies in their daily lives (Wilson-Pessano & McNabb, 1985). Providing children with performance accomplishment experiences is believed to be one of the strongest factors motivating behavioral change (Bandura, 1982, cited in Wilson-Pessano & McNabb, 1985).

AIR POWER consists of four 1-hr sessions that are conducted on a weekly basis with small groups of children, and separate but parallel sessions for their parents. Due to resource constraints, children and parent groups were combined for the purposes of this study. Each session consisted of three components: giving of information, group discussion, and reinforcement of previous lessons. Content and activities are designed to be developmentally appropriate, and focus on teaching children to be competent in the day-to-day management of their asthma. Some minor alterations and additions were made to the program materials in order that the lessons reflect current knowledge and practice, as the AIR POWER materials are ten years old. Phone conversation with one of the principle creators of AIR POWER, Dr. Sandra Wilson (personal communication,

August 10, 1994) confirmed that with some up-dating of the material, the instructional techniques remain quite valid.

The focus for parents attending the sessions was on teaching them to become active supporters of their children's self-management efforts. Classes were taught by the researcher and other appropriately prepared pediatric clinic staff members (a child psychologist, and two pediatricians). A preprogram session was held the week before the classes began in order to allow time for completion of instrumentation and informed consent/assent. The first session, which focused on pathophysiology of asthma, asthma symptoms, and asthma medication was taught by the researcher. The second session, which focused on learning relaxation techniques, was taught by the Luke AFB pediatric psychologist, and the third and fourth sessions, which focused on prevention of symptoms, avoidance of asthma triggers, and development of an emergency plan were taught by Luke AFB Pediatric Clinic pediatricians.

Setting

The setting for this study was the Pediatric Clinic at Luke AFB Hospital, located at Luke Air Force Base, Arizona.

Sampling Plan and Statistics

Research subjects were: between the ages of eight and twelve; English speaking; and with any degree severity of asthma. The sample used in this study was consistent with that used by the developers of the program (Wilson-Pessano & McNabb, 1985). Subjects were identified through response to either the information letter, flyers, or through physician referral. Every effort was made to ensure that potential subjects did not feel pressured, obligated, or coerced into participation. Respondents were contacted by telephone, and the program explained. Informed consent/assent was obtained from parents and children participating in the study during the pre-program registration session, and their confidentiality carefully guarded.

The intent was that both descriptive and inferential statistics would be used to analyze the data. The original intent of the researcher was to use Student's $t$ to compare differences between the follow-up and baseline measures in each group. A two-way Analysis of Variance (ANOVA) was to be employed to examine the main effects of the independent variables (family adaptation and asthma self-care training) on the dependent variable (adherence to therapeutic regimens) as well as any interaction effects they might demonstrate. It was recognized that due to a probable small sample size, ANOVA may not provide valid results. Unfortunately, through no fault of the researcher, a very disappointing sample size of only 5 children and their parents completed the program, even with extensive recruitment efforts and the full support of the medical and nursing staff at the Luke AFB hospital. Therefore, only descriptive statistics relevant to the study will be reported.

Data Collection Procedure and Instruments

Power analysis revealed that to demonstrate a 32% difference between experimental and control groups using a one-tailed test, at a 5% level of statistical probability, a sample size of 58 would be required. This level of probability was selected to minimize chances of both Type I and Type II errors. Although the researcher recognized that it would probably be impossible to recruit and provide the treatment to this number of subjects, it was expected that there would be sufficient persons electing to participate in the program to allow comparisons to be made.

Forms used in the evaluation and implementation of AIR POWER are provided as part of the AIR POWER package, and a copy of each of these instruments may be found in Appendix A. The Enrollment Questionnaire for Parents was used to collect date about the child's asthma, treatments, medical care use and the family demographics. The Medical Records Summary Form was used by the researcher to capture information about the child's asthma treatments, and emergency and non-emergency medical care use for the three months preceeding and following attendance. Asthma Inventories were

filled out by both the child and parents. The Asthma Inventory for Children is a four-part questionnaire containing an asthma knowledge test, a self-management behavior report, an asthma attitude inventory, and questions about the child's asthma. The inventories for children and parents were completed during the enrollment session, and information useful in planning content of the classes was obtained. These inventories were again completed by the children and parents after the conclusion of the program. The inventories were sent to each participant, along with a stamped, self-addressed envelope in which the completed inventories were returned to the researcher in a timely fashion. Efforts were made and were successful to keep the time gap between completion of the inventory and beginning of classes equivalent for all the subjects.

The asthma knowledge test consists of 12 multiple-choice questions designed to assess asthma knowledge. The second part of the inventory is a self-management behavior report, which consists of 18-items designed to elicit information about the child's self-management behaviors, and is scored using a Likert scale. The asthma attitude inventory consists of 12 True/False questions related to how the child feels about having asthma. The fourth part of the inventory specifically addresses the child's asthma symptoms, medications, precipitating factors, and management behaviors.

The Asthma Inventory for Parents is also a four-part questionnaire. It includes a 12-item multiple-choice asthma knowledge test, an 18-item parental report of the child's self-management behaviors, and two attitude measures, a nine-item scale describing the parents' attitude towards the child's asthma, and a 12-item True/False questionnaire asking the parents to report how their child feels about asthma. Follow-up questionnaires were also utilized to gain participants' feedback on the program. Guidelines for the scoring and interpretation of the instruments are provided as part of the AIR POWER package, but no reliability or validity information on the instrumentation is available, and this is stated in the introductory materials for the program. Content validity may be presumed as the authors may be considered experts

in the field of asthma education. The principal author, Dr. Sandra Wilson, was contacted by phone in an effort to determine if any reliability or validity data on the instruments had become available (personal communication, August 10, 1994). She stated that no reliability or validity data were available on these instruments.

Method for Protecting Human Rights

Demographics and information acquired through administration of the course instruments were coded and recorded in such a manner as to preclude the subjects from being in any way identified with their responses. Subject codes were used on all data collected, and a master list was kept secure and separate from the data. Results will be published only in aggregate form. It is believed that subjects were exposed to very little risk through their participation in this study, and it is hoped that they derived significant benefit from exposure to the educational program.

Data Collection Process for Each Individual

Parents and children electing to participate in this research were contacted by telephone by the researcher's assistant, and provided with a letter (Appendix D), which many of them already had, explaining the research, and what their participation in AIR POWER would mean for them. They werealso informed of the time and location where the classes were to be held. A preprogram session was held for participating children and parents. At this time, the program was again explained by the researcher, and questions pertaining to the program addressed. Informed consent/assent from participating parents and children (Appendices D & E) was obtained, and they were allowed time to complete the Enrollment Questionnaire for Parents, their respective Asthma Inventories, and address any questions or concerns they had. Completion of the instrumentation took approximately 45 minutes. The children and parents also participated in an informal discussion of what it meant to them to have asthma, or for the parents, to have a child with asthma. Using information provided in the Enrollment questionnaires, the researcher was able to review the children's records and complete the

Medical Records Summary Forms for each child. The inventories, as described above, were also administered one month after program completion for the purpose of evaluating changes in knowledge, attitudes, and management behaviors. The Parents' Follow-up Questionnaire was also completed at that time. These were all mailed to the participants with an enclosed stamped envelope to allow ease in their return to the researcher. A weekly session report was completed by the instructor of each session in order to track whether the weekly assignments were completed successfully, and whether the participants felt the assignments were helpful. Exit Questionnaires for Children and Parents were administered at the end of the last session. These instruments allowed participants to evaluate the program and describe ways in which it was beneficial to them. Finally, the Follow-up Medical Records Summary, used to capture information about the child's medical treatment for asthma and other information about the medical management of asthma, was completed three months subsequent to the end of the program. A timetable for admininstration of the instrumentation is given in Figure 2 (Adapted from AIR POWER, NIH, 1984).

| TITLE OF FORM | WHEN ADMINISTERED |
|---|---|
| **Preprogram Assessment** | |
| Enrollment Questionnaire for Parents | During registration session |
| Medical Records Summary Form | Before the first session |
| Asthma Inventory for Children | During registration session |
| Asthma Inventory for Parents | During registration session |
| **Program Operation** | |
| Weekly Session Report | During or immediately after sessions, one , two, three, and four |
| **Postprogram Evaluation** | |
| Exit Questionnaire for Children | At end of session four |
| Exit Questionnaire for Parents | At end of session four |
| Asthma Inventory for Children | 1 month after completion of AIR POWER program |
| Asthma Inventory for Parents | 1 month after completion of AIR POWER program |
| Followup Questionnaire for Parents | 1 months after completion of AIR POWER program |
| Followup Medical Records Summary Form | 3 months after completion of AIR POWER program |

Figure 2

AIR POWER evaluation schedule

Data Analysis Plan

Given the small sample size, the only appropriate descriptive statistical measure the researcher was able to use to describe the sample was group means. Thus, only inferences may be made regarding answers to the research questions, as the small sample size precluded the application of more sophisticated statistical methods.

Each of the items in the asthma inventory was designed to target one self-management concept area: prevention, intervention, medication, or adjustment (AIR POWER, NIH 1984). Information obtained from the asthma attitude inventory and the impact of asthma on the family questionnaires was specifically used to answer the question "What are the adaptation patterns of children with asthma and their families?" The researcher had hoped to use Pearson's Product Moment (PPM) correlations to compare the child's attitude toward asthma with the parents' report of the child's attitude. The Parents' Inventory--Impact on Family is set up so as to yield a low score for the least negative impact on the family, with a high score demonstrating the greatest impact. Data obtained preprogram was to be compared with postprogram data using Student's $t$ to determine if the intervention had an influence on family adjustment. Again, it was only possible to make inferences based on the means of the scores obtained.

The second question, "What is the level of adherence to therapeutic regimens of children with asthma and their families" was answered through the capture of data from the medical records reflecting the number of acute visits for asthma treatment in the three month period prior to the program (Rachelefsky, 1987). Scores obtained on the Behavior Report completed by the child, a self-report of the child's self-management behaviors, and the child's behavior report completed by the parents were also compared to each other for similarities or differences.

Ignacio-Garcia and Gonzalez-Santos (1995) conducted a controlled trial of peak expiratory flow rate (PEFR) to determine the usefulness of an objective measure of lung function in association with an eduction program and self-medication plan in reducing

morbidity in a group of 70 adult asthma patients. They found in the experimental group (35 patients) that home use of a peak-flow meter in association with a self-management plan led to improvement in a patient's condition as measured by fewer days lost from work, fewer acute asthma episodes, and reduced need for antibiotic therapy, physician consultation, and emergency room visits. A decrease was also noted in the use of inhaled beta-agonist medications, oral theophylline, and oral prednisone. PEFR meters may be used successfully by children as young as four-five years of age (Rachelefsky, 1995; Rachelefsky, Fitzgerald, Page, & Santamaria, 1993). PEFR readings may be used to monitor the response to therapy (Rachelefsky et al., 1993), either immediate, as in the case of medication administration, or over time. Therefore, PEFR readings obtained from the children pre and post-program were also compared, but there are so many factors influencing such readings that cannot be controlled for, that it is recognized that the changes noted may not be significant.

It was the researcher's intention that comparison of adherence data and adaptation data would be achieved using two-way ANOVA in an effort to answer the question "What is the relationship between child and family adaptation to asthma, and adherence to therapeutic regimens?". Again, it was only possible to make inferences due to the sample size.

The original plan was that Student's *t* would again be used to compare pre and postprogram adherence data in order to identify any effect the treatment, participation by child and parents in an asthma self-management course (AIR POWER) may have on adherence, in answer to the question "What is the relationship between participation by child and parents in an asthma self-management education course and adherence to therapeutic regimens?". Emergency Room use for acute treatment of asthma, and PEFRs before and after the program provided some basis to infer a positive effect due to the program. MANOVA techniques were to be used to determine if any interaction effects are present between child and family adaptation, participation in AIR POWER,

and adherence to therapeutic regimens. Here, again, it was only possible to draw inferences from the data available. Ancillary analysis of data would be applied to any questions other than the stated research questions which emerged from the data. The sample size once again precluded applying other than descriptive statistical methods to the data.

# CHAPTER 4

## Findings

### Introduction

The purpose of this study was to investigate the adherence and adaptation levels of children with asthma and their families, and to determine if these could be influenced in a positive way through participation in an asthma self-management course. Included in this chapter are the sample characteristics, findings discovered by the researcher, and a review of the data collected as they relate to the original research questions. The chapter concludes with a summary of the findings.

### Sample Characteristics

Initially, fifteen parents of children with asthma expressed their interest and intent to attend the program sessions. However, at the preprogram session, there were only seven parents and eight children present. Of this group, five parents and their children completed the full five sessions.

One of the children who did not complete the program, a seven year-old girl, became seriously ill with an asthma exacerbation in the second week of the program, and was admitted to the hospital with a diagnosis of status asthmaticus the evening following her attendance at the second session. The researcher, at the time of the session noted that the child had a cough, and was restless and irritable, and asked her father if she was OK. He did not seem terribly concerned, and stated that she hadn't used her inhaler before coming to class, and would be fine after using her inhaler. It was unfortunate that they were unable to complete the program, as they would seemingly have benefitted from it.

The other two children who did not complete the program were sisters, aged ten and eleven, who also attended only the first two sessions. Both of these girls had very mild asthma, with only occasional as-needed use of an inhaled beta-agonist. Neither girl had missed any days from school or seen a physician for their asthma in the three

months preceeding the program. As the mother worked full-time in downtown Phoenix, and had two other small children, which she brought along to the class each night, it may be assumed that the logistics overcame her, preventing completion of the program.

Five children and their parent(s) completed all five program sessions. These children ranged from age eight to twelve. Two were girls, and the remaining three boys. Four were Caucasian, and one was Asian. All of the children were part of intact families, with two parents living in the home. All parents had at least a high school education. Only one child was currently receiving allergy injections, and, with the exception of one child, all were living in non-smoking households. Only one of these families had a furry pet, which was kept indoors most of the time. The inability to keep a pet was quite an issue with one of the participants, and she stated that was the main reason she disliked having asthma. All of these children were participating in normal daily activities, to include participation in regular P.E. at school, except during exacerbations of their asthma. All of the children participating in the program were taking medications for their asthma, at least some of the time, and none were newly diagnosed as having asthma.

Areas of the children's lives that parents identified as being restricted in some way or affected by asthma included: exercise and sports, social activities, having pets, furnishings permitted in their room, and sleep. Three of the five parents answered that asthma limited the things their child was able to do. One little girl especially remarked that it was hard for her not to be able to go over to her friends' houses because they had pets, that they always had to come to her house.

Triggers that the parents identified as having caused asthma attacks in their children included: smoke, fumes, or air pollution; hot, cold, or damp weather, or a change in the weather; physical activity; anger; excitement or laughing; a cold or infection; exposure to an allergen; and an insect bite. Only one of these children had no known allergies. Substances, or groups of substances identified as allergens for the

other children included: cat hair, dog hair, cattle hair, horse hair, rabbit hair, grass pollens, weed pollens, tree pollens, molds, and housedust.

The entire group was extremely motivated, and participated freely in the class discussions. The small size of the group was conducive to an informal atmosphere which facilitated the sharing of anecdotal information, coping strategies, and techniques for environmental control and avoidance of asthma triggers. Comments on the Exit Questionnaires were very positive. Parents appreciated the explanation of what happens in the lungs during an asthma attack, the understanding that they gained of their child's feelings when having an asthma attack, the way in which the relaxation techniques were helping their child to cope with an asthma attack, that their children now realized they were not the only ones suffering from asthma, and the personalized care plans provided for each child. Children's comments included such things as: knowing what to do when they have a problem with their asthma, sleeping better, knowing more about their asthma, and that the program helped them learn how to relax. All felt the program went well, and one parent added that the program could be made more worthwhile if it were possible to review the actions of the medications more in depth.

Findings

1) What are the adaptation patterns of children with asthma and their families? The small sample size makes it impossible to apply any generalizations to the larger population. However, it may be said about this population of children with asthma and their families that their adjustment to their disease was actually fairly good. In order to answer this question, scores in the adjustment areas including knowledge, behavior, attitudes, and impact on the family were analyzed. Actions demonstrating the child's adjustment or adaptation to the condition include: 1) discussing asthma with peers and seeking their support; 2) accepting responsibility for self-management; 3) showing determination to overcome limitations imposed by the disease; 4) cooperating with the medical regimen, to include those aspects which are frightening, painful, or restrictive;

5) avoiding denial of the condition and self-blame; and, 6) avoiding manipulative behavior (McNabb et al., 1985).

In the area of asthma knowledge, the mean adjustment score before attending AIR POWER was .67. After AIR POWER, the mean adjustment score in the knowledge area was increased to .80. Mean adjustment score in the child's behavior area before attending AIR POWER was .85. Parent's report of the child's behavior was fairly consistent with the child's report at .83. The child's behaviors score in the adjustment area after attending the program was slightly increased at .93. Parent's report of child's behaviors score was only very slightly increased after the program at .85. The scores are summarized in Table 1.

Table 1

Summary of Asthma Inventory Adjustment Scores Before and After AIR POWER

| | Mean Adjustment Scores before AIR POWER | Mean Adjustment Scores after AIR POWER |
|---|---|---|
| Child's Knowledge | .67 | .80 |
| Child's Behavior | .85 | .93 |
| Child's Attitudes | .62 | .58 |
| Parent Report of Child's Behavior | .84 | .85 |
| Parent Report of Child's Attitudes | .68 | .63 |
| Impact on the Family | .36 | .38 |

The instrument measuring child's attitudes towards having asthma consisted solely of questions in the adjustment area. Mean score before AIR POWER on the children's scale was .62. Again fairly consistent was the parent's report of the child's attitude mean score of .68. Surprisingly, the attitudes scores after attending the program were reduced for both the children and parents at .58 and .63, respectively. Due to the small sample size, it is not possible to determine if this is a significant change. One wonders if increased awareness and knowledge of their condition may have adversely affected their attitude, an outcome certainly other than that intended. Even after attending the program, 100% of the children answered "True" to the question "I really hate having asthma". All except one child again answered "True" to the question "I don't like having to take medicine for my asthma". Three of the five children felt sad about having asthma. One child, however, commented that his parents didn't worry about him having an asthma attack, because they "know I can take care of myself".

Some of the interventions the children mentioned that they employed when they first noticed asthma symptoms included: getting a drink of water, and resting on a bench, getting away from what was causing it, taking their medication, and using their nebulizer machine. It would have been gratifying to see a change for the positive in adjustment, or attitude toward having asthma, but perhaps that was unrealistic given the time frame of this study.

In terms of impact of asthma on the family, these families seem to be adapting to their illness in a fairly positive manner. On this instrument, a lower score equated to less impact. Surprisingly, the mean score after attending the program was slightly higher at .38, than the before program score of .36. These scores would still seem to indicate that these families are coping well enough with their illness to keep the impact on the family to a somewhat minimal level. It does not appear that the intervention had much influence on the adaptation patterns of these families.

2) What is the level of adherence to therapeutic regimens of children with asthma and their families? A previously cited study conducted by Christaanse et al. (1989) used mean theophylline levels to measure adherance. As none of these children were taking theophylline, this yardstick was not available. Medical Record review for the three months preceeding the program revealed a total of five asthma-related Emergency Room visits for this group of children. Mean PEFR was 284. In order to shed further light on this question, scores on the child's behavior instrument in the areas of prevention, intervention, and medication concepts were examined, and compared to the parent's report of the child's behavior. These scores are summarized in Table 2.

Table 2

Summary of Mean Behavior Scores Before and After AIR POWER (AP)

| | Prevention Concepts Before AP | Prevention Concepts After AP | Intervention Concepts Before AP | Intervention Concepts After AP | Medication Concepts Before AP | Medication Concepts After AP |
|---|---|---|---|---|---|---|
| Child's Behavior | .68 | .92 | .73 | .83 | .95 | .92 |
| Parent Report of Child's Behavior | .78 | .76 | .72 | .78 | .83 | .94 |

Before attending AIR POWER, the children's mean score for prevention concepts was .68. Parents' score for their child's reported behavior was slightly higher at .78. The children's mean score for intervention concepts was .73, with the parents reporting a similar .72. An impressive mean score of .95 was achieved by the children in the area of medication concepts prior to the program. Unexplainably, the mean score after the program was slightly reduced to .92. Parents' mean scores for their child's reported behavior relating to prevention and intervention concepts were slightly increased after the program, and behavior related to medication concepts was increased to .94. It is unfortunately not possible to determine if that is a significant difference.

3) What is the relationship between child and family adaptation to asthma, and adherence to therapeutic regimens? Due to the small sample size, statistical analysis in an effort to answer this question was not possible. The available figures (reported above) would seem to indicate that this group was coping fairly well with their asthma, and also that their level of adherence to therapeutic regimens was fairly good. Further study with an adequate sample is needed in order to properly address this issue.

4) What is the relationship between participation by child and parents in an asthma self-management education course and adherence to therapeutic regimens? With the exception of the child who did not complete the program, none of the participants were hospitalized for their asthma either in the year before or the three

months after participation in AIR POWER. Fewer asthma-related visits to the Emergency Room were noted in this group of children following their exposure to the intervention. Although this is not a great measure of adherence due to the impossibility of controlling for season, allergens, air pollution, and other factors, it would seem to indicate that the participants were managing their asthma better after participation in AIR POWER. These figures are summarized in Table 3. It should also be noted that the children's mean behavior scores after AIR POWER were increased in the areas of prevention, intervention, and in the parents' report of the child's behavior in all areas (Table 2).

Table 3

Summary of Mean Visits for Asthma-Related Problems in the Three Months Preceeding and Following AIR POWER

| Emergency Room before AP | Emergency Room after AP | Clinic before AP | Clinic after AP |
|---|---|---|---|
| 2 | 0 | 2 | 3 |
| 2 | 0 | 0 | 1 |
| 0 | 0 | 2 | 1 |
| 0 | 1 | 2 | 1 |
| 1 | 1 | 1 | 0 |
| 5(1) | 2(.4) | 7(1.4) | 6(1.2) |

As already discussed, PEFR is a tool frequently used to assess the efficacy of therapy. Mean PEFRs were also increased to 332 from the preprogram mean of 284. Additionally, each particpant increased his/her PEFR. The before and after PEFRs are summarized in Table 4.

Table 4

Summary of Mean PEFR Values Obtained Before and After AIR POWER

| Before AIR POWER | After AIR POWER |
|---|---|
| 350 | 410 |
| 240 | 300 |
| 290 | 310 |
| 260 | 330 |
| 280 | 310 |
| 1420(284) | 1660(332) |

5) What is the interaction between child and family adaptation, participation in an asthma self-care training course, and adherence to therapeutic regimens? The answer to this question must await a study with a larger sample size. It is possible to say that this population seemed to be coping fairly well with their asthma, and it appears probable that their adherence to therapeutic regimens was improved after participation in the AIR POWER program, based on a reduction in acute visits for asthma to the Emergency Room, and improved PEFRs, but no statistical analysis can be done to illuminate any relationships these factors might have with each other.

Ancillary Analysis

The question "What is the knowledge level of children and their families about asthma before and after participation in an asthma self-,management course?" was not originally a question that was asked as part of this research. However, it appears based on pre and posttest data, that asthma knowledge was increased by participation in AIR POWER for both parents and children. These scores are summarized in Table 5.

Table 5

Mean Scores of Children and Parents on Asthma Knowledge Test Before and After AIR POWER

| | Prevention Concepts | Intervention Concepts | Medication Concepts | Adjustment | TOTAL |
|---|---|---|---|---|---|
| Child's Knowledge before AP | .53 | .54 | .27 | .67 | .50 |
| Child's Knowledge after AP | .93 | .87 | .74 | .80 | .83 |
| Parents' Knowledge before AP | .73 | .80 | .80 | 1.00 | .83 |
| Parents' Knowledge after AP | 1.00 | 1.00 | .87 | 1.00 | .97 |

It can be seen that the parents scored higher than the children both before and after the intervention, which would be somewhat expected. However, both groups overall improved their scores on the Asthma Knowledge Test after participating in AIR POWER.

Summary of Findings

Improvements were noted in the areas of asthma knowledge for children and parents, asthma self-management behaviors in the areas of prevention and intervention concepts, ER visits for acute management of asthma, and PEFR readings. A slight decrease worse was observed in the children's attitude towards having asthma, medication concepts, in the parents' report of child's behavior in the areas of prevention and medication concepts, and in the parents' report of Impact on the Family. Due to the small sample size, it is not possible to discuss whether these changes have any significance.

# CHAPTER 5

## Conclusions and Recommendations

### Summary of Main Findings

This study was conducted in order to investigate adaptation and adherence levels of children with asthma and their families, and to determine if participation in an asthma self-management program, AIR POWER, would be beneficial to them. A military population was chosen, as this is the area in which the researcher will be practicing in the future. One of the major findings relevant to this research was that it is possible to offer an asthma self-management course to a population of children and their parents with asthma at no cost, and have a very disappointing turn-out. This occurred in spite of a vigorous publicization effort, and the full support of hospital and clinic staff who were knowledgable about this course, and urged their patients with asthma to participate in it.

For those who attended the course, it was found that all except one had numerous allergies, and most had some limitations on their activities. All of the children agreed that they hated having asthma, and disliked having to take medications for their asthma. Parents, in nearly all instances, were aware of these feelings. Most of the children experienced no difficulties in telling their friends and significant adults about their asthma.

The parents and children who completed the program were enthusiastic, motivated, and contributed freely to the class discussions, sharing feelings, concerns, and management issues. Impact of asthma on these families was fairly low, based on scores on the Impact of Asthma on the Family instrument, and the intervention had little effect on this aspect of their lives, as measured by the instrument. Emergency Room visits for acute asthma were reduced after participation in AIR POWER, and PEFRs were increased. Children's mean asthma-related behavior scores were increased in the areas of prevention and intervention concepts. Their medication concepts scores were slightly decreased after participation, but the parents' report of child's behavior in the

area of medication concepts was increased after participation in AIR POWER. Parents' report of behavior in the area of intervention concepts was also increased after participation in AIR POWER. The slight decrease in the scores on the parents' report of the child's behavior in the area of prevention concepts may have been related to the parents not observing enough behavior in the one-month follow-up period to notice the changes in their child's behavior that the children reported. Asthma knowledge was increased for both children and parents.

Interpretation of Findings

Lewis & Lewis (1987) reported that developers of self-management programs have had difficulty finding adequate numbers of subjects for their research. This research unfortunately was able to replicate that problem. Lack of physician support was cited by Lewis & Lewis (1987) as a major obstacle. That was not the experience of this researcher in any way. Physician support for this program was abundant and enthusiastic, to the extent that several health care providers volunteered their unpaid time to assist in teaching the course. One of the reasons that AIR POWER was chosen as the vehicle for teaching asthma self-management was that it was available from NHLBI at no cost, while some of the other programs were associated with rather significant costs. A.C.T. for Kids literature recommended that costs be recouped through charging the participants to attend. It would seem that people would be less likely to attend such a program if a fee was involved, but conversely, perhaps that would result in them according the program greater value. Lewis & Lewis (1987) also pointed out that third-party payers have expressed reluctance in paying for these programs, although this is changing as cost-containment becomes more of a priority. Reimbursement issues were not a factor in this research, or in the lack of participants attending and completing the program.

Taggart et al. (1991) noted that parents and children experienced difficulties with attendance at many of the existing programs. It would seem that this research was

also able to demonstrate that result. Recognizing that in this day and age, parents and children are extremely busy with school, sports activities, and work, perhaps a more effective intervention could be employed. Zuckerman et al. (1991) reported on a program they developed, (You Can Control Asthma" [YCCA] designed to be used in an emergency room or inpatient setting. Participants in this program demonstrated an increase in asthma knowledge and greater internal Health Locus of Control, with a chart review 15 months later showing a decrease in emergency room visits for study participants. Perhaps a program such as this could be modified for use in the typical outpatient, or clinic setting, thus avoiding some of the problems encountered with attendance.

Howell et al. (1992) reported an improvement in the relationships between parents and physicians as one of the many positive outcomes of self-management training. Increased adherence has been found to be positively associated with satisfaction with the care provided, the perception that the health care provider is approachable, and interested, and close supervision of home management (Smith et al., 1986; Spector, 1985). Although this was not an outcome intended to be measured during this research, the overwhelmingly positive responses of the children and parents to the nurse researcher and the physicians involved in teaching the course would imply that this was indeed achieved. Perhaps future researchers in this area might find this a topic of interest.

The implied, or suggested increases in asthma knowledge, and asthma self-management behaviors found by this researcher after children and parents participated in the self-management training is consistent with that noted by other researchers. Tehan et al. (1989) reported that participants in their "Breathe Free" program demonstrated a reduction in their use of emergency facilities for asthma exacerbations, showed increased asthma knowledge, and felt increased satisfaction with their activity level and asthma control. Moe et al. (1992) noted that an intervention must be tailored

to the population being served. In their report on implementation of the program, "Open Airways" in an HMO setting, they found that parents intervened earlier when they noticed symptoms, felt more awareness about their child's asthma, and were knowledgeable and comfortable in dealing with their child's asthma. This researcher also found that parents enjoyed a better sense of what their children were going through and feeling about their asthma after participation in self-management training. Clark (1989) reported that the programs developed by NHLBI such as Open Airways, AIR POWER, Living with Asthma, and Airwise, are generally accepted to be effective in increasing asthma self-management skills. Results of this research would seem to support that assumption, at least in the case of AIR POWER.

Participants in A.C.T. for Kids, reported on by Lewis et al. (1984) demonstrated increases in knowledge and change in beliefs about asthma. Participants in this research showed increases in knowledge about asthma, but attitudes, or adjustment were not affected in a positive way.

Conceptual Framework

Regarding the Conceptual Framework for this study, it was found that knowledge about asthma was increased for both children and parents after attending AIR POWER. Some of the children reported gains in relaxation skills, and some parents reported having a better understanding of what it meant to their child to have asthma. Beliefs about having asthma may have been positively influenced, particularly self-efficacy, as measured by the increase in asthma self-management behaviors. This would also imply that changes in the child's access to and use of medications was affected, and adherence improved. Outcomes were improved PEFRs and a reduction in ER use. It is hoped that these outcomes are somewhat indicative of an improved quality of life for the children and their families.

Limitations on the Generalizability of the Findings

The small sample size consisting of 5 children and 5 parents, and lack of control group constitute significant limitations to the generalizability of the findings. Another limitation is that it was conducted on a very homogeneous sample of children and military parents receiving free health care at a military medical facility (Luke AFB Hospital). The group experienced no financial barrier to access to care, and were being cared for appropriately by pediatricians, with access to an allergist on a referral basis. A comment was made by one of the providers that perhaps because this population is accustomed to having all of their medical care needs met, they may be less motivated to commit to self-care activities. This question may constitute fertile ground for future research. Efforts were made by the researcher to limit threats to internal validity. The time elapsed between the pretest and the intervention was the same for all participants, and all participants received the posttest via the mail at approximately the same time.

Directions for Future Research

Future research should be encouraged to increase knowledge of those behaviors of children with asthma that facillitate their care and prevent exacerbations, increase knowledge of methods to improve the acquisition and practice of effective health promoting behaviors, and refine educational programs for maximum effectiveness in improving health behaviors and reducing morbidity and mortality. It would have been interesting to determine what, if any differences in asthma knowledge and attitude exisited between those who elected to participate in the program, and those who did not. Descriptive data concerning the characteristics of children and families who elect to participate in asthma self-management training, and those who do not, might be useful in planning educational interventions. It might also be useful to discover what sort of a program children with asthma want, and what incentives would be sufficiently enticing that people would make time in their busy lives to participate in an asthma self-management educational program. What are the barriers to participation in this type

program, and how might they be circumvented? Exploration of the attitudes of children with asthma, and how these attitudes might be influenced in a positive way to improve self-management behaviors should be conducted. Development of an effective self-management program for office, or outpatient use, that recognized the reality of time and staffing constraints might be extremely useful to those providing health care to children and their families with asthma.

Implications of the Findings for Practice

The findings of this research replicate to a certain extent those of previous research (Wilson-Pessano & Mellins, 1987), and suggest that utilization of an asthma self-management program, AIR POWER, may increase asthma knowledge and self-care behaviors. The advanced practice nurse, aware of the importance of asthma self-management is ideally situated to develop and implement such programs for children and their families with asthma. Lewis & Lewis (1987) point out that there exists strong support at the governmental level and among physician organizations for these programs. Perhaps it is time for nursing to become involved in their advocacy at the level of our professional nursing organizations, and locally as well.

It is important to recognize that children with asthma may have some very negative feelings about their disease, and allow them opportunity to openly discuss their feelings, and provide emotional support. Parents should be encouraged and supported in allowing their children to manage their asthma, with a clear understanding of when intervention by an adult or health care provider is required. Parents and children should be instructed in environmental control, and avoidance of asthma triggers. If it is not possible to organize a group intervention, education should take place at every visit for asthma. Children and families with asthma should be instructed in record-keeping, proper use of PEFR meters, medications, and devices such as spacers and nebulizers (Rachelefsky, 1995). All children should have a written management plan, to include what to do in an emergency (Rachelefsky, 1995; NAEP, 1991).

School teachers, nurses, and coaches need to be educated concerning asthma management, to include avoidance by the child of asthma triggers, and allowing children to keep their medications available for use as-needed. It should be made clear to them that children with asthma should not be singled out, and should participate to the best of their ability in the activities of the other children. Having their medication available for use at appropriate times is one way of helping normalize these children's lives, and avoiding dangerous exacerbations of their asthma.

Patient education is an area in which nurses excel. If it is not possible to implement an asthma education program as a group effort, the materials and methods may still be used for individual children and families, to allow them the benefits of improved self-mangement of their asthma.

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# Appendix A

Instruments

# AIRPOWER

## ENROLLMENT QUESTIONNAIRE FOR PARENTS

### Information About Child and Family

A. Name of child _____ (last / first / middle)

B. Your name _____ (last / first / middle)

C. Relationship to child _____

D. Child's date of birth _____ (month) / _____ (day) / _____ (year)

E. Sex _____(1) Male _____(2) Female

F. Child's ethnic identity (optional)

_____(1) Asian _____(4) Hispanic

_____(2) Black _____(5) Native American

_____(3) Caucasian _____(6) Other (specify: _____)

G. _____ Number of brothers and sisters

H. _____ Child's birth order (begin with "1" for first born)

I. How many people live in the child's home? (List the relationship to the child and the age of each person who lives in the home. Include step-relations, family, friends, housekeeper, etc. Do not give names.)

| Relationship to child | Age | Relationship to child | Age |
|---|---|---|---|
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ |

_____Total number of adults in home (16 and over)

_____Total number of children in home under 16 (including subject)

J. Does the child share a bedroom with anyone else?

_____(1) Yes _____(2) No

(continued)

K. Parents' occupations and levels of education. (List job titles and type of employer of parents or other persons who provide financial support for the child. **Circle** number corresponding to highest level of education for each person using codes in box below.)

| Relationship to child | Job title and type of company | Education |
|---|---|---|
| _____ | _____ | 1 2 3 4 5 6 |
| _____ | _____ | 1 2 3 4 5 6 |

1—less than high school graduate
2—high school graduate
3—trade school or junior college
4—some college (not graduate)
5—college graduate (completed 4-year degree program)
6—graduate degree (e.g., M.A., Ph.D., M.D., etc.)

## Asthma History

L. When was your child first treated by a doctor for asthma (i.e., wheezing and/or labored breathing that was *not* diagnosed as a cold, bronchitis, pneumonia, or other pulmonary disease)?

_____ year first treated for asthma _____ age first treated

M. When did your child first develop asthma symptoms (i.e., recurring episodes of labored breathing or wheezing)?

_____ year of first asthma symptoms _____ age at first symptoms

N. Do any of the child's close relatives have asthma? (List relationship to child; do not give names.)

_____ _____
_____ _____
_____ _____

## Information About Home Environment

1. Does anyone smoke at home? _____(1) Yes _____(2) No

2. If "yes," how many smoke at home? _____

3. Does the family have any furry pets? if so, do they stay in or outdoors?
_____(1) No furry pets
_____(2) Yes, kept outdoors only
_____(3) Yes, kept indoors occasionally or always

(continued)

4. If the child's bedroom has a carpet, what type of pad is under the carpet?
   _____(1) Jute or felt
   _____(2) Synthetic or other than jute or felt
   _____(3) Don't know

5. What type of mattress does the child sleep on?
   _____(1) Cotton batting
   _____(2) Spring & synthetic construction (polyester)
   _____(3) Foam w/o cover
   _____(4) Kapok w/o cover
   _____(5) Other
   _____(6) Don't know

6. What type of pillow does the child use?
   _____(1) Synthetic
   _____(2) Down or feather
   _____(3) None
   _____(4) Don't know

7. What type of blanket, comforter, or quilt is on the child's bed?
   _____(1) Synthetic material
   _____(2) Wool or down
   _____(3) Other material
   _____(4) Don't know

8. Are there any stuffed animals in the child's room?
   _____(1) Yes _____(2) No

9. Are there any houseplants in the child's room?
   _____(1) Yes _____(2) No

## Current Asthma Problems

10. About how often did your child have an ***asthma attack*** during the last *3* ***months?*** An asthma attack is any time when your child reported asthma-related discomfort such as wheezing and chest tightness. (Check one)
    _____(1) No attacks in last 3 months
    _____(2) Only once or twice
    _____(3) About three times
    _____(4) Six to nine times
    _____(5) About 12 times
    _____(6) Several times each week for the last 3 months
    _____(7) Nearly every day for the last 3 months

11. How many days did your child miss from school because of asthma during the last *3* ***months?***
    _____ + _____ (enter "0" if none)
    Full Days  Half Days

12. How many days did your child spend in bed because of asthma during the last *3* ***months?***
    _____ + _____ (enter "0" if none)
    Full Days  Half Days

(continued)

13. Does asthma limit the kinds of things your child can do?
_____(1) No _____(2) Yes

14. If "yes," indicate areas of the child's life that are restricted or in some way affected by asthma:
_____(1) Diet
_____(2) Exercise and sports
_____(3) Social activities
_____(4) Schoolwork
_____(5) Having pets
_____( 6) Furnishings in room
_____( 7) Travel or vacation
_____( 8) Work (chores, part-time job, etc.)
_____( 9) Sleep
_____(10) Other (specify: _____)

15. What kind of P.E. program does your child have? (Check one)
_____(1) Regular P.E.
_____(2) Limited P.E. or special classes
_____(3) P.E. is not required or offered at child's school
_____(4) No P.E. because of asthma

## Current Asthma Treatment

16. Is your child now taking any medicine for asthma, including over-the-counter drugs or nebulizers?
_____(1) Yes _____(2) No

17. If "yes," what medicines and on what schedule?

| **Name or type of drug** | **How often taken** (number times per day)* |
|---|---|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |

*If child is to take medicine only when having symptoms, write "as needed."

18. Is your child receiving allergy injections? (Check one)
_____(1) Yes _____(2) No
If "yes," how often? (Check one)
_____(1) Every other week or less _____(3) Twice per week
_____(2) Once per week
If "yes," what time of year? (Check one)
_____(1) Fall _____(4) Summer
_____(2) Winter _____(5) All year round
_____(3) Spring

(continued)

19. If you know, check the substances or groups of substances to which your child is allergic.

| | | |
|---|---|---|
| _____( 1) Grass pollens | _____( 8) Cattle hair | _____(15) Housedust |
| _____( 2) Weed pollens | _____( 9) Horse hair | _____(16) Molds |
| _____( 3) Tree pollens | _____(10) Rabbit hair | _____(17) Drugs |
| _____( 4) Cotton linters | _____(11) Hemp | (specify: _____) |
| _____( 5) Feathers and down | _____(12) Kapok | _____(18) Foods |
| _____( 6) Cat hair | _____(13) Wool | (specify: _____) |
| _____( 7) Dog hair | _____(14) Jute | _____(19) No known allergies |

20. Have any of these substances caused your child to have an **asthma attack*** in the past?

_____(1) No

_____(2) Yes

_____(3) Don't know

*An "asthma attack" is an episode of labored breathing requiring medical treatment and/or medication

21. Check any of the following that have caused your child to have an asthma attack.

| | |
|---|---|
| _____(1) Smoke, fumes, or air pollution | _____(5) Anger |
| _____(2) Hot, cold, or damp weather, or change in weather | _____(6) Excitement or laughing |
| _____(3) Physical activity | _____(7) A cold or infection |
| _____(4) Fear or worry | _____(8) Some other reason(s) (specify: _____) |

## Use of Medical Facilities

22. Was your child hospitalized for asthma or breathing problems during the last *3 months*?

_____(1) No _____(2) Yes

23. If "yes," how many times and how long each time?

_____ Number of hospitalizations

1st hospitalization: _____Days 3rd hospitalization: _____Days

2nd hospitalization: _____Days

24. How many times did your child see a physician because of asthma or breathing problems during the last *3 months*? (Do not count hospitalizations listed above or visits for allergy shots only.)

_____ Number of physician visits

25. If any physician visits, by whom was the child seen?

| | |
|---|---|
| _____ Pediatrician or family physician | _____ Emergency room or emergency clinic physician |
| _____ Allergist | _____ Other physician, e.g., pulmonary specialist (specify: _____) |

26. If any physician visits, how many required emergency treatment (i.e., a shot of epinephrine or something similar; intravenous aminophylline, hydrocortisone or other steroid; IPPB with bronchodilator)?

_____ Number of emergency visits

# AIRPOWER

## MEDICAL RECORDS SUMMARY FORM

Regular Physician _____ Summary Prepared by _____

Date _____

**Demographic Data**

Name _____

Sex: _____ Male _____ Female

Record Number _____

Age _____ Date of Birth _____

Parents' Names _____

Address _____

_____

Phone: Home _____ Work _____

**Medical Charts Reviewed**

_____ Office

_____ Clinic

_____ Outpatient

_____ Hospital

_____ Other (specify: _____)

**Medical Information**

**Established Diagnosis of Asthma**

_____ No _____ Yes (Specify: _____

_____ )

**Most Recent Treatment for Asthma**

_____
month/day/year

_____
physician

_____
place of treatment

**Number Emergency Visits in Past 3 Months**

Physician's office: _____ Asthma

_____ Other

Emergency room or acute care facility:

_____ Asthma

_____ Other

**Number Nonemergency Physician Visits in Past 3 Months**

_____ Asthma

_____ Other

**Number Hospitalizations in Past 3 Months**

_____ Asthma (total days _____)

_____ Other (total days _____)

(Specify diagnosis: _____)

**Currently Prescribed Asthma Medication**

| Daily | Acute | p.r.n. | |
|---|---|---|---|
| ___ | ___ | ___ | oral theophylline |
| ___ | ___ | ___ | oral sympathomimetic |
| ___ | ___ | ___ | inhalent sympathomimetic |
| ___ | ___ | ___ | cromolyn sodium |
| ___ | ___ | ___ | beclomethasone (Vanceril) |
| ___ | ___ | ___ | oral steroid (prednisone) |
| ___ | ___ | ___ | other (specify: _____ _____) |

**Injection Therapy**

_____ No

_____ Yes (_____ date last injection)

**Other Relevant Chart Notations** (Results of allergy tests, PFT's, etc.)

# AIRPOWER

## ASTHMA INVENTORY FOR CHILDREN

**Part 1**

Please circle the letter in front of the *best* answer to the following questions.

1. Steve is allergic to dogs. He should
   A. not keep a dog.
   B. keep his dog and take extra medicine.
   C. only play with dogs at his friends' houses.
   D. sleep with his dog in the same room to build up resistance.

2. Cold air makes Sandra wheeze. To help prevent asthma attacks she should
   A. stay in the house all winter.
   B. take more of her asthma medicine.
   C. sleep with the windows open in the winter.
   D. wear a scarf around her mouth and nose when it's cold.

3. Students who have asthma should
   A. choose quiet, less active games.
   B. avoid all sports because exercise causes coughing.
   C. try to keep up with their friends when running laps.
   D. do as much exercise as they can, but tell their P.E. teacher when they need to rest.

4. Angela has had asthma attacks when she gets upset. If other children tease her, she should
   A. keep her feelings to herself.
   B. pretend she's wheezing so they will quit teasing her.
   C. talk about the problem with her teacher or her parents.
   D. tell them she's going to have an asthma attack if they don't stop.

5. John's doctor gave him asthma medicine to take three times a day all year long. He should
   A. take it at regular times when it is convenient.
   B. take it only when he feels an attack coming on.
   C. take it at regular times even if it is inconvenient.
   D. take it at different times each day to build up resistance.

6. When John isn't having asthma symptoms, he should
   A. relax and enjoy himself.
   B. take his medicine less frequently.
   C. take advantage of the opportunity to do such things as wash his dog or his friend's dog.
   D. experiment with such things as foods or physical activities to find out which ones bring on an attack.

7. When you have done the things that usually help you, and your wheezing and tightness are getting worse, you should
   A. breathe quickly and shallowly.
   B. insist on going to your doctor immediately.
   C. let your parents know that you need some help.
   D. try a medicine that has worked well for a friend.

8. You should remember to have your prescription for asthma filled
   A. when you run out.
   B. before you run out.
   C. when you are really sick.
   D. each time that you go to the doctor.

9. In trying to control wheezing or asthma attacks, all of the following actions are okay *EXCEPT*
   A. taking a hot shower.
   B. drinking lots of water.
   C. deciding to manage the attack on your own.
   D. acting like your asthma problem doesn't exist.

10. When symptoms of asthma first start, it is a good idea to
   A. call your doctor.
   B. try to take it easy.
   C. breathe rapidly to get more air.
   D. take twice as many pills as usual.

11. Judy only has symptoms in the fall and spring. She is probably allergic to
   A. grass.
   B. animal fur.
   C. rainy weather.
   D. cigarette smoke.

12. John's doctor gave him an inhaler for his asthma. He should use it
   A. only at night.
   B. three times every day.
   C. only when he first starts to have symptoms.
   D. according to the schedule his doctor gave him.

(continued)

**Part 2**

Please circle the number that best describes how often you do each thing listed below.

| | Never | Once in a while | About half of the time | Most of the time | Always |
|---|---|---|---|---|---|
| 1. I stay away from things that cause breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 2. When having trouble breathing, I get away from what's causing it. | 1 | 2 | 3 | 4 | 5 |
| 3. I do breathing exercises when I have trouble breathing. | 1 | 2 | 3 | 4 | 5 |
| 4. I try to make myself relax when I have trouble breathing. | 1 | 2 | 3 | 4 | 5 |
| 5. I try to get my mind off my breathing when I start to have breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 6. I try something else when I have trouble breathing and the first treatment doesn't work. | 1 | 2 | 3 | 4 | 5 |
| 7. I seek help from other people at the first sign of breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 8. I let friends talk me into doing things that could cause breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 9. If my medicine makes me feel sick, I tell my parents or my doctor. | 1 | 2 | 3 | 4 | 5 |
| 10. I stay calm when I am having breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 11. I let adults make me do things that could cause breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 12. If I have an asthma attack at night, I take it easy the next day. | 1 | 2 | 3 | 4 | 5 |
| 13. I tell my friends that I have asthma. | 1 | 2 | 3 | 4 | 5 |
| 14. I stop playing and take it easy when I start to have breathing problems. | 1 | 2 | 3 | 4 | 5 |
| **Answer THIS QUESTION if you are supposed to receive allergy shots.** | | | | | |
| 15. I forget to get allergy shots on schedule. | 1 | 2 | 3 | 4 | 5 |
| **Answer the THREE QUESTIONS below if you have any prescribed asthma medications.** | | | | | |
| 16. I keep asthma medicine handy at home, school, and when away from home. | 1 | 2 | 3 | 4 | 5 |
| 17. I take the correct medicine when breathing problems begin. | 1 | 2 | 3 | 4 | 5 |
| 18. I take the correct medicine on my prescribed schedule. | 1 | 2 | 3 | 4 | 5 |

## Part 3

Please circle T (true) or F (false) to describe your feelings.

| | True | False |
|---|---|---|
| 1. I feel that I can take care of my asthma. | T | F |
| 2. I'm embarrassed if other children know I have asthma. | T | F |
| 3. I really hate having asthma. | T | F |
| 4. I worry about having asthma. | T | F |
| 5. Asthma keeps me from doing the things I want to do. | T | F |
| 6. My parents worry about me having an asthma attack. | T | F |
| 7. I feel sad about having asthma. | T | F |
| 8. People treat me better when I have an asthma attack. | T | F |
| 9. I feel that having asthma is my own fault. | T | F |
| 10. I don't like having to take medicine for my asthma. | T | F |
| 11. If people tease me about my asthma, I get angry. | T | F |
| 12. It's important for me to tell my teachers that I have asthma. | T | F |

## Part 4

Please write your answer in the space under each question.

1. Name three things that cause you to have asthma symptoms.

   _____

   _____

   _____

2. List the medicines that you are supposed to take regularly, even when you have *no* asthma symptoms.

| Name of Medicine | How much should you take | How often should you take it |
|---|---|---|
| | | |
| | | |
| | | |

3. List the medicines that you are supposed to take when you have wheezing or tightness in the chest.

| Name of Medicine | How much should you take | How often should you take it |
|---|---|---|
| | | |
| | | |

4. When did you last have an asthma attack? _____

   Why did it happen?

   _____

   _____

   What did you do to help yourself?

   _____

   _____

# AIRPOWER

## ASTHMA INVENTORY FOR PARENTS

**Part 1**

Please circle the letter in front of the *best* answer to the following questions.

1. Steve is allergic to dogs. He should
   A. not keep a dog.
   B. keep his dog and take extra medicine.
   C. only play with dogs at his friends' houses.
   D. sleep with his dog in the same room to build up resistance.

2. Cold air makes Sandra wheeze. To help prevent asthma attacks she should
   A. stay in the house all winter.
   B. take more of her asthma medicine.
   C. sleep with the windows open in the winter.
   D. wear a scarf around her mouth and nose when it's cold.

3. Students who have asthma should
   A. choose quiet, less active games.
   B. avoid all sports because exercise causes coughing.
   C. try to keep up with their friends when running laps.
   D. do as much exercise as they can, but tell their P.E. teacher when they need to rest.

4. Angela has had asthma attacks when she gets upset. If other children tease her, she should
   A. keep her feelings to herself.
   B. pretend she's wheezing so they will quit teasing her.
   C. talk about the problem with her teacher or her parents.
   D. tell them she's going to have an asthma attack if they don't stop.

5. John's doctor gave him asthma medicine to take three times a day all year long. He should
   A. take it at regular times when it is convenient.
   B. take it only when he feels an attack coming on.
   C. take it at regular times even if it is inconvenient.
   D. take it at different times each day to build up resistance.

6. When John isn't having asthma symptoms, he should
   A. relax and enjoy himself.
   B. take his medicine less frequently.
   C. take advantage of the opportunity to do such things as wash his dog or his friend's dog.
   D. experiment with such things as foods or physical activities to find out which ones bring on an attack.

7. When your child has done the things that usually help and the wheezing and tightness are getting worse, he/she should
   A. breathe quickly and shallowly.
   B. let you know that he/she needs some help.
   C. insist on going to the doctor immediately.
   D. try a medicine that has worked well for a friend.

(continued)

8. Your child's prescription for asthma should be filled
   A. when it runs out.
   B. before it runs out.
   C. when he/she is really sick.
   D. each time that he/she goes to the doctor.

9. In trying to control wheezing or asthma attacks, all of the following actions are okay for your child *EXCEPT*
   A. taking a hot shower.
   B. drinking lots of water.
   C. deciding to manage the attack on his/her own.
   D. acting like his/her asthma problem doesn't exist.

10. When symptoms of asthma first start, it is a good idea for your child to
    A. call your doctor.
    B. try to take it easy.
    C. breathe rapidly to get more air.
    D. take twice as many pills as usual.

11. Judy only has symptoms in the fall and spring. She is probably allergic to
    A. grass.
    B. animal fur.
    C. rainy weather.
    D. cigarette smoke.

12. John's doctor gave him an inhaler for his asthma. He should use it
    A. only at night.
    B. three times every day.
    C. only when he first starts to have symptoms.
    D. according to the schedule his doctor gave him.

**Part 2**

Please circle the number corresponding to the word that best describes how frequently your child does each thing listed below.

| | Never | Once in a while | About half of the time | Most of the time | Always |
|---|---|---|---|---|---|
| 1. Stays away from things that cause breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 2. When having trouble breathing, gets away from what's causing it. | 1 | 2 | 3 | 4 | 5 |
| 3. Does breathing exercises when having trouble breathing. | 1 | 2 | 3 | 4 | 5 |
| 4. Tries to make self relax when having trouble breathing. | 1 | 2 | 3 | 4 | 5 |
| 5. Tries to get mind off his/her breathing when starts to have breathing problems. | 1 | 2 | 3 | 4 | 5 |

(continued)

| | Never | Once in a while | About half of the time | Most of the time | Always |
|---|---|---|---|---|---|
| 6. Tries something else when having trouble breathing and first treatment doesn't work. | 1 | 2 | 3 | 4 | 5 |
| 7. Seeks help from other people at the first sign of breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 8. Lets friends talk him/her into doing things that could cause breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 9. Reports side effects of medicine to parents or physician. | 1 | 2 | 3 | 4 | 5 |
| 10. Stays calm when having breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 11. Lets adults make him/her do things that could cause breathing problems. | 1 | 2 | 3 | 4 | 5 |
| 12. Takes it easy the day following a night attack of asthma. | 1 | 2 | 3 | 4 | 5 |
| 13. Tells friends that he/she has asthma. | 1 | 2 | 3 | 4 | 5 |
| 14. Stops playing and takes it easy when having breathing problems. | 1 | 2 | 3 | 4 | 5 |
| **Answer THIS QUESTION if your child is supposed to receive allergy shots.** | | | | | |
| 15. Forgets to get allergy shots on schedule. | 1 | 2 | 3 | 4 | 5 |
| **Answer the THREE QUESTIONS below if the child has any prescribed asthma medications.** | | | | | |
| 16. Keeps asthma medicine handy at home, school, and when away from home. | 1 | 2 | 3 | 4 | 5 |
| 17. Takes the correct medicine when breathing problems begin. | 1 | 2 | 3 | 4 | 5 |
| 18. Takes the correct medicine on the prescribed schedule. | 1 | 2 | 3 | 4 | 5 |

(continued)

## Part 3

Please circle T (true) or F (false) to describe how you believe your child feels about asthma.

| | True | False |
|---|---|---|
| 1. Feels able to take care of his/her asthma. | T | F |
| 2. Is embarrassed if other children know he/she has asthma. | T | F |
| 3. Really hates having asthma. | T | F |
| 4. Worries about having asthma. | T | F |
| 5. Feels that asthma interferes with doing the things he/she wants to do. | T | F |
| 6. Thinks that parents worry about his/her having an asthma attack. | T | F |
| 7. Feels sad about having asthma. | T | F |
| 8. Feels that people treat him/her better when he/she is having an asthma attack. | T | F |
| 9. Feels that having asthma is his/her own fault. | T | F |
| 10. Doesn't like having to take asthma medicine. | T | F |
| 11. If teased about asthma, gets angry. | T | F |
| 12. Feels it's important to tell teachers that he/she has asthma. | T | F |

## Part 4

Circle the number corresponding to the word that best describes how often the following things occur.

| | Never | Once in a while | About half of the time | Most of the time | Always |
|---|---|---|---|---|---|
| 1. I am very concerned about my child's asthma. | 1 | 2 | 3 | 4 | 5 |
| 2. I avoid or soften disciplining my child because of the asthma. | 1 | 2 | 3 | 4 | 5 |
| 3. Caring for my child's asthma is a drain on my time and/or energy. | 1 | 2 | 3 | 4 | 5 |
| 4. I resent the fact that my child has asthma. | 1 | 2 | 3 | 4 | 5 |
| 5. My child's asthma has been a cause of tension in our home. | 1 | 2 | 3 | 4 | 5 |
| 6. My child's asthma interferes with the recreational and social activities of the family as a whole. | 1 | 2 | 3 | 4 | 5 |
| 7. My child's asthma interrupts my own sleep and/or that of my spouse. | 1 | 2 | 3 | 4 | 5 |
| 8. I am afraid to let my child do some things because of asthma. | 1 | 2 | 3 | 4 | 5 |
| 9. My child's asthma interferes with our family's routine activities. | 1 | 2 | 3 | 4 | 5 |

# AIRPOWER

## WEEKLY SESSION REPORT

**Session #_____**

Homework assignment: _____

_____

How many participants successfully completed assignment?

_____ of _____ participants

Obstacles reported by participants in completing assignment: _____

_____

_____

Was assignment considered beneficial by participants in self-management?

Yes _____ Partially _____ No _____

How did assignment help self-management efforts? _____

_____

_____

_____

Suggested program modifications: _____

_____

_____

_____

# AIRPOWER

## EXIT QUESTIONNAIRE FOR CHILDREN

1. Has the AIR POWER program been helpful to you? If so, how?

2. Have you made any changes in how you handle asthma because of the program? If so, what is the most important change?

3. Have there been any changes in how your parents handle your asthma since the program began? If so, indicate what.

4. How could the program be made better?

# AIRPOWER

## EXIT QUESTIONNAIRE FOR PARENTS

1. Has the AIR POWER program been helpful to you and/or your child? If so, in what ways?

2. Have there been any specific changes within the past month in how your child handles asthma problems?

3. Have there been any changes within the past month in how you and/or other members of your family handle your child's asthma?

4. In what ways could the program be made more worthwhile?

Appendix B

Scoring Information

# ASTHMA INVENTORY: SCORING INSTRUCTIONS

Answer keys and scoring instructions for the parents' asthma inventory and the children's asthma inventory are included in this section. The four parts of each inventory yield slightly different kinds of information.

**Part 1. Knowledge test.** The child's knowledge test measures the **child's** knowledge of asthma; the parents' test measures the **parents'** knowledge.

**Part 2. Behavior report.** The behavior report for the child is a self-report of his/her self-management behaviors; the behavior report for the parents is a parental report of the **child's** behavior. Thus, the two can be compared against one another for discrepancies or concurrence.

**Part 3. Attitude inventory.** The attitude inventory assesses the child's attitudes about asthma; the parent inventory assesses the parents' perception of the child's attitudes toward having asthma. Thus, the two can be compared for similarities and differences.

**Part 4. Self-care: child's.** In the child's inventory, part 4 provides some information about the child's knowledge of those situations/substances which precipitate bronchospasm and provides brief anecdotal reports of the child's last asthma attack.

**Part 4. Impact of asthma on family: parents'.** In the parents' inventory, part 4 provides information on the parents' attitudes toward the child's asthma, particularly as it impacts on the family.

## Answer Keys Scoring

Section I provides answers and scoring instructions for the various parts of the asthma inventory. Part II provides a means of scoring each part of the inventory according to four concept areas: prevention, intervention, medication, and adjustment. Part III is a summary sheet, onto which scores for all parts of the inventory can be summarized.

It should be noted that no norms are yet available for the inventory; hence scores can only be used as a general guide in assessing a particular child's performance, suggesting areas in which self-management skills may be weak and thus in need of strengthening. Reliability coefficients of scores on the inventory have not yet been determined.

# I. Answer Key

**Part 1: Knowledge Test** (1 point for each correct answer)

| | | | |
|---|---|---|---|
| 1. A | 4. C | 7. C | 10. B |
| 2. D | 5. C | 8. B | 11. A |
| 3. D | 6. A | 9. D | 12. D |

**Part 2: Behavior Report** (1 to 5 points for each answer)

| Item | Never | Once in a while | About half the time | Most of the time | Always |
|---|---|---|---|---|---|
| 1. | 1 | 2 | 3 | 4 | 5 |
| 2. | 1 | 2 | 3 | 4 | 5 |
| 3. | 1 | 2 | 3 | 4 | 5 |
| 4. | 1 | 2 | 3 | 4 | 5 |
| 5. | 1 | 2 | 3 | 4 | 5 |
| 6. | 1 | 2 | 3 | 4 | 5 |
| 7. | 5 | 4 | 3 | 2 | 1 |
| 8. | 5 | 4 | 3 | 2 | 1 |
| 9. | 1 | 2 | 3 | 4 | 5 |
| 10. | 1 | 2 | 3 | 4 | 5 |
| 11. | 5 | 4 | 3 | 2 | 1 |
| 12. | 1 | 2 | 3 | 4 | 5 |
| 13. | 1 | 2 | 3 | 4 | 5 |
| 14. | 1 | 2 | 3 | 4 | 5 |
| *15. | 5 | 4 | 3 | 2 | 1 |
| *16. | 1 | 2 | 3 | 4 | 5 |
| *17. | 1 | 2 | 3 | 4 | 5 |
| *18. | 1 | 2 | 3 | 4 | 5 |

*If child is not on injection therapy or is not receiving asthma medication, these items are not scored.

**Part 3: Attitude Inventory** (1 point for each correct answer)

| | | | |
|---|---|---|---|
| 1. T | 4. F | 7. F | 10. F |
| 2. F | 5. F | 8. F | 11. F |
| 3. F | 6. F | 9. F | 12. T |

### Part 4: Self-Care—Children's Inventory

This part of the child's inventory is not scored, but it provides some important information to the instructor regarding the child's perceptions of his/her asthma management. It might be helpful to summarize the information given by the child, place it on an index card, and refer to it during the sessions, especially during discussions.

**Question 1.** "Name three things that cause you to have asthma symptoms." This provides information on those substances/situations that the child feels precipitate episodes of bronchospasm. Examples of possible responses include **allergens** (grass, weeds, housedust, pets, etc.), **irritants** (cigarette smoke, cold air, smog, etc.), **emotions** (getting angry, tense, nervous, etc.), **upper respiratory infections** (colds, flu, etc.), and/or **overexertion** (running hard, certain sports, etc.). Some children may report bronchospasm associated with **aspirin**, common in a very small subset of asthmatics, or with certain foods to which they are allergic such as chocolate.

(continued)

Many children are quite accurate in their reports of precipitants; others may report only general information that may or may not be correct. Accuracy of the child's report can be checked against the parent's report in the Enrollment Questionnaire or against the child's medical record. In conducting session #3, the instructor might want to compare the information obtained here with the information generated by the child's working through the exercise on identifying personal precipitants.

**Question 2.** "List the medicines that you are supposed to take regularly, even when you have no asthma symptoms." This provides information on the child's perception of his/her medical regimen. Some children will know the names of their medications; many will only be able to describe a particular pill or liquid. Seldom will a child know the dosage; generally he/she will report the number of pills taken. Most children will be able to tell you how many times they take their medicine per day. Children who do not take routine asthma medications, of course, should leave this question blank, or write in "none."

The accuracy of the child's report can be checked against the medical records and/or the parents' Enrollment Questionnaire. If you note a discrepancy between the child's report and the medical records, you should correct the discrepancy when helping the child complete his/her medical regimen in session #1. **It is very important that accurate information be entered on the medication schedule** in booklet #1.

**Question 3.** "List the medicines that you are supposed to take when you have wheezing or tightness in the chest." This provides information on any special medication that has been prescribed for an acute asthmatic episode. In many cases, the child will have none, or will have been prescribed some type of inhaled sympathomimetic. As with question 2, this should be checked against the medical record for accuracy.

**Question 4.** "When did you last have an asthma attack?" "Why did it happen?" "What did you do to help yourself?" This question provides an anecdotal report of the child's last asthma attack and his/her behavior during the attack. The information will be helpful when discussing the prevention plan in session #4.

**Part 4: Impact on Family—Parents' Inventory** (1 to 5 points for each answer)

| Item | Never | Once in a while | About half the time | Most of the time | Always |
|---|---|---|---|---|---|
| 1. | 5 | 4 | 3 | 2 | 1 |
| 2. | 5 | 4 | 3 | 2 | 1 |
| 3. | 5 | 4 | 3 | 2 | 1 |
| 4. | 5 | 4 | 3 | 2 | 1 |
| 5. | 5 | 4 | 3 | 2 | 1 |
| 6. | 5 | 4 | 3 | 2 | 1 |
| 7. | 5 | 4 | 3 | 2 | 1 |
| 8. | 5 | 4 | 3 | 2 | 1 |
| 9. | 5 | 4 | 3 | 2 | 1 |

Note: Scoring set up so as to yield high score for least negative impact on family and low score for high negative impact.

# II. Concept Scores

*Instructions*: Each item in the asthma inventory is keyed to one self-management concept area: prevention, intervention, medication, or adjustment. Once each part has been scored, enter the numerical score for each item in the appropriate concept column, as indicated by the ***underlined*** space. Then enter scores for each part onto the summary score sheet to get a profile on the child's performance on the inventory. Do the same for the parents' version of the inventory.

**Part 1: Knowledge Test** (Child)

| | Prevention | Intervention | Medication | Adjustment |
|---|---|---|---|---|
| 1. | _____ | | | |
| 2. | _____ | | | |
| 3. | | | | |
| 4. | | | | _____ |
| 5. | | | | _____ |
| 6. | | | _____ | |
| 7. | | _____ | | _____ |
| 8. | | | _____ | |
| 9. | | _____ | | |
| 10. | | _____ | | |
| 11. | _____ | | | |
| 12. | | | _____ | |
| Total | _____ /3 | _____ /3 | _____ /3 | _____ /3 = _____ /12 |

**Part 1: Knowledge Test** (Parent)

| | Prevention | Intervention | Medication | Adjustment |
|---|---|---|---|---|
| 1. | _____ | | | |
| 2. | _____ | | | |
| 3. | | | | |
| 4. | | | | _____ |
| 5. | | | | _____ |
| 6. | | | _____ | |
| 7. | | _____ | | _____ |
| 8. | | | _____ | |
| 9. | | _____ | | |
| 10. | | _____ | | |
| 11. | _____ | | | |
| 12. | | | _____ | |
| Total | _____ /3 | _____ /3 | _____ /3 | _____ /3 = _____ /12 |

**Part 2: Behavior Report** (Child)

| | Prevention | Intervention | Medication | Adjustment |
|---|---|---|---|---|
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |
| 5. | | | | |
| 6. | | | | |
| 7. | | | | |
| 8. | | | | |
| 9. | | | | |
| 10. | | | | |
| 11. | | | | |
| 12. | | | | |
| 13. | | | | |
| 14. | | | | |
| 15. | | | | |
| 16. | | | | |
| 17. | | | | |
| 18. | | | | |
| Total | /15* | /35 | /20* | /20 = /90* |

*If child is not on injection therapy or is not taking asthma medication, adjustments in scoring are required.

**Part 2: Behavior Report** (Parent's report of child's behavior)

| | Prevention | Intervention | Medication | Adjustment |
|---|---|---|---|---|
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |
| 5. | | | | |
| 6. | | | | |
| 7. | | | | |
| 8. | | | | |
| 9. | | | | |
| 10. | | | | |
| 11. | | | | |
| 12. | | | | |
| 13. | | | | |
| 14. | | | | |
| 15. | | | | |
| 16. | | | | |
| 17. | | | | |
| 18. | | | | |
| Total | /15* | /35 | /20* | /20 = /90* |

*If child is not on injection therapy or is not taking asthma medication, adjustments in scoring are required.

(continued)

**Part 3: Attitude Inventory** (Child)

| | Prevention | Intervention | Medication | Adjustment |
|---|---|---|---|---|
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |
| 5. | | | | |
| 6. | | | | |
| 7. | | | | |
| 8. | | | | |
| 9. | | | | |
| 10. | | | | |
| 11. | | | | |
| 12. | | | | |
| **Total** | NA | NA | NA | /12 = /12 |

**Part 3: Attitude Inventory** (Parent's report of child's attitude)

| | Prevention | Intervention | Medication | Adjustment |
|---|---|---|---|---|
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |
| 5. | | | | |
| 6. | | | | |
| 7. | | | | |
| 8. | | | | |
| 9. | | | | |
| 10. | | | | |
| 11. | | | | |
| 12. | | | | |
| **Total** | NA | NA | NA | /12 = /12 |

**Part 4: Self-Care** (Child inventory)
Not scored

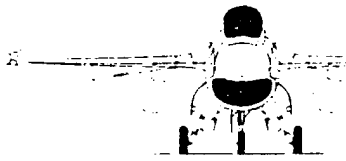
**Part 4: Impact on Family** (Parent)

| | Prevention | Intervention | Medication | Adjustment |
|---|---|---|---|---|
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |
| 5. | | | | |
| 6. | | | | |
| 7. | | | | |
| 8. | | | | |
| 9. | | | | |
| **Total** | NA | NA | NA | /45 = /45 |

(continued)

Appendix C

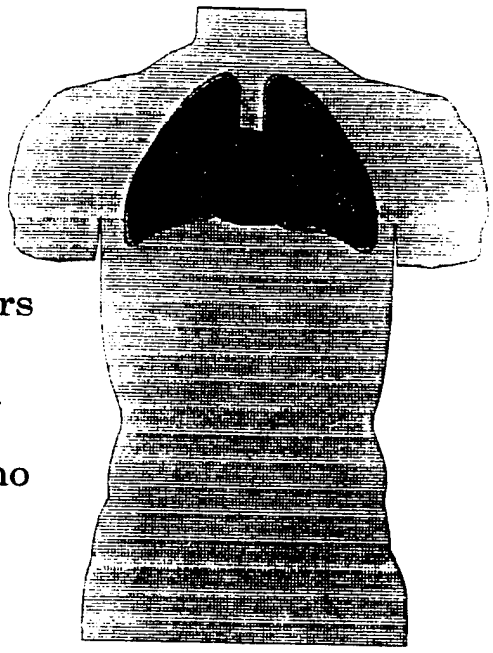
AIR POWER Flyer



# AIR POWER ASTHMA SELF MANAGEMENT COURSE

# Asthma Season is Here

Learn how you and your children can manage asthma to reduce Emergency Room visits and lost days from school!



Class begins Nov 1, 1994 at 1800 hrs in the main conference room of the 56th MED GP (base hospital).

Class will meet every Tuesday for 4 weeks.

**FREE** Peak Flow Meter to those who complete this program.

## For additional information and to register: Contact Pediatric Clinic 856-7571

Appendix D

Parents' Information Letter

and Consent Form

DEAR PARENTS:

I am a registered nurse, and currently a graduate student under the direction of Dr. Frances Thurber, in the College of Nursing at Arizona State University. I am conducting a study with the assistance of Luke Air Force Base Hospital Pediatric Clinic physicians and nurse practitioners in order to see if we can help children with asthma and their families learn how to manage their asthma better. If you agree to be a part of this study, we hope that we can teach you and your child management skills that will help your family cope better with asthma. Better asthma management can mean an improved quality of life with fewer school absences, emergency room visits, and family disruptions.

The program we will be using is called AIR POWER. This is a program which was developed for families and children with asthma to help them learn the skills they need to manage asthma better. If we find that this program is useful and helps children stay healthier, we hope to offer it in the future to other children and families with asthma.

The program will consist of five weekly sessions lasting about an hour each time, and will be held in the Luke AFB Hospital Conference Room and/or Dining Hall. I will ask you and your child to complete some questionnaires. These questionnaires won't take much time, and will provide us with important information about how your child feels about having asthma, how your child is currently managing asthma, and the impact asthma has on your family. I will ask you to complete the same questionnaires after the program is complete, in order to evaluate any impact the program may have had. I will also review your child's chart before and after the program in order see what medications your child is on, tabulate visits to the emergency room and clinic for asthma attacks, and check theophylline levels (if applicable to your child).

Participation in this study is totally voluntary, and you or your child may withdraw at any time with no penalty or change in the quality of treatment you receive. There are no known risks associated with participation in this program, which is supported and distributed by the National Heart, Lung, and Blood Institute. If you think you and your child would be interested in participating in this program, please contact the Luke AFB Pediatric Clinic at 856-7571. Your signature on the attached form indicates permission for yourself and child to participate. If you have any questions at any time, please feel free to contact me at my home at 877-1326.

Sincerely,

Lara M. Runger, CAPT, USAF NC

Dear Parent:

I am a graduate student under the supervision of Dr. Frances Thurber in the College of Nursing at Arizona State University. I am conducting a research study entitled "The Effects of Family Coping and Asthma Self-Management Training on Adherence to Therapeutic Regimens in Children with Asthma". The purpose of this research is to see if it is possible to help children with asthma learn skills they need to take care of themselves by providing group education to them and their families.

You and your child's participation will involve attending asthma care training sessions for one hour a week for four weeks. In order to allow us to evaluate the effectiveness of the program, we will ask you to fill out several questionnaires before the program begins, and then again, at the end. This will take approximately 30 minutes of your time. You and your child's participation is voluntary. If you received notification of this course in a letter from your school nurse or physician, they will not know whether you elected to participate or not. If you choose not to participate or to withdraw from the study at any time, it will not affect your child's treatment in any way. The results of this research study may be published, but your's and your child's name will not be used.

Although there may be no direct benefit to your child, the possible benefit of participation is better health with fewer asthma attacks.

If you have any questions concerning the research study or your child's participation in this study, please call me at 877-1326, or Dr. Thurber at 965-7230.

Sincerely,

Lara M. Runger

* * * * * * * * * * * *

I give my consent for myself, and my child _____, to participate in the above study, and also give permission for Lara Runger to review my child's medical chart.

Date_____ Signature_____

If you have any questions about your rights as a participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through Carol Jablonski, at (602) 965-6788.

Appendix E

Childrens Assent Form

My name is Lara Runger and I am a nurse doing a project to see if we can teach children and parents skills to help them take care of their asthma better. We believe that taking better care of your asthma will help you feel better and do more of the things you would like to do.

If you agree to be in this project, I will ask you to fill out some short questionnaires that will help me understand what you know about asthma, and how having asthma makes you feel. There are no right or wrong answers to any of the questions. I will also take a look at your health record to see what sort of treatments you have had for asthma in the past. The children and parents that decide to be part of this project will meet with the teachers five times for about an hour each time. When this project is over, I will ask you to fill out the questionnaires again.

Information from your record and about you will not be mentioned to other people, or in the report I will write about the project.

You don't have to be a part of this project if you don't want to, and may stop at any time. You don't have to answer any questions you don't want to. If you have any questions about any thing please feel free to ask me. You won't be treated any differently if you decide not to be a part of this project. Signing this paper means that you would like to be a part of this project, and answer the questions.

I, _____, understand that my parents have given permission for me to take part in a project about asthma, under the direction of Lara Runger.

I am taking part because I want to. I have been told that I can stop at any time I want to and it will be okay if I want to stop.

Signature_____

# Appendix F

## Public Domain Statement

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