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THE EVALUATION OF A HOME VISITATION PROGRAM FOR FAMILIES WITH ASTHMATIC CHILDREN

By

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ABSTRACT

THE EVALUATION OF HOME
VISITATION PROGRAM FOR FAMILIES WITH
ASTHMATIC CHILDREN

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Asthma is one of the most common conditions of childhood. The purpose of this study was to create and evaluate an intervention in which parents of asthmatic children train other parents of asthmatic children. The primary objective was to evaluate the effect of this self care instruction in the home on the parents' attitude, parents' knowledge, parents' self management skills and the asthma activity (attacks and wheezing symptoms) of the child. In this study a simple experimental design was used in which the experimental group received self care instruction at home and the control did not receive this instruction.

Results of this study indicate that this self care program for parents of asthmatic children did not affect the parents on these expected domains. A small sample size caused by a high attrition rate might have contributed to these outcomes. This high attrition rate was researched by

following-up on those who dropped out of the study at various phases of the experiment. These responses were presented and discussed. Additionally, socio-demographic, family dynamic, and self management correlates were derived to make inferences about program effectiveness.

DEDICATION

It is God who girdeth me with strength, and maketh my way perfect. He maketh my feet like hinds' feet and setteth me upon my high places.

Psalms 18:32-33 KJV

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CHAPTER 1

INTRODUCTION

The Problem

Asthma is a public health problem in this country. It afflicts people from all strata of life and is especiallly common among children. Estimates of incidence, although difficult to obtain, depict it as a condition that needs to be treated as a public health problem.

According to one 1978 survey there were 6,034,000 people afflicted with asthma (National Institutes of Health (NIH), 1980). Estimates were that from 5 to 15 percent of the children in the United States suffer from asthma (Burns, 1982). It is one of the most common conditions of childhood and is a major cause of school absenteeism.

On the other hand mortality rates from asthma are low and getting lower. In 1978 it was estimated that only 493 person died from asthma. It is not the life-threatening aspect of asthma that makes it such an important condition to consider. What makes asthma so important, besides the number of people affected, is that the individual suffering from asthma is often faced with restricted activity. Asthma is considered

the third leading chronic condition causing limitation of activity (NIH 1982).

The chronic and acute nature of asthma make it a difficult health problem to manage. In one study it accounted for 134,000 hospital admissions in one year. Another study showed it accounting for 27 million physician visits, 85 million days of restricted activity, 33 million sick days and five million lost work days. Money spent for medical care was estimated to be 1.3 billlion dollars for the year (NIH, 1977).

It is clear that asthma is a common condition among all people and it is especially common among children. It is difficult to manage and can result in a high use of medical services. Childhood asthma can, as well, have a substantial impact on family life. The social and economic consequences of this condition can be extensive. A description of the condition can elucidate why asthma is a difficult condition to manage.

Clinical Picture of Asthma

Definition

Asthma is a syndrome characterized by episodes causing impairment of the free flow of air in the lungs. The basis for this obstruction is mucosal

swelling, hypersecretion of mucus and smooth muscle hyperactivity. The clinical manifestations include: wheezing respiration, dyspnea, cough and the production of excessive mucus. An important characteristic of asthma, as opposed to other conditions that may impair the body's ability to transport air is that symptoms are reversible. That is, asthmatics may have complete normal functioning in their lungs either through drugs or by virtue of the remissions between attacks.

Ashtma is considered either extrinsic or intrinsic. In extrinsic asthma the attack is brought on by the person having an allergic response to some exogenous allergen. Common allergens are trees, grass, weeds, pollen, mold, fungi and animal feathers. Most extrinsic asthmatics have wheezing symptons early in life and these initial episodes can be mistaken for attacks of bronchitis. On the other hand, the intrinsic asthma patients have all the same signs of the syndrome but the relationship of their asthma attacks to exposure to such exogenous allergens is not evident. Intrinsic asthma is common in individuals whose asthma begins later in life. In this group asthma is often associated with a respiratory tract infection (Sattar, 1985). Most asthmatics fall into a category consisting of elements of intrinsic and extrinsic asthma (Prokop & Bradely, 1981).

Understanding Asthma As a Biological, Psychodynamic and Social Condition: The Role of Emotions

In order to effectively operate a self management program asthma needs to be considered in its biopsychosocial context. Although the following discussion focuses on the psychological issues associated with asthma, it should be understood that asthma is a complex condition influenced by a range of variables including, those that are social, cultural, medical, biological and environmental.

An individual is a complex emotional being and a member of a web of systems that may affect the onset of an asthma attack. It is now generally accepted among health care providers that emotions play a powerful role in the the onset of an asthma attack and the management of any chronic illness. Historically, attempts were made to pinpoint psychodynamic conflicts such as expressive infantile dependency as the cause for the asthmatic condition. Unique personality characteristics or types were also sought to explain why the disease had occurred among particular people or flared up at specific times.

However it is currently believed that psychological factors are only one component among a number of other factors that may determine how an

illness or disease develops. This point of view also rejects the notion that there are specific psychological dynamics responsible for a specific disease. No linear relationship exist between emotions and disease formation but a multicausal, multiplefeedback relationship exist (Millon, 1982).

In the case of asthma this multicausal approach suggests that there maybe many factors contributing to the onset of asthma including: biological, social and psychological factors. This theoretical position also suggests that complex interactions among several variables may influence the occurrence and management of the condition. Given this framework, the role of emotions in asthma needs to be explored in a wider context . There have been a number of theoretical positions used to examine the role of emotions in the onset of asthma in children. These positions usually focus on the individual child or the family.

Mathus (1981) developed a schema for the manner by which psychology can contribute to childhood asthma. He suggested that there are three ways that psychological factors can enter into and effect the course of the condition. A psychological stimulant may lead to respiratory changes and an attack (precipant). The child may have an emotional reaction because of

the change in respiration (exacerbation) and in the orientation toward maintaining the condition and improving health. Thus the child must deal with the issue of acceptance and must confront dependency and strive for or retreat from health.

Steinhauer, Mushin, and Grant (1974) examined a number of psychological factors that may influence the course of chronic disease in childhood. They determined that the following issues can become important: separation from parents, restrictions, sensory impairment and isolation, dependency and lack of consistency, pain and deformity, threat of death, medication and absence from school.

Staudemayer (1982) derived five psychosocial factors involved in medical management from a questionnaire which was administereed to 175 asthmatic children. The outcome yielded three measures of anxiety: "despair over social debilitation", "quality of life"and "dread of illnes". One attitude scale called "orientation toward compliance" and one scale labelled "family communication" were also derived.

Friedman (1984) determined that there are several psychological factors implicated in pediatric asthmatic death. As a framework for her study she determined that these factors were part of a multivariate

approach in which demographic and medical variables were also considered. Among some of the factors noted were emotional stress, emotional precipation of fatal attacks, emotional exacerbation of fatal attack, preterminal panic, psychological dependency on hand nebulizers and disregard of symptoms, and psychopathology resulting from a negative reaction of parental and child attitudes toward asthma and family dysfunction.

Any discussion of childhood asthma, means the family's role must be considered. Hookham (1985) looked at how parenting styles affect the family's adjustment to asthma. She was specifically interested in how families cope with the asthmatic condition A major factor in the coping patterns appeared to be each family's hierarchy of intervention. That is, what they would do if someone in the family had an attack. Although there was no verbalized stepwise order of intervention, each famly had a particular manner for dealing with an asthmatic child.

Minuchin, Baker, Rosman, Liebman, Milman and Todd (1974) developed a conceptual model of psychosomatic illness in children. Their well recognized theoretical position espouses that there are disturbances within the familial context that are linked to psychosomatic illness. This

position stresses that when the child is physiological vulnerable to asthma, the child's family has the following four transactional characteristics: (1) emeshment, (2) overprotectiveness, (3) rigidity and lack of conflict resolution and the (4) sick child plays an important role in the family's pattern of conflict avoidance. These four family characteristics are described as follows:

(1) emeshment- interdependence of relationships, intrusion on personal boundaries, poorly differentiated perception of self and other family members.

(2) overprotectiveness- unusually high degree of concern for each others welfare

(3) rigidity- families that are heavily committed to maintaining the status quo

(4) lack of conflict resolution- the above characteristics make thresholds for conflict very low

But these aforementioned psychological variables cannot be viewed as standing alone. As previously emphasized there is a trend for the examination of chronic illness from a psychobiosocial perspective in which biological, psychological and social aspects are evaluated and

considered in treatment (Engel, 1980).

Types of Treatment

The immediate treatment for a child diagnosed as asthmatic consists of three processes. First, the child undergoes a complete examination with special emphasis on the chest, heart and blood pressure. Second, laboratory procedures are administered. The third process occurs when a skin test is performed to identify the allergen (s) that the child may be allergic to. There are three treatments for the asthmatic: pharmacotherapy, immunotherapy, and patient education.

Pharmacological Treatment involves the use of drugs. There are four types of drugs; bronchodilators, expectorants, corticorsteroids and cromolyn sodium. These drugs may be applied through injections or adminstered orally. Each of these drugs deal with different aspects of asthma under varying degrees of severity. For instance, corticosteroid is only used for severe cases because of the side effects associated with it.

Immunotherapy involves controlling the allergic reaction of the individual. This maybe accomplished through eliminating or reducing contact with the allergen such as avoiding animal feathers or dust. Or, hyposensitization shots maybe administered which involves injecting a bit

of the allergen into the individual to stimulate the invdividual's immune system. This leads to the development of antibodies. These hyposensitization injections are usually adminstered weekly and then given at intervals up to six weeks or seasonally.

At other times the treatment addresses preventing symtoms other than the asthma reaction. Some of the conditions associated with asthmatics are dehydrations hypoxia, respiration acidosis and emphysema. In some cases the administration of fluids intravenously or the adminstration of oxygen will relieve these conditions (McCombs, 1976).

There are some children who are so incapacitated by their disease that they require admittance to residential centers. These treatment centers provide up to date medical procedures and psychological support to the asthmatic children. In one center, the average stay during a one year period was 325 days (Creer & Burns, 1978).

The fourth treatment addresses the issue of Self Care Through Patient Education. In this case it involves teaching patients how to take medications and avoid situations that might lead to an attack. This form of treatment is growing in popularity as evidenced by more recent

emphasis on self care interventions for asthmatic children (Creer & Burns, 1978,; Clark, Feldman, Millman, Wasitewski, Vallen, 1981; Fireman, Friday, Vierthaler, Michael, 1981; Maiman, Green, Gibson, Mackenzie, 1979; Pituch & Broggeman, 1981 and Richard, Church, Roberts, Newman and Garon, 1981).

Self Care Programs for Asthmatics

Following is a review of the literature on self care programs involving asthmatics. There is a limited number of studies that deal exclusively with asthmatic children and self care, therefore two important studies involving asthmatic adults will be included (Avery, March & Brook, 1980) (Mainman, 1979).

More (1985) in his review of self management programs for childhood asthma uses these two categories; residential programs and community education programs. In this review a third category is considered which is called assessment studies. These studies examine existing self care behavior among asthmatics. There are two assessment studies and seven self care interventions; in which two take place in residential centers and

the remaining five are situated in a variety of outpatient facilities.

Self Help Educational Programs

Assessment Studies

In one study (Avery, March & Brooks, 1980) the purpose was to evaluate the adequacy of self care for adult asthmatics. The results are baffling. One hundred and fifty seven adult asthmatics were interviewed for one hour on medication usage, physician contact and response to asthma attacks. Prior to the interviewing a criteria was established of appropriate behavior in these three domains. The standards were established by a panel of experts. The most striking results were in regular physician contact: 68% of the respondents did not see a physician regularly, 40% of the respondents were not practicing adequate self care behavior in medication usage and physician contact when faced with increasing symptoms.

However, there seems to be an important point missing in this research. Here are adults who are experiencing asthma, but they apparently don't behave in ways that would lessen the severity of their attacks. Perhaps the deciding factor is in producing the motivation for

making self care decisions. Or, perhaps the criteria or standards are not appropriate. The researchers have pointed to the fact that only a limited number of physicians were used in establishing the criteria. Thus there is a question of their standardized criteria for self management behavior.

In contrast, Clark et al (1980) did an extensive and thorough needs assessment. This was in preparation for a self management education program. One of the most significant aspects of their study was that it was done with black and hispanic asthmatic children and their families in low income communities in New York. The purpose was to find out what information or skills these families wanted. A secondary purpose was to collect baseline data describing attitudes, skills and practices of these families and finally the study attempted to define self management from the family's perspective. In comparison to the above study (Avery et al. 1980), this study included the subjective experience of the population.

From over two hundred completed questionnaires, data was tablulated to get statistical profiles of the poulation. A self management index from the adult questionnaire was developed.

An educational program was developed around the questionnaire data which focused on medication usage, activity limitation, asthma attacks at

home, relationship with doctors, health promotion and school achievement. These were areas that the families indicated were important. Thus the outcome of this needs assessment was the development of an educational self care program based upon the perceptions of the asthmatic population.

Community Education Programs

The preliminary outcomes of the educational session designed from the previous needs assessment study were shown in a follow-up study of 140 families in which 97 were in the experimental group and 43 were in the control group. Pre-intervention data revealed no statistically significant differences between the experimental and control group on demographics. The intervention consisted of the experimental group participating in a series of educational sessions focusing on six self management areas while the control group received no intervention. The significant outcomes of this study were that the experimental group completed more self management steps, described their children as having fewer symptoms, was less fearful of their asthmatic child and reported that their children missed fewer gym classes. Even though the experimental group showed a trend toward a reduction in emergency room visits and

school absences, when tested for significance the experimental group did not have a greater drop in these two outcomes compared with the control group. In addition, this study did not find a significant difference between the experimental and control groups on hospitalization and wheezing symptoms.

One of the most suggestive outcomes of this study came from an analysis of covariance. When controlling for the number of educational sessions attended, the attendance at educational sessions accounted for the differences in the control and experimental on their ability to self manage. The findings also suggested that the difference between the experimental and control groups on hospitalization and wheezing symtoms might be due to attendance at educational sessions, although this finding did not reach statistical significance.

Another important outcome was the subjective experience of the family and how the family members experienced the asthmatic child. The goal was for the mother to experience the asthmatic child as less fearful or less burdensome. Although the specific effects of the family environment on the asthmatic child were not clear, creating an accepting

positive attitude in the family was significantly related to effective self management. Mothers were less fearful of their asthmatic child after the self management training.

The child can also be the primary recipient of the self care education. In another study, the most significant results were found in changing the health locus of control to the child. This was a self care school health education program specifically designed for asthmatic children (Parcel & Nader, 1977). There were two especially novel aspects to this study. First, there was a target population in a school setting. Most school health education programs are geared toward all children, groups of children are not usually the sample. This group approach toward self management was used with asthmatic children in a school setting. A second feature was that the educational sessions were used to develop five skill areas for self management for asthmatic children. These five skill areas have been used in one other study (Fireman, et al., 1981).

This pilot program had no control group, therefore it was impossible to determine whether changes occurred because of the educational sessions. A pre and post test design was used with five outcome measures: (1)

number of school days missed, (2) number of emergency room visits, (3) number of asthma attacks, (4) self concept, (5) illness anxiety and health locus of control. As far as research design is concerned, maturation, regression and practice effect maybe threats to internal validity. Nevertheless, the most immediate change resulting from the self care education was in the locus of control scores. In this case the group moved toward being more internally oriented as opposed to externally oriented on the Health Locus of Control measure. Thus the two important aspects of this study were the use of a school health program to reach asthmatic children and the change in health locus of control.

In another study (Maiman, Green, Gibson & MacKenzie, 1979) the effectiveness of an asthmatic nurse educator in dealing with asthmatics was the most important outcome. The major objective of this study was to evaluate the effectiveness of various self care educational interventions on the reduction of the emergency room visits made by adult asthmatics. Different educational methods were devised to which the asthmatics were randomly assigned. The study procedure used a (3x3)x2x2 randomized factorial design in which interventions were introduced

sequentially. The interventions consisted of nurse educators (either asthmatic or regular) positive written appeal, interviews and telephone follow-up. The study ran from July 1976 to May 1977 until a total of 289 patients were randomly assigned. By using an analysis of variance the effect of the interaction of nurse and written material was considered and no interaction effect was found.

The most outstanding finding from this study was that the subjects who received education from an asthmatic nurse were more likely to have no additional visits to the emergency room up to six weeks during the experimental period. The six month follow-up showed the same trend. But with the small number of subjects in each group it was not indicated whether the long range results were significant. Even though the group with the asthmatic nurse educator seems to have been the most effective, causative reasons are obscure. The findings could mean that the asthmatic nurse was a better communicator or that she became a coping model for the adult asthmatics or some other personal factors may have been involved. Nevertheless reducing emergency room visits is a potential savings to society in light of skyrocketing medical care.

There was another study of self managment education using an

experimental design. This intervention was addressed to parents and their asthmatic child (Fireman, Friday, Gira, Viethaler, Michaels, 1980). The outcome variables were: reducing severity of asthma, reducing emergency room visits, reducing school absenteeism, developing positive family self help attitudes and incorporating patient-parent education in a doctor's' office.

In this study the subjects were drawn from (1) a population of asthmatic children and their parents who were under the care of a particular pediatric allergist or (2) who attended a particular allergy clinic in the Pittsburgh area. It covered a narrow geographic area. As a result, this sample did not represent the general population on socio-economic variables. It was stated that this sample represents a group of middle class and "intact" families. Therefore the generalizability of this study maybe limited to middle class intact families. The results, however, show that the experimental group had fewer severe asthma attacks, fewer wheezing days per month, less school absences, fewer emergency room visits and fewer hospitalizations.

The most outstanding aspect of this study is that an educational intervention for self managment was developed for individual families and

found to be effective. It is interesting to note that the asthmatic child along with the parent was part of this self care instruction effort. This is in contrast to the studies discussed thus far.

On the other hand Alexander & Cropp (1985) evaluated the effectiveness of a twelve hour group patient education program for children with asthma and their parents. Using a pre and post design they found significant changes in knowledge and attitude. Furthermore a change in the desired direction for medication usage, emergency room visits, hospital admissions and school attendence was also detected.

Residential Center Approach

In contrast to the above studies which take place in various community facilities, some self care efforts take place in residential centers. Asthmatic children may be sent to residential treatment centers if their asthma is severe or the family cannot take care of them. Children can live in these homes for up to a year. One self care education program took place in a residential center in which the asthmatic children were initially categorized according to age and level of understanding (Richard, Church, Roberts, Newman, Garon, 1981). As a result of this categorization,

individual goals for the self help educational effort were established for each family. The evaluation of these children after the educational effort consisted of helping them understand the effects of medication and why it is necessary to take their medication. The results show that all participants were able to achieve high performance ratings and maintain them during the study period.

The research design is limited. There were only twenty-three cases and no comparative data was available. Therefore it is impossible to make any definitive statements about the effectiveness of this approach.

Similarly, another approach in a residential setting was used in teaching self managment to asthmatic children (Creer &Burns, 1978). In this case the emphasis was on using a basic approach which consisted of looking at antecedent conditions to an asthma attack and the attack's behavioral consequences. This is the basic framework for contingency management in behavior therapy. The research article described this approach as one which enabled the provider to control the rewards in the environment that might encourage an asthma attack. This approach was found to be effective with individual asthmatic children in the residential setting. Moore et al (1985) described three limitations of the residential

self management programs; they are not readily available, there are not enough beds and it requires a number of trained specialist. A major limitation of this research was that it was carried out without a comparison or control group.

Moore also identified two other approaches to self management and childhood asthma in which research has not been done. One approach is the summer camp for asthmatic children in which the following is available: recreation, education, self management programs and psychosocial help. Another approach is the general public education programs available through mass education. These include: "Winning Over Wheezing" "Superstuff" and "ACT". Research (Rakos, Godek & Mack, 1985) suggest that self help kits alone are not as effective as educational programs in increasing self management skills. But their effects can be enhanced by encouragement, demonstration and clarification.

Compliance, Self Care And Asthma

In medical treatment, compliance is defined as "the extent to which a person's behavior (in terms of taking medication, following diets or executing lifestyle changes) coincides with health advice given " (Haynes, Taylor and Sackett, 1979). This definition suggests that the individuals' behavior is measured against a standard established by the dictates of medical treatment. The degree to which an individual behaves in accordance with this established standard is the degree to his/her compliance.

Since the advent of modern medicine people have relied on the medical profession for treating illness. But only since the Renaissance has the issue of compliance in medical treatment emerged. The reason for this is that before the Renaissance most treatment was administered by force, such as leeching and bloodletting rather than being prescribed (Davidson, 1982).

Davidson (1982) also suggest that sometime around 1800 the issue of compliance became important because individual rights arose as a major political issue and accordingly the treatment modality changed from

forced treatment to our current voluntary procedures. But the medical literature indicates that there has been little reference to compliance before this decade.

Some of the first indications of compliance in the medical literature was related to public health issues such as food laws, innoculations and isolation of infectious person (Robertson, 1985). Currently a plethora of studies have been conducted on this issue mainly to determine what factors seem to make some people comply while others do not comply. Some of the factors related to noncompliance are: complex medical regiments, asymptomatic or psychiatric disorders, long treatment period and drugs causing side effects Sackett & Haynes, (1976) Gentry, (1977) Van Putten, (1974). Moreover Conrad, (1985) found compliance was unrelated to age, sex, race, religion, education, SES, illness, onset of illness, attitude and personality characteristics and Davidson (1982) also found that compliance is unrelated to situational factors such as doctor/patient interaction, type of agency, family interaction and location of treatment site.

Davidson (1982) suggests the literature on compliance presents physicians as taking a moral stance. That is the patient is morally bad, at

fault for not following the medical regiment which is to insure his/her good health. Essentially the unstated questions are "What is wrong with you that you can't comply? or What a bad person you are for not wanting to be well? Therefore physicians may operate as if there are traits within the person that cause noncompliance without giving condsideration to situational factors. But, previously stated, research shows compliance is also unrelated to these situational variables. Although physician may oeprate under a personality trait perspective, research shows that personality as well as situaitonal factors are not predictive of compliance. This issue of compliance is furthe complicated by the unpredictability and high rate of noncompliance. Statistics show that the rate of non-compliance as currently conceptualized, is extremely high. About one third of patients were not compliant in drug regimes and other statistics have shown that over a long period of times these percentages increase to 50%.

Since noncompliance is defined as occurring when the patient/client is perceived to have deviated from the regimen designed by the medical profession. The pressure to conform is often very strong. Even so it is often met with resistance.

For many the compliance question has become , "how can we conceptualize this issue so that the client is not resistant to doing the things that will insure his/her good health Conrad (1982). He suggests a patient centered perspective in which patients are seen as active participants rather than passive recipients of medical regiments designed by medical professionals . Ziesat (1980) suggest some specific patient centered strategies in order to aid the patients in fulfilling their therapeutic regime. These strategies would maximize an individual's control over treatment. He describes some behavioral strategies eg. self reinforcement, self monitoring, behavioral contracting and self instruction training. All of these strategies are patient focused and can lead to more autonomous behavior on the part of the patient in these health process.

Another strategy is to move beyond an active role of the client to a self care model. Self care has four components: individual, family, social networks and mutual aid within a self help group (Dean, 1986). Dean defines self care as " the range of individual behavior involved in symptom recognition and evaluation and in decisions regarding symptom responses, including decisions to do nothing about symptoms, to treat the

symptoms by self determined actions or to seek advice regarding treatment. Self care thus includes consultation in the lay, professional and alternative care networks as well as evaluation of decisions regarding actions based on the advice obtained in consultation."

The emergence of self care in ilness parallels the social development of individual rights. During the 1960s a great deal of attention was paid to the equal rights of the individual. In the traditional medical bureacracy physicians exercised complete authority. The self care movement reflects the individual's plea for more control over his/her own body and treatment processes. The individual is seen as the key player in this movement toward health and he/she elicits the support and expertise of the medical professional. Therefore the issue of compliance becomes irrelevant. The individual engaging in self care is choosing to be well and uses health care providers in his/her journey toward health.

Aronson (1984), a noted social psycholoigist, studied individual behavior in social situaitons. He suggests that an individual will comply to the rules of the system when his/her sense of gain outweigh the loss. The reward maybe material, such as money or immaterial such as recognition and acceptance. The next stage is identification. The

individual engages in the behavior because he/she is attracted to the person who proposes the behavior. The sick person strongly identifies with an individual and therefore wants to be like that individual by practicing equivalent behavior. Because of his/her identification with the individual he/she will engage in the behavior. Internalization of the behavior occurs when the individual automatically engages in the behavior because he/she believes it is right. He/she may have been influenced by a credible source about the benefits of enngaging in a certain behavior but the motivating force is the person's desire to be correct. He/she engages in the behavior because he/she is convinced it is right. An individual will most likley permanently adopt a behavior when he/she internalizes the behavior. On the other hand the most temporary behavior change occurs when it is tied to a sense a gain or less.

A parallel development can be seen in the issue of self care and patient compliance. The focus is on getting the individual to engage in a behavior that was designed by the medical system. In self care the individual seeks the support/expertise and advice of the medical professional. If successful, the individual internalizes the desire for wellness.

Currently the most prominent example of self care involves the

chronically ill. One of the most influential factors responsible for this new surge in self care has been the increase in the number of those affected with chronic disease. That is, the shift form acute illness to chronic illness in the last few decades may have contributed to the need for self care skills.

Thus our current awareness of self care behavior is primarily at the level of prevention, it is aimed at preventing further disability. The indivdual and/or family are instructed about particular self care activities that foster independence and self control. One of the frightening aspects of many chronic illnesses is the lack of control that people often feel. They often believe that they are at the mercy of a condition. It is for this reason that the family and the individual are the focus of educational efforts to teach self management skills. Most providers are willing to teach them and accept them as partners in their own health care. In chronc disease the importance of self care from the provider's as well as from the patient's point of view serve as a matter of common interest.

Thus self care should also be thought of as a collective effort; it should not be viewed exclusively as an individual effort. One should

consider the role of the individual, the family and the community. Usually self care in a group context means involving the family in health behavior on behalf of the individual. This happen because of the family is the most readily accessible group to the individual and it can provide special nurturance and social support (Pratt, 1977).

Asthma is a chronic disease that is suited to self care. Childhood asthma, in particular, has an effect on the child and the family. Both the child and the family need to be involved in self care activities to help them cope with the condition.

The self care method should be effective with families with asthmatic children because it is a chronic illnesss. Asthma is a disease that leaves its victim with a feeling of being out of control. He/she is at the whim of an attack at any moment in time. Self care allows the individual to gain control over his/her situation rather than being a victim of the disease. In self care the individual is encouraged and empowered to gain control over his/her asthmatic condition.

Teaching Self Management Skills in the Home

A variety of ways in which self management skills are learned by

asthmatics; both direct and indirect approaches have been presented. Another setting for training self management skills is in the home.

There are several theoretical and empirical reasons why home visiting should have a positive effect on the self management instruction. First, home visiting is one way to provide the client with social support. On one hand the visitor can provide the client with social support just by being there. On the other hand, the home visitor can involve the family, thereby eliciting support from those in the client's environment. In a behavioral framework the home environment is the major "shaper" of all behavior; including behavior that maybe connected to the health or illness state (Levy, 1983). Since home visiting has been found to increase social support and social suppport has been found to increase compliance to medical regiments we can assume that the home visit will have a positive effect on compliance (Heller, 1979).

Home visiting is not new. Social workers have been making home visits for decades (Holbrook, 1983). There have been emergency psychiatric crisis that have forced home visits by professionals. Moreover some psychologists have used home visits as part of their private practice

(McFadden, 1979). Recent developments in health have encouraged treating the elderly and dying in their homes (Houghton & Martin, 1976). There are now new populations in maternal and child health identified for home visits. These include teenage parents, parents of biologically handicapped infants, expectant parents and parents of constitutionally vulnerable infants (Halpen, 1984). Home visiting for the sick child is a growing trend. This all stems from the recognition of the importance of the home environment on the health and illness states.

Furthermore, home visting allows the visitor to make a ready assessment of the famiiy interaction, living arrangement, financial and environmental factors. So the home visit can be used for a rapid diagnostic assessment (Kirscher & Rosengarten, 1982). It has traditionally been used by social workers for this purpose since many of the known environmental factors may not be evident in an office visit.

Moreover, home visiting can have a positive effect on a client. It increases, at least momentarily, the power of the recipient of the service since the caregiver is on the clients's "turf" instead of vice versa. Typically the client is on the unfamiliar ground (Mc Fadden , 1979). This increased power for the client is especially conducive for self

management training since an increase in the sense of control is an expected positive outcome.

Using Non-Professionals in Treatment

Power & Wouldridge's (1982) study with hypertensive patients showed that an attitude of self care or responsibility for self did not increase after an education effort made by a nurse. They conjectured that the patients saw the nurse as co-responsbile and they were therefore less accountable. Thus the model of professionals advocating for individual responsibility for self care may not be the most effective way to increase self responsibility among this client population.

Parents training other parents is a nonprofessional approach. Numerous studies have discussed the benefits of using nonprofessionals. In a review of 42 studies comparing the helping effectiveness of paraprofessionals and professionals the outcome shows that paraprofessional achieve as good or better results than professionals (Durlak, 1979). In behavior therapy terms the parent doing the training can become a "coping model" for the other parents (Rimm & Masters, 1979).

Bartlett (1983) cites the use of peer educators as one of the criterion for an effective self help approach in childhood asthma. Janis (1983) points out in his discussion of social support and adherence to stress decisions that Alcoholic Anonymous participants capitalize on the buddy system approach and considers it as a major factor in keeping individuals sober. He further cites other research in which subjects in a weight reduction clinic who were assigned to high contact partnerships lost significantly more wieght than those not included in these relationship. In light of these developments the use of buddy trainers is expected to enhance the effectiveness of self management education programs for families with asthmatic children. Goldstein (1985) states the the most effective self management programs can be conducted by nonphysicians.

Summary

This background information has focused on the problem of asthma. This review showed that there is a growing phenomenum of self management in health and how this self management is applied to asthma. The literature on self management education programs for asthmatic children and their families shows the need for further research .

Four major issues were identified that can be evaluated in educational programs to increase self management among asthmatic children. The first issue is whether a group or individual approach is better. In the group approach the individual differences are obscured and the educator is unable to tailor the presentation to the individual's needs. Secondly, the literature showed the positive effects of involving the parents in the education for increased self management skills. Those studies which had a tangential role for the family did not show whether the self management behavior continued once the child was home. The asthmatic child is part of a system that is primarily shaped by parental relationships. Thus an inclusive parental role seems essential to self care instructions. A third issue is the growing recognition of the need for a biopsychosocial approach to asthma which necessitate family involvement and may also require a nontraditonal approach to self care instruction.

Does the educator need to be a professional or a paraprofessional? Who should do the training? The review of professional contrasted with paraprofessional suggests that the paraprofessional is as effective as shown by several studies in the area of health behavior management.

A fourth issue is where training toward self management should be

done. All the discussion on home versus office treatment suggests that the home can be more effective for both the service provider and the client. It is particularly conducive for training in self management because it is where the behavior will take place. Home treatment encourages a sense of power and control for the client.

Purpose of This Study

The information discussed so far suggests that there are several variables that need to be included if answers to the aforementioned questions are to be found. The purpose of this research is to create and evaluate an intervention in which parents of asthmatic children train other parents of asthmatic children.

This experiment is designed to test the intervention by comparing it with a control group of parents of asthmatic children who have not received the training.

The effectiveness of the intervention of self management education can be measured in many different ways. The outcome measures used here can be considered multi-leveled. These levels are knowledge, attitude and

behavior. These are three levels of measurement applied to many health education programs. The outcome levels and their application to self management with asthmatics are explained below.

Level 1- Knowledge is the most direct level of impact for a self management program. The expectation is that the self management education should increase and standardize the level of knowledge about asthma and its treatment for both the parent and child.

Level 2 - This is contingent on level 1. If the family is aware of the proper behavior and understands the conditions, one can expect that their attitudes toward asthma would be better.

Level 3 - This is also contingent on the preceding levels . This is a measure of their behavior. One would expect that as a result of the self management program that self management behavior would improve. because of better compliance with a medical regiment. Goldstein (1985) states that a goal of self management programs is to increase knowledge and convert that knowledge into behavior.

Level 4 - This could be considered the benefits from all of the above. With asthmatic children one would expect a decrease in asthma attacks/wheezing symptoms, etc., as a result of the change in knowledge, attitude and behavior. The outcome on this level is not always seen immediately. Sometimes a trend toward a reduction on this level can be detected (See Figure 1).

Although this model is useful, it is limited in that it focuses on a hypothetical linear relationship among knowledge, attitudes and practice. To be more complete we need to look at health behavior from an ecological point of view in which there are historical effects. Therefore this study will also view the asthmatics from an historical perspective using the socio-demographic and family dynamic correlates of self management behavior among asthmatic children and their families to aid in making inferences about program outcomes. Clark (1983) states that research needs to be done into parental management style and self management among asthmatic children. Moreover Thoresen and Gray (1983) note that self management models that focus on multiple sources of influences will be more effective over time. Bruhn (1983) also promotes a self

management model with an ecological point of view that is integrated and seeks to find the relationships among several select variables.

A total of four comparative hypotheses are tested in this study.

Experimental Hypotheses

Hypothesis One. The experimental parents will have a significantly higher level of asthma knowledge than the controls.

Hypothesis Two. The experimental parents will show significantly less fear and anxiety regarding childs' asthma than controls.

Hypothesis Three. The experimental parents will show a significantly greater increase in self management level than the controls.

Hypothesis Four. Asthmatic children of the experimental parents will show a significantly greater decrease in wheezing symptoms and asthma attacks.

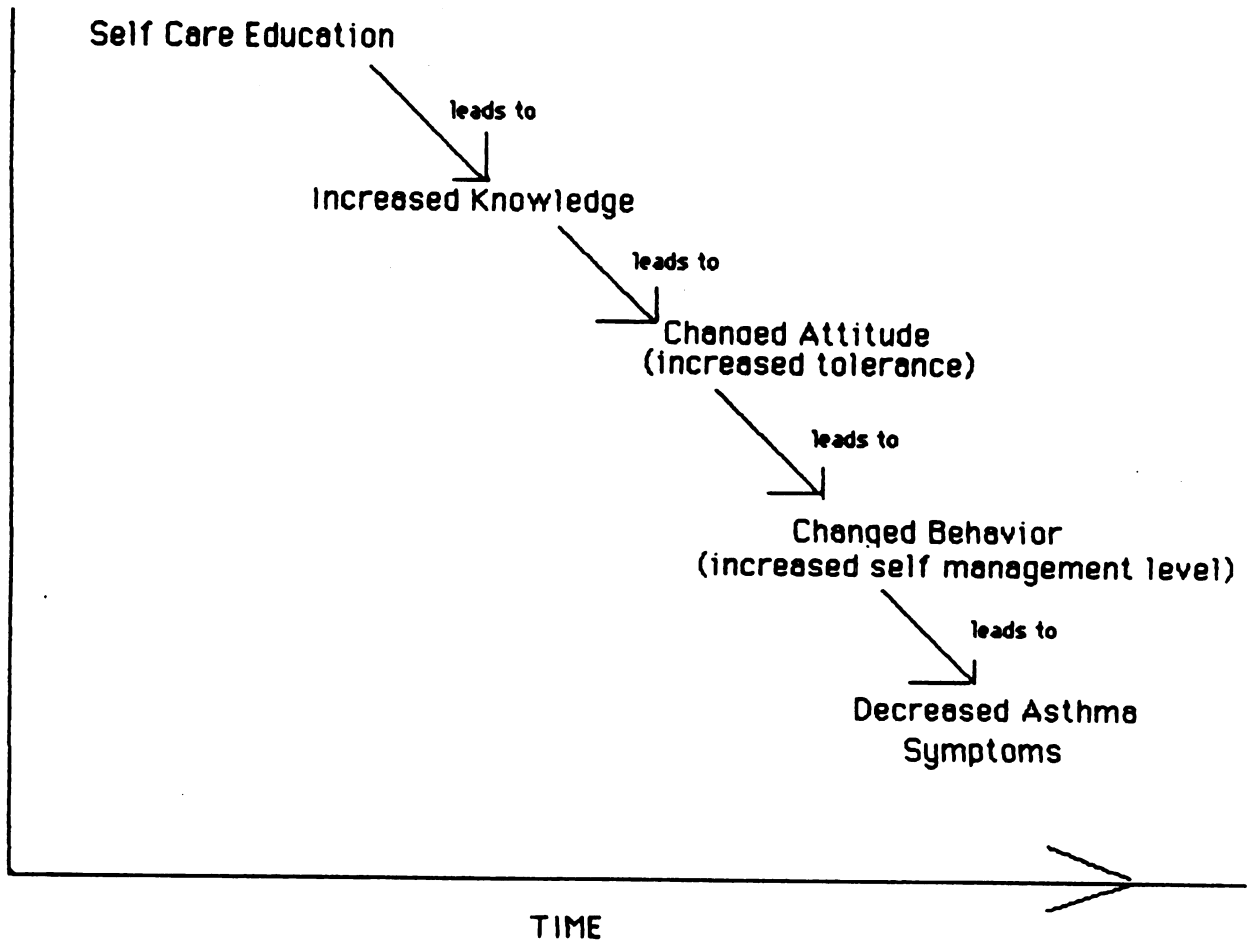


Figure 1 - The Theoretical Effects of a Self Care Education Program on Families With Asthmatic Children

CHAPTER II

METHODS

Sampling Procedures

The pool of asthmatic families was drawn primarily from the mailing list of the Asthma Parents Support Group, a self help group for parents of asthmatic children in the Greater Lansing Area and the mailing list of people requesting the Superstuff Kit, a self care kit for asthmatic children and their families, from the American Lung Association of Michigan.

Each family was initially approached by telephone and informed about the nature of the study at which time those families consenting to participate in the study were immediately sent by mail three questionnaires; the Family Adaptability and Cohesion Evaluation Scales, the socio-demographic questionnnaire and the Self Management Index.

The sample size changed during the course of the experiment. This is presented in Figure 2.

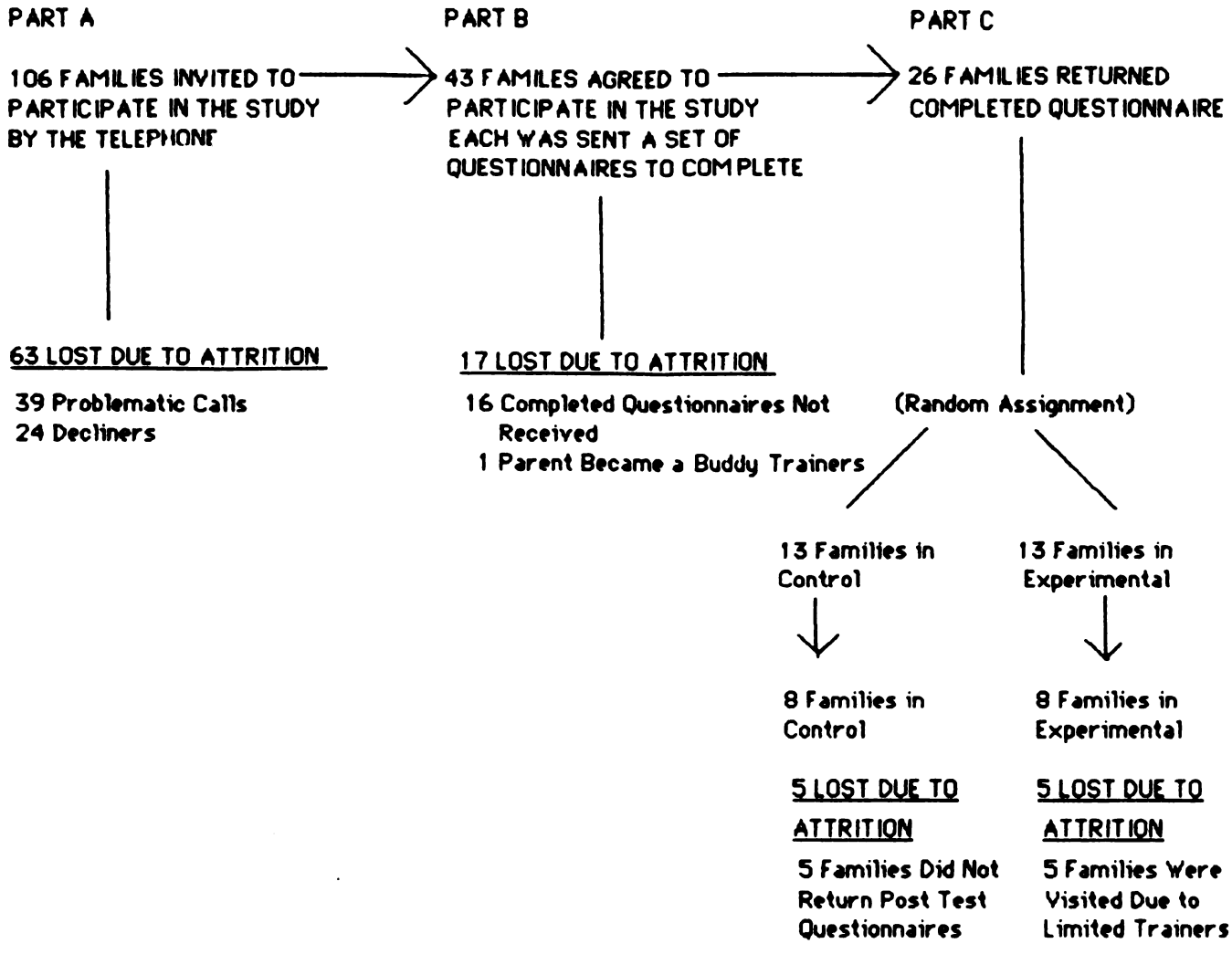


FIGURE 2 - SCHEMATIC REPRESENTATION OF THE CHANGE IN SAMPLE SIZE

Part A of Figure 2 shows that one hundred and six families were called. Of this total, thirty-nine were problematic. This basically meant that the desired party could not be reached. Of the sixty-five families reached, twenty-four were not interested in being part of the study, which left forty-three families involved.

Part B of the Figure 2 shows that of the forty-three families interested in the study, one family was eliminated because the parent wanted to be trained as a 'buddy trainer'. Of the remaining forty-two families, only twenty-six returned the pre-test questionnaire.

With twenty-six families in the sample pool, random assignment was done. The procedure for random assignment involved putting the coded number for each of the twenty- six families on a separate sheet of paper; placing them in a hat and alternately drawing from the hat for assignment to the experimental and control groups. This procedure insured random assignment of families into the control and experimental groups.

Part C of Figure 2 shows that of these twenty-six families who were randomly assigned another ten families were lost. Eight families in the experimental group received the home visits from the buddy trainer and and eight families in the control group returned the post test. A total of sixteen families remained in the study through its entire length.

The self management group received two home visits by a 'buddy trainer' while the control group did not recieve any visits. This is shown in the Table below.

TABLE 1- Experimental Design

Experimental Conditions	Number in Each Experimental Condition
Received two home visits by budddy trainer	n=8 Experimental
Did not receive any home visits	n=8 Control
	N=16 TOTAL

Attrition

The attrition of 90 families from the 106 which were originally contacted constitutes a 85 % loss of sample size. It is now necessary to examine this attrition at the different phases of the sampling processs.

TABLE 2 Problematic Calls (N=39)

Type of Problem	Number	
No Answer		
Called once	3	
Called twice	3	
Called three times	5	
		11 Subtotal
Telephone Number Problematic		
Wrong Number	5	
Telephone Disconnected	4	
Long Distance	4	
Number Changed	1	
		14 Subtotal
Unable to Reach Parent		
Called three times	4	
Called twice	2	
Called once	1	
Busy	1	
Call Back	1	
		9 Subtotal
Status Indeterminent	5	5 Subtotal
		39 TOTAL

Thirty nine subjects of the original sample of one hundred six was lost due to problematic calls. Problematic calls fell into four broad categories: no answer, telephone number problematic, parent not reachable and status indeterminent. Each category is explained as follows: No answer- these numbers were dialed from one to three times and each time there was no answer

Telephone number problematic- The telephone numbers were problematic making it difficult to reach the desired party. Under this category there were four different types: (1) wrong number- the number recorded and therefore dialed did not lead to the desired party (2) telephone disconnected (3) long distance - the number required a toll call and the MSU telephone was unable to handle this (4) number changed- the number for the desired party had changed to an unpublished number.

Unable to Reach Parent-In this case there were three categories. In category 1 the families were called from 1 to 3 times and each time the parent was not available. In category 2 thc number was busy and in cateory 3 the party was supposed to be call back.

Status Indeterminent- In this case the notation on the telephone tally forms were unclear and/or not filled in. Since many of the calls were made by research assistants this could not always be controlled.

Table 3 Follow-up of 24 Families Who Declined to Be in the Study

A. Reason Stated For Declining	Number	
1. Asthma not as severe or child outgrew it	9	
2. No Asthma in immediate family	3	
3. No Definitive Diagnosis of Asthma	2	
4. Other Personal Reasons		
believed program for younger children	1	
husband died	1	
no time	1	
don't remember	1	
	18	Subtotal
B. Families That Could Not Be Located		
Reason Unable to Locate 6 of the Familes		
1. no answer	3	
2. telephone disconnected	2	
3. wrong number	1	
	6	Subtotal
	24	TOTAL

The most frequent reason stated for declining to be in the study was that the child's asthma was not severe or the child outgrew it. Three of the families who declined to be in the study did not have an asthmatic in their immediate family. One of them was a school nurse who treats asthmatic children in her school, one had an asthmatic granddaughter and one did not state her relationship with asthmatic children. The manner in which a portion of the sample pool was derived, from the list of families

requesting the superstuff kit, made possible the inclusion of families without an asthmatic child. The other respondents either had personal reasons for not being involved or did not remember their reasons. Of the twenty-four families who were in this group of decliners, six could not be reached for this follow-up study.

Table 4- Follow-up of the 16 Families Who Agreed to Participate But Did Not Complete Pre-Test Questionnaire or From Whom It Was Not Received

Questions	Response	Number
1. Do You Remember the study?	Yes	11
	No	2
	Total	13
2. Response to....never completed the questionnaires?	I sent them	6
	Completed , unsure of mailing	2
	Did not do them	2
	Don't recall	2
	Refused to answer	1
	Total	13
3. Why did you drop out?	Not considered a dropout	7
	Never got to it	2
	Don't remember	2
	Daughter outgrew it	1
	Refused to answer	1
	Total	13
4. What did you think of the questions?	Don't remember	8
	Not problem with them	2
	Repetitive	1
	Did not understand them	1
	Refused to answer	1
	Total	13
5. Were the questions what you expected?	Yes	5
	No	2
	Don't remember	4
	No answer	1
	Refused to answer	1
	Total	13

6. Did you need more prodding?	Did not consider themselvess dropout	7
	Yes	2
	No	1
	Don't know	1
	Possibly	1
	Refused to answer	1
	Total	13
7. Prefer interview in home instead of mail-in questionnaire?	No preference	5
	Would not like it	5
	Preferred interview in home	2
	Refused to answer	1
	Total	13
8. What did you think of the number of questions?	Don't remember	8
	Alot of questions	4
	Refused to answer	1
	Total	13

In this telephone follow-up questionnnaire eleven of the thirteen respondents remembered the study. Six of them were sure they had completed the original questionnaires and had sent them in. Two were sure they had completed the questionnaires but were unsure about whether they mailed them. Two respondents stated that they had not completed the

questionnaire and two did not remember the situation. One respondent refused to answer.

In looking at the reason for the dropout rate, seven respondents did not consider themselves dropouts. Of the remaining six respondents; two could not recall, two did not have the time to do it, one felt it was inapplicable and one refused to answer.

Almost two years had elapsed since the questionnnaires were originally distributed therefore most of the respondents could not remember any details about the questionnaires. In response to question four, eight said they could not remember anything about the questions. Of the remaining five; two stated that they felt the questions were acceptable, the other two either felt the questions were repetitive, or they did not understand them. One respondent did not answer.

Although question five also involved remembering the questions, most of the respondents were sure about their answer. Five said the questions were what they expected while two said they were not what they expected. Four of the respondents could not remember, two respondents did not answer the question.

Question six was designed to determine if the dropouts needed more prodding in order to respond to the questionnaire. The seven respondents

who did not consider themselves dropouts were eliminated. Of the remaining five; two said yes, one said no, one said don't know, one said possibly and one refused to answer.

In response to their feelings about the home interview versus the mail-in questionnaire: five of the respondents had no preference, five would not have preferred the home interview, two respondents preferred the home interview and one respondent refused to answer.

In terms of the number of questions asked, eight could not remember if the quantity of questions was a factor, four respondents said there were "alot" of questions and one respondent refused to answer.

Table 5- Comparison on Demographic Characteristics of the 16 Participants in the Final Experimental and Control Groups to the 10 Participants who were Lost in the Final Phase of the Experiment
N=26

VARIABLE	Participants n=16	Non-Participants n=10	Test of Significance	
Mean Age	9	10	t= .65	1
Sex				
males	9(56%)	8(80%)	x= .65	1
females	7(44%)	2(20%)		
Mean Number of Attacks Last Week	1.15	.4	t=1.86	1
Mean Number of Attacks Last Month	3.85	1.1	t=1.65	1
Mean Number of Emergency Room Visits to Hospital	2.65	.9	t= .60	1
Mean Number of School Absences	2.35	1	t=1.08	1
PARENTS				
Mean Number of Months Knew About Asthmatic Condition	71(5yrs.9mo)	101(8yrs.4mo)	U=8*	1
Mean Number of Children	2.3	2.4	t=.4	1

Schooling of Respondent				
High School Graduate	4	4		
Some College of Technical Business School	6	4	x=5.26	3
Completed College	4	0		
Graduate School	2	2		
Marital Status				
Married	11	7		1
Single/Separated/Divorce	5	3		
Income				
≤ 19,000	5	3		
20,000-40,000	9	4	x=5.52	3
40,000+	2	1		
no answer	0	2		
Race				
White	15	10		
Black	1	0		

*significant at .05 level

Table 5 presents a comparison of those families in the final experimental and control groups, sixteen participants, to those families who had returned the original socio-demographic questionnnaires but did not continue with the rest of the study - ten families.

On the indices of severity of asthma, such as mean number of attacks, mean number of emergency room visits and mean number of school absences the participants were consistently and signficantly higher. This may suggest that those families who remained in the study became a

select group on these demograhphic characteristics.

Consistent with this finding is the fact that the ten famiiles who did not continue with the study had a signficantly longer time to deal with the asthmatic condition of their child than the sixteen remaining participants. Length of time dealing with an asthmatic child was found to be positively correlated with mastery ofthe asthmatic condition by the family (Nix,1984). This may again suggest that these nonparticipants did not perceive themselves as needing the program as much as the participants.

The other demographic variables did not reveal any differences between the sixteen participants and the ten non-participants.

Summary of Attrition

Most of the sample was lost during the initial phase of the experimenting. About one third of the sample was lost due to problematic phone calls and this continued to be a problem during the follow-up of the attrition groups. The next major loss, also during the early part of the experimental phase, was of those who were not interested in being a part of the study. About one fourth of the sample was lost here. Six of the sixteen who were considered dropouts claimed

that they had completed and sent their questionnaires in and therefore did not consider themselves dropouts. There were significant results found for the months they knew about the asthmatic condition between the particpants and nonparticipants.

The Treatment Models

The experimental innovation consisted of the training of the parents of asthmatic children by other parents of asthmatic children during home visits. The training program was designed to increase the self management skills of those families with an asthmatic child who were visited.

Each family in the experimental group recieved two home visits by a trained 'buddy trainer' (this was the term used to refer to those parents trained to make the home visit). The 'buddy trainer' was required to follow the outline covered in the manual specifically designed for this program. (see Appendix I).

The manual was reviewed by two cardio-pulmonary nurse specialists and one pediatrician. All of these health professionals had had first hand experience with asthmatic children and their families.

Buddy Trainers

The concept of 'buddy trainer' was derived from work done with paraprofessionals. Basically the word buddy trainer is meant to connote an educator and friend. The work and research done with paraprofessionals has consistently shown that paraprofessionals achieve equivalent results to the professionals when looking at the various clinical outcomes of client change in the area of mental health. (Durlak 1979)

The buddy trainers for this study were drawn from the Asthma Parents Support Group in Lansing Michigan, a self help group for parents of asthmatic children. Four parents were originally trained as 'buddy trainers.' The training consisted of six hours of lecture and discussion which were spread over two evenings. Conceptually the training was divided into two main areas; medical and psychosocial. The medical training was completed by a nurse who also taught self management classes to asthmatic children and their families at St. Mary's Hospital in Grand Rapids Michigan. The psychosocial training was completed by this researcher with the assistance of a professor in social work at Michigan State University. This psycho-social training was designed so that the

buddy trainers in training were able to see themselves on viedeotape as they practiced the home visit during a role playing situation. The American Lung Association of Michigan (ALAM) provided support by donating their site and their equipment for the training. A staff member from the ALAM office, who is normally assigned to provide technical assistance for the Asthma Parents Support Group, was available at the training to provide assistance as the need arose.

After the training, each 'buddy trainer' was required to visit three families. Attempts were made to match buddy trainers to experimental families in close geographic proximity. The expectation was that there would be twelve families in the experimental group. But one buddy trainer dropped out after the training, leaving nine families in the experimental group. There were several other unexpected events that effected the activities of the buddy trainers. One buddy trainer trained four families; a second buddy trainer trained only one family; a third buddy trainer trained three families. This resulted in eight experimental families. Similarly there were eight families in the control because five families out of the orginal control group did not return the post test even though several attempts were made to retrieve them.

Data Collection

There were two collection points; before the home visit and after the home visit. These are referred to as the initial assessment period and the follow-up period, respectively.

The initial assessment data was obtained from all families who consented to be in the study. This consisted of written questionnaires, which upon completion were mailed back to the experimenter at Michigan State University. The instruments comprising the initial assessment data consisted of: a socio-demographic questionnaire, a family dynamic questionnnaire (FACES) and a self management Index. After a two week wait, twenty-six persons had completed the questionnaires and mailed them back. They were considered the experimental sample. These participants were then randomly assigned to the experimental and control conditions.

After the experimental period, the self management group and control groups were given the post test. This consisted of: the Self Management Index, The Asthma Knowledge Test and the Asthma Attitude Survey. The

experimental group also recieved a Satisfaction with Home Visit questionnaire which was designed for this study. These questionnaires were also sent by mail and were received in a self addressed stamped envelope. If the completed questionnaires were not returned, telephone contacts were made to hasten the response. Some completed questionnaires were lost in the mail and resulted in further delay, since it was necessary to replace them. All of these factors contributed to the follow-up occuring over 120 days.

The Buddy Trainers were required to keep case notes on each visit made which was mailed back at the completion of the home visit. They were also asked to complete an evaluation form regarding their perception of the home visit program.

Instruments

Most of the variables of interest in this study were measured by administering written questionnaires. The specific questionnaires are described below:

Initial Assessment Measures

FACES

FACES is the Family Cohesion and Adaptability Evaluation Scale consisting of 111 items (Olson, Russell, Sprenkle, 1979) (Appendix A). Family Cohesion is defined as the "the emotional bonding that family members have toward one another and the degree of individual autonomy they experience". There are four levels of cohesion ranging from extremely low (disengaged) to extremely high (emeshed). The levels in between (moderate) are considered more conducive for family functioning, Family adaptability is defined as the "ability of a family system to change its power structure, roles, relationships and relationship rules in response to siltuational or developmental stress". The four levels of adatability also range from low (rigid) to extremely high (chaotic). Adaptability is defined as the ability of the family system to change. The central levels of adaptability are more viable for family functioning. There are sixteen possible types of families. They are: chaotically disengaged, chaotically separated, chaotically connected, chaotically enmeshed, flexibly disengaged, flexibly separated, flexibly connected, flexibly enmeshed,

structurally disengaged, structurally separated, structurally connected, structurally enmeshed, rigidly disengaged, rigidly separted, rigidly connected, and rigidly enmeshed.

The cohesion dimension consist of 54 items and the adaptability dimension consist of 42 items. There are 5 items making up a social desirability scale. One study found an internal consistency of r=.75 for adaptability and r=.83 for cohesion using a sample size of 603 (Portner and Bell, 1980).

The Asthma Self Management Index

The Asthma Self Management Index (Appendix B) is a 16 item measure with yes/no type questions. Scoring for this index ranges from zero to sixteen. This measure includes behaviors that are currently thought to be effective in controlling asthma. The three areas covered are: information seeking, managing an attack and preventing wheezing.

This index was developed and tested on families with asthmatic children and found to have a reliability of .54 as measured by Cronbach's alpha. Although no general norms have been set for high and low levels of

self management, the index was used to describe each subject's self management level in relation to the total group.

Demographic Questionnaire

The Demographic questionniare (Appendix C) was developed specifically for this study. It covers socio-demographic variables and self reports of the severity of asthma. This socio-demographic questionnaire covered information that describes this population. Three indices of severity of asthma were used in a previous study and found to have a reliabiliity of .83. The four indices of social status were found to have a reliability of .92 with this population (Nix, 1984).

Monitoring Asthma Activity

During a six week period after the home visits for the experimental families and after the assessment period for the control families, all the families were responsible for monitoring the asthma attacks and wheezing symtoms of the child (See Appendix D). The number of asthma attacks and wheezing symptoms were derived from this questionnare. Some parents were asked the number over the phone because their responses were never received in the mail.

Post-Experimental Measures

Asthma Self Management Index

The sixteen item Self Management Index, a central outcome variable for this experiment was measured again after the experimental intervention

Asthma Knowledge Test

The Asthma Knowledge Test is a twenty-four item measure which was orginally developed to evaluate the effectiveness of Superstuff Self Care Kit (a self care kit for asthmatic children and their parents designed by the American Lung Association) (See Appendix E). Scoring for this measure was calculated as the number of items answered correctly.

Attitude Survey

Another outcome variable which was measured is the attitude of the caregivers of the asthmatic child. This Asthma Attitude Survey, a

twenty-four item questionnaire was designed as a diagnostic tool for professionals working with families with asthmatic chidren (Creer, Ullman, Leung) (See Appendix F). For this study, the survey was graded to reflect from poor to positive attitudes. The experimental and control groups were compared on the twenty-four dimensions of attitudes using this scale.

Satisfaction with Home Visit By Clients

At the completion of the home visits by the buddy trainers, the experimental group was asked to complete an evaluation of the home visits. This was a simple ten item likert-type questionnaire to determine their feelings about the home visitation program and their experience with the home visitor (See Appendix G).

Satisfaction with Home Visits By Buddy Trainers

Similarly, the buddy trainers were asked to write case notes on each home visit they made. This qualitative data was included in the analysis of the effectiveness of the program. Moreover, they were also asked to

complete a ten item questionnaire to determine their feelings about the home visitation program and their experiences during the home visit (See Appendix H).

CHAPTER III

COMPARATIVE RESULTS

Intake Results

After the sixteen subjects were randomly assigned to the two conditions several tests were used to determine whether significant differences between the experimental and control groups had occurred on any of the socio-demographic variables. Table 6 indicates that the only significant difference between the control group and the experimental group was on the number of months the parents knew about the asthmatic condition of their child. Persons in the control group knew about the asthmatic condition a significantly greater number of months than those in the experimental group (See Table 6).

TABLE 6 - Comparison of the Self Managers and Control Group on Demographic Characteristics

	EXPERIMENTAL CONDITIONS		
VARIABLE	SELF MANAGERS	CONTROL	TESTS OF SIGNIFICANCE
CHILD			
Mean Age	8	10	t=1.15
Males	5 (62%)	4 (50%)	
Females	3 (38%)	4 (50%)	x=1.32
Mean Number of Attacks Last Week	1.1	1.2	t=3.12
Mean Number of Attacks Last Month	4.4	3.3	t= .92
Mean Number of Emergency Room Visits to Hospital	3.6	1.7	t=1.46
Mean Number of School Absences	3.6	1.1	t =1.76
PARENT			
Mean Number of Months Knew About Asthma	51	91	U=26*
Mean Number of Children	2.3	2.3	t =4.4

*p<.05

Table 7 shows the distribution of the experimental and control groups on the sixteen types of families for the Family Adaptability and Cohesion Evaluation Scales. As previously stated cohesion is the emotional bonding that family members have toward one another and adaptability is the ability of a family to change its structure in response to situational stress. The central levels of adaptability (flexible and structured) and cohesion (separated and connected) are more viable for family functioning.

TABLE 7- The Distribution of All Families on FACES

ADAPTABILITY	COHESION: Disengaged	Separated	Connected	Enmeshed	TOTALS
Chaotic			1E		1 Family
Flexible			3C 1E	1E	5 Families
Structured	1C	1E 1C		1E 1C	5 Families
Rigid	1E		1E	1E 1C	4 Families
TOTALS	2 Families	2 Families	6 Families	5 Families	15 Families

The distribution appears to reflect a sample in which almost half of the families on the cohesion scale were in the separated and connected categories and almost half of the families on the adaptability scale were in the flexible and structured categories. Even with the small sample size, this distribution approximates that attained by Olson et al (1979) for both the experimental and control groups.

Comparative Results: Testing the Experimental Hypotheses

The primary hypotheses of this study involved evaluating the effectiveness of a home visitation self management training program with families who had asthmatic children. The specific hypotheses tested were whether the experimental families had significantly different attitudes, more knowledge, practiced more self management skills and had fewer asthmatic symptoms than the untreated control group as a result of the program.

Attitude Toward Asthm

The attitude survey was designed as a diagnostic tool and hence there

are no total scores. There are frequency counts of the response of the experimental and control group subjects to a list of 24 statements. To most of the statements on the Attitude survey there was a consistency of response among and between the experimental and control group subjects, which suggests that there was no significant effect on attitude as a result of the intervention.

Knowledge of Asthma

Table 8 shows the comparison between the experimental and control groups on the Knowledge of Asthma Scale. Fishers Exact Probability Test of .3 does not reach the .05 level of significance, thus suggesting no significant differences between the self management and control conditions

TABLE 8- Comparison of the Self Managers and Control Group on Knowledge of Asthma

Number of Correct Answers	EXPERIMENTAL CONDITION Self Managers N	%	Control N	%
At and Above Median	5	62	3	37
Below Median	3	28	4	50

Self Management Level

Table 9 presents the change in self management level from the pre-test to post test for the experimental and control group. A one tail sign test reveals no significant difference between the experimental and control group on change scores from the pre-test to the post test.

TABLE 9- Change in Self Management Level for the Self Managers and Control Group

Self Managers	Score Pre/Post	Change	Control Subjects	Score Pre/Post	Change
1	13/14	+1	1	13/14	+1
2	10/14	+4	2	11/10	-1
3	15/14	-1	3	14/14	0
4	12/11	-1	4	7/9	+2
5	9/13	+4	5	14/14	0
6	14/13	-1	6	15/15	0
7	11/12	+1	7	13/13	0
8	9/12	+3	8	11/11	0

Asthma Attacks and Wheezing Symptoms

Another measure of the effectiveness of the home visitation program is its indirect effect on the occurrence of asthma attacks and wheezing symptoms of the asthmatic child. The expectation was that the self

management groups would have significantly fewer asthma symptoms than the control group during the six-week monitoring period.

Table 10 shows the comparison of the experimental and control groups on the occurrence of asthma attacks during a six week period after the cessation of the experiment. Fisher's Test does not reach the .05 level of significance suggesting no significant differences between the experimental and control conditions.

TABLE 10- Comparison of the Self Managers and Control Groups on the Occurrence of Asthma Attacks on Follow-up

	EXPERIMENTAL CONDITION			
	Self Managers		Control	
Asthma Attack	N	%	N	%
Yes	1	12	2	25
No	7	82	6	75

The experimental and control groups were also compared by Fisher's Test of .3 on the number of wheezing symptoms. Again no significant differences were found as shown in Table 11.

TABLE 11 - Comparison of the Self Managers and Control Group on Wheezing Symptoms on Follow-up

	EXPERIMENTAL CONDITION			
Number of Wheezing Symptoms	Self Managers		Control	
	N	%	N*	%
At and Above Median	5	62	3	37
Below Median	3	28	4	50

CHAPTER IV

ASSOCIATIVE RESULTS

It is now important to examine the data from the perspective of the correlations among the major areas of measurement used in the study. This was done using the BC Try cluster analysis program (Tryon and Bailey, 1970). The cluster analysis revealed seven clusters that are presented in Table 12.

Table 12 Cluster Analysis of Three Experimental Measures

Cluster	Loading
Cluster 1.- Family Dynamics	Reliability .97
1. Tended to be low on individual autonomy	.99
2. Tended to spend alot of time together	.94
3. Tended to be dependent on family members	.91
4. Tended to be high in the emotional bonding among members	.89
5. Tended to be very lenient when it comes to discipline	.71
6. Tended to need little or no private space at home	.68
7. All decisions tended to be made by whole family	.63
8. Tended to have parent-child coalitions	.59
9. More likely to be single	.50
10 Tended to have limited individual friends	.47

Cluster 2. - Managing the Severe Asthmatic Child Reliability .98

1. More frequent doctor visits	.96
2. Tendency to score high on self management- post	.96
3. Tendency to score high on self management-pretest	.91
4. Parents not likely to be single	.74
5. Tendency to have a high number of asthma attacks	.64
6. Not likely to spend night in hospital	.58
7. Asthma in Family	.40

Cluster 3 - How Asthma Affects the Family Reliability .91

1. Child does not need constant watching	.98
2. Knowledge of the warning signs of asthma	.76
3. Low on need for space among family members	.64
4. High on boundaries around the family unit	.52
5. Knowledge of the effects of using more medicine	.52
6. Child cannot control asthma	.46
7. Low on adaptability scores	.45
8. Aware of the medication theophylline	.44
9. More asthma attacks in a one week period	.42

Cluster 4 - Controlling the Asthmatic Condition In A Family Context Reliability .98

1.Tendency to have a higher number of attacks	.97
2.Tended to score high on negotiation on family issues	.80
3.Family perceives asthma as being under control	.64
4.Tended to score high on roles structure & definition	.50
5.Tended to be low-income	.49

Cluster 5 - The Effects of Social Standing on Behavior Reliability .84

1. Tends to have good attendance in school	.91
2. Tends to be divorced	.72
3. Spouses tended to be more highly educated	.66
4. Families have more children	.59

5. Knowledge of medicine for asthma	.54
6. Knowledge of the anatomy of an attack	.42
7. Tended to score high on social desirability	.41

Cluster 6 - Self Management in Reverse Reliability .97

1. Tended to be older	.85
2. Tended to feel that missing a dose won't hurt	.82
3. Tended to know about asthmatic condition for many months	.82
4.Tended to feel that child needs to be more responsibile	.51

Cluster 7 - Family In Control Reliability .90

1. Knowledge of change in lungs during an attack	.87
2. Low on discipline	.69
3. Child does not makes asthma worse	.65
4. Childrearing has influence	.57
5. Mostly asthmatic boy children	.55
6. Tended to complete a higher level of education	.55
7. Low on conflict among family members	.47
8. Low on role structure	.47

Cluster 1 THE FAMILY DYNAMIC

The family dynamic cluster consists mainly of the subscales describing closeness, cohesion and emeshment drawn from the family dynamic questionnaire. It was also found that marriage was negatively loaded on

this cluster while being separated and single was positively loaded. This suggest that emeshed and overly cohesive ties were more likely found in single parent homes. Table 13 shows that it is related -.40 to cluster 4. This suggest that these high cohesion family skills are negatively correlated to the adaptability family skills necessary for controllling asthma in a family context. The definers for this cluster are: low autonomy, spending alot of time together, high dependence on one another and high emotional bonding. The reliability for this cluster is .97.

Cluster 2 - MANAGING THE SEVERE ASTHMATIC CHILD

This cluster introduces an interesting relationship in that those with severe asthma achieved high self management scores while at the same time they still made many visits to the doctor's office. This cluster consists of pre and post self management level items which indicates that those with a tendency to score high on self management also had a tendency to visit the doctor a great deal and have many asthma attacks. On the other hand, they were not likely to spend the night in the hospital and were not likely to be single parents. Table 13 shows that this cluster has a correlation of -.24 with cluster 3 and -.27 with cluster 6. These correlations suggest time is an underlying variable. This cluster

represents those family who were dealing with an early stage acute asthma. Clusters 3 and 6 depict families who have lived with the asthma longer and therefore are more comfortable and relaxed. The definers for this cluster are: number of times child went to doctors' office, pre/post self management score usually parents were not single. The reliability for this cluster is .98.

Cluster 3 - HOW ASTHMA AFFECTS THE FAMILY

This cluster describes the effects of the child's asthmatic condition on the parents over time. It shows the effects of attitude, knowledge and family dynamics. There is a tendency toward an increased understanding of medication and a positive attitude toward responsibility. The cluster also shows a tendency to take more medication as a prevention measure. In terms of family dynamics there was a tendency to score low on the need for space, high on boundaries and low on adaptability. It is correlated -.24 with cluster 2 and .25 with cluster 5. These correlations suggest that there is an active or passive role that parents can take regarding asthma. Clusters 3 and 5 reveal a passive stance while cluster 2 shows a family more actively engaged with the asthmatic condition. The definers

for this cluster are: child does not need constant watching and knowledge of the warning signs of an asthma attack. The reliability for this cluster is .91.

Cluster 4 -CONTROLLING AN ASTHMATIC CONDITION IN A FAMILY CONTEXT

This cluster reveals specific family skills that are necessary for feeling in control of the asthma. This cluster shows that those families with a high number of attacks and those families who felt asthma was under control also scored high in negotiating and well defined roles. They also tended to come from lower socio-economic levels which suggests that they may be accustomed to negotiation around income issues. Table 13 shows that this cluster is correlated -.40 with cluster 1, .29 with cluster 6 and -.31 with cluster 7. These correlations suggest that certain family skills are necessary for controlling an asthmatic condition while other are detrimental. High emeshment variables of cluster 1 and low structure variables of cluster 7 are negatively related to controlling an asthmatic condition while high structure and adaptability variables of cluster 4 are conducive to controlling an asthmatic condition. The definers for this cluster are: number of attacks after the experiment and negotiation. The reliability for this cluster is .98.

Cluster 5- THE EFFECTS OF SOCIAL STANDING ON BEHAVIOR

This cluster indicates that social standing is related to knowledge of asthma, school absences and having high social desirability test scores. Fewer school absences were found among those families whose parents were divorced, whose spouses had more schooling and those with more children. This cluster suggests that school absences are less an indicator of ashma severity and more of an indicator of social status. These families also tended to score high on social desirability. In terms of knowledge they understood medication and the anatomy of an asthma attack. Table 13 shows that this cluster is correlated .25 with cluster 3. This suggest that specific demographic variables influence family behavior around the child's asthma which in turn affects the family self management skills and knowledge of asthma. The definers for this cluster are: fewer school absences, and being divorced. The reliability for this cluster is .84.

Cluster 6- SELF MANAGEMENT IN REVERSE

This cluster is called self management in reverse because as the child gets older and the family has lived longer with the asthmatic condition, the family members appear to be more relaxed about medication usage.

The child's attitude toward taking a more responsible role and a growing parental sense of confidence emerges. Table 13 shows that this cluster is correlated -.27 and .29 with clusters 3 and 4 respectively. These correlations suggest a relationship among these clusters where family members are either in control of the ashma, as with cluster 3 or being controlled by the asthma, as with cluster4. The definers for this cluster are : age, missing a dose won't hurt, and number of months parents have known about the asthmatic condition of their child. The reliability for this cluster is .97.

Cluster 7 FAMILY IN CONTROL

This cluster consist of items that depict the parents of the asthmatic child is in control of the asthmatic condition. These families tend to be low in discipline, low in role definition and structure, low in conflict, they feel their child rearing is influential and they tend to feel that their child does not control the severity of the asthma. These families tend to be aware of the changes in the lung and also to be more highly educated. These families often have an asthmatic son. Table 13 shows this cluster is correalted -.31 with cluster 4 suggesting that the family dynamic skills of this cluster inhibit the family's ability to control their child's asthma.

The definers for this cluster are: aware of changes in lungs during an attack, low in discipline, and child does not make asthma worse. The reliability for this cluster is .90.

Table 13 presents the intercorrelations among the clusters.

TABLE 13 Correlations Between Oblique Cluster Domains

CLUSTERS	#1	#2	#3	#4	#5	#6	#7
1 Family Dynamics	1.0	-.16	00	-.40	.10	-.07	.06
2 Managing the Severe Asthmatic	-.16	..1.0	-.24	.04	.09	-.27	.12
3 Asthma Affects The Family	00	-.24	1.0	- .04	.25	.12	-.06
4 Controlling The Asthmatic in A Family Context	-.40	.04	-.04	.1.0	.01	.29	-.31
5 The Effects of Of Social Standing	.11	.09	.25	.01	1.0	.13	-.00
6 Self Management In Reverse Control	-.07	-.27	-.12	. 29	.12	1.0	-13
7 Family In Control	.06	.12	-.06	-.31	-00	-.13	1.0

CHAPTER V

DISCUSSION

In the introduction a theoretical model was discussed which depicted a linear relationship from knowledge to attitude to behavior. This model was used to develop the experimental hypotheses. The expectation was that the experimental group would have more knowledge, improved attitudes and a higher self management level. None of these hypotheses were confirmed. Not a single test of significance showed that these advantages occurred. Another expectation was that the experimental group would have fewer asthma attacks and wheezing symptoms after the program. Again the findings were not significant. Although the findings were not significant a further exploration of data suggest that the self management group tended to have more knowledge, a higher self management level and fewer asthmatic symptoms than the control group.

There were several drawbacks to this study some of which may have contributed to the findings. As just mentioned the first and major one was the small number of participants. The plan included an experimental and control group of 15 each, but practicality reduced each to half its expected

size. It is difficult to make statistical inferences from such a small sample. Popham & Yalow (1983) in their evaluation of self management programs for asthmatic site participant attrition as a common problem. This results in problems with data interpretation and therefore generalizability.

In the follow-up study of the attrition problem there were four specific groups that were examined: those 39 families who could not be reached because of problematic calls, those 24 families who declined involvement in the study during the initial approach, those 18 families who verbally agreed to participate but apparently never returned the pre-test questionnaires and those ten families who were lost in the final phase of the experiment. Among these ten families; five were lost because of the limited number of buddy trainers and five refused to return the post test questionnaires.

Thirty-nine of the total sample could not be reached due to problematic phone calls. This is 37% of the total sample. The two major reasons people fell into this category were because of nonfunctioning phone numbers or no answer to telephone rings.

In following up the twenty-four families who declined to be in the study, the major reason stated was that their child outgrew the condition. In light of this one might assume that they either concluded that the study was not applicable to them or that they would not benefit the program by their involvement. One-fourth of these decliners could not be reached, although several attempts were made. These twenty-four decliners represent 23% of the total sample of one hundred-six families. This percentage increases to one-third when excluding the thirty-nine families who could not be reached ie., one third of those families actually reached refused to be in the study while two-thirds agreed to be in the study. This shows a high rate of interest and willingness to be involved in the program which might reveal that the program as described was perceived to be answering a need for this group.

The eighteen families who agreed to participate in the research but for whom no questionnaire was received presented the most surprises. A significant percentage of these families did not percieve themselves as dropouts. They claimed that they completed the questionnaires and sent them it. Assuming this is true, only 12 of the 42 actually dropped out of the study at this point, instead of the eighteen originally thought. This

makes about a 70% retention rate during the experimental phase of the study.

The final attrition group that was explored were those who were lost during the final phase of the experiment. Ten families out of the twenty-six families who were not visited or had not returned post-test questionnaires were compared to the sixteen final participants on the demographic data derived from the pre-test questionnaire. This comparison was designed to answer the question of whether a select group left the experiment at the final phase of the experiment. The only significant difference found between these two groups was in the number of months they knew about the asthmatic condition. The dropouts knew about the asthmatic condition a significantly longer time than the participants. This could be an important indication of mastery, comfort level and the degree of the severity of the condition. Time spent dealing with the asthmatic condition usually correlates with increase mastery and an increased comfort level (Nix,1984). Moreover, the severity of childhood asthma usually decreases over time which may indicate that the final participants also represent families whose children were having the most acute asthma. This information suggests that the experimental

group probably had more severe asthmatic children and a greater need for mastery over the condition

Related to the issue of self selection is the significant finding found between the self management group and the control on number of months each knew about the asthmatic child before the intervention. The control group knew about their asthmatic child a significantly greater number of months than the experimental group despite random assignment. It appears that this time difference could have made self management differences harder to find; especially since other findings suggest that self management behavior increases over time

The next major problem with the study was the measures. The results from the attitude and knowledge measures needs to be carefully interpreted because there is insufficient normative data available. Although, the self management index was calculated on a sample of inner city families with asthmatic children and previously tested for reliability, the reliability score was relatively low (r=.54). Thus one could question the generalizability of this index to the larger population of families with asthmatic children. Wilson (1981) in her evaluation of self management programs for asthmatic children states that there measures

fall short in adequate test construction. The state of the art and science of evaluative measures for determining the effectiveness of self management programs is young. More needs to be done in developing and testing effective measures.

One expected result was found in the significant differences between the experimental and control group on attitude. While this occurred on only one item in the attitude survey, if substantiated by later research, it would constitute an important finding. This difference was found in their perception of what constituted control of the child's asthma. A significantly higher number of the self management subjects felt the asthma was under control than did the control subjects in post experimental measurement. This suggest some positive effects of the home visitation program. Perhaps the family's perception of control is increased as a result of the interaction with the buddy trainers. Other studies also show the positive effects of these self management programs on this affective domain. In particular Clark et al. (1981) showed that the self management subjects (experimental parents) in their program experienced less fear and anxiety regarding asthma as a result of the self management program. This one significant result should not be over

stated but it might suggest that other significant results might be found if the sample size were larger. This seems plausible since there were differences in the desired direction even though they did not reach significance. Nonetheless, it cannot be overlooked that this study shows the self management program itself may not produce the desired results. These results would be in keeping with the multitude of studies showing a lack of relationship between knowledge and action (Fairweather, Davidson, 1985).

Even so an important contribution of this study could be the use of peer training in this area of asthma self management. In this case it is parent to parent. This project combines a para-professional model and a self care model. The results of the evaluation of questionnaires from the "Buddy Trainers" and the visitees revealed some issues about the home visitation program. First, the evaluation questionaire administered to the buddy trainers was designed to measure four areas. These areas are: their sense of preparednesss for doing the home visits, their enjoyment of the home visits, their sense of the relevancy of the manual to the home visitees and their sense of the value of the overall program.

In terms of preparedness, the response to question four (Appendix H)

showed that two of the trainers felt prepared for the home vists. The two parents who felt most prepared were also the two who fullfilled their complete obligation to the program by making the home visits to the three families assigned to them. These two parents were also actively involved in the Asthma Parents Support Group before the home visitation program was developed. These two parents were also friends, which might suggest that the social contact helped support their continued involvement in the program.

An issue that was most strongly and consistently expressed in the evaluation was the trainers' enjoyment of the program. As reflected in question one and five of the trainers questionnaire (Appendix H), all the parents enjoyed the visits and felt well recieved by the parents they visited

However, the buddy trainers' response to the issue of the relevancy of the manual was somewhat mixed. As reflected in their repsonse to questions three and eight, all the parents either felt the manual was not totally relevant to the parents they visited or found themselves discussing subjects not covered in the manual.

The response to the value of the program was revealing. All the buddy

trainers wished that they had been visited during the early onset of the illness of their dealing with an asthmatic child. This may suggest the need for an intervention for parents in the early stages of the illness with an asthmatic child. On the other hand, when asked how they felt about the overall program, the response was somewhat mixed. The three trainers were equally divided in their response from neutral, good to excellent. Some of the issues revealed in the evaluation questionnaires also appeared in the case notes. Thus a narrative format may reveal issues that shed further light on the program effectiveness. There were positive feelings of warmth expressed. One parent expressed a desire to see the trainee again. Another parent decided to bring her asthmatic daughter along on the second home visit so that asthmatic child at home could have a playmate. In this case the trainer went beyond the program guidelines because of her committment to the parent trainee.

But there were also aspects of the home visit in which it appeared that the trainers seemed to be unsure . One parent described her trainee as being involved with homeopathic medicine as her way of dealing with the asthma. In this case the trainer listened. Another parent asked the trainer how to deal with a smoker visiting the home because the smoke

has an affect on her asthmatic child. Moreover, one parent trainee expressed the desire for more technical information regarding asthma. She clearly wanted to go beyond the level of competency she found in the manual, while two of the parent trainees asked specific questions about travelling with an asthmatic child.

Although the training session for the 'Buddy Trainers' appeared adequate the comments suggest that a few important areas were left out. Their comments suggest that future training should include: travelling with an asthmatic child and smoking and the asthmatic child. In addition, more practice time in role playing may also increase the confidence and comfort level of the 'Buddy Trainers' in dealing with a variety of topics.

In order to standardize the content of this self management training a manual was developed. The manual, which was prepared and developed by the researcher also represents a contribution to the research on self management programs for asthmatic children. Its specificity in terms of the script format allows for use by those parents with minimal training or for parents lacking the the ability to communicate effectively. Perhaps one drawback of this format is that the particular style of the writer, may or may not fit with a particular 'Budyy Trainer.' Notwithstanding the two

key elements to be communicated in the style of this manual was the clear need for 'empathy' and 'information'.

Another important finding of this study is the need to use an ecological model. Little has been done in this area. Clark et al. (1983) states that there is a need for an examination of other variables and their effects on self management. The research presented here begins this process by incorporating a well known and well test family dynamic questionnnaire among its assessment instruments. From these results a distribution of family types among the sample was found as well as how the subscale of the family dynamic questionnnaire related to the other variables in the study. This was revealed in the BC Tryon Cluster Analysis.

Among some of the highlights from the cluster analysis are cluster 2 and cluster 5. There were several interesting relationships revealed in these cluster. Cluster 2 revealed that frequent doctor visits can be associated with a high self management level. This may suggest that a high self management level and frequent doctor visits can be two important ways of dealing with a more severe asthmatic child. Initially, frequent doctor visits was used as an indicator of severity and poor self management. But this cluster suggest that, instead, it may be a valid way

of treating a severe asthmatic child along with the other self management behaviors.

Another interesting cluster was cluster 5. In this cluster it was suggested that social status may be a key variable in school absences with asthma. Fewer school absences were found among those families who were divorced and those families where the spouses had more education. This may suggest that it is likely that some asthmatic children go to school even though they have symptoms. Rather school absenteeism may be more related to socioeconomic level. Asthmatic children from families where spouses had more education were less likely to be absent. The more upwardly mobile families are less likely to permit the asthmatic children to stay home. Alternatively it may not be feasible for a divorced parent to have their child stay home simply because there is no one to care for him/her at home duirng the day. Although school absences are often used as an indicator of asthma severity, (Mak et al. 1982), Fireman et al. 1981) perhaps it is reflective of social status as well.

In summary this study contributed to the field of research on self management and childhood asthma. In at least three ways: (1) Future studies will need to create procedures to minimize attrition; (2) New

relationships were revealed through the cluster analysis of multiple measures and (3) the development of a peer training manual for home visitation was created. The major limitation of this program was due to attrition, which made it difficult to assess the significance of measures of program effectiveness.

In ecological psychology Fairweather and Davidson (1985) state that each field experiment signals the next field experiment. The process is never complete. The results and inferences drawn from one experiment serve to build the theoretical conceptualizaiton for the next experiment. There are several directions that the present research leads.

Implications for Future Research

Since the home visitation prgram was so well received by the parents who continued to participate, as revealed by the results from the evaluation survey, it is emcumbant upon the future researchers to build upon the peer training model. In order to do this effectively and at the same time attempt to reduce the high attrition rate, there needs to be incentives for the 'Buddy Trainers' to do home visitation., This could be in the form of money and/or certificates upon the completion of this work.

As explained in behavior theory, (Rimm and Masters, 1979) self management like behaviors can be enchanced by environmental reinforcement. There needs to be environmental support. Stachnik & Stoffelmayr & Hoppe (1983) suggest building in positive health behavior reinforcements where reinforcements for negative behaviors currently exist. Some behaviors that might be reinforced in future self management programming could include: specific roles for family members, periodic meetings among families with asthmatic children to sustain the self management behavior.

Another important area for further development should involve families with newly diagnosed asthmatic children. These families are most likely to benefit from a program like this. In order to do this, the program needs to be considered an ongoing effort with an open ending period. The reason for this is that families with a newly diagnosed asthmatic child occur continuously and change continuously. In order to take maximum advantage of a home visitation progam a "Buddy Trainer' should visit the home as soon as the asthma is diagnosed.

In order for this to be done effectively a good relationship between the medical providers and the program developers needs to be developed. An

effective model for any home visitation program is probably best done as an extension of the medical care that the family is receiving. In this way the medical providers can be assured that a quality service is being delivered in the home. Moreover the 'Buddy trainer' would have the resources available to them for ongoing support from the medical community.

If used in other studies the instrumentation from this study needs further development to assure quality measures. This had particular ramification in terms of the relationship among variables. The cluster analysis raised new questions about self management. To answer these questions, a large sample size with reliable and valid measures is needed and additional work needs to be done in the model development, particularly in the process of movement from knowledge to appropriate action. This research was based upon a linear and ecological model. But the finding pose questions about this linearity since they suggest that cognition is a necessary bul not sufficient step toward action. Continued work need to be done in the area of the relationships among these variables for further model development

APPENDICES

APPENDIX A

FACES

APPENDIX A

FACES

4= TRUE ALL THE TIME

3= TRUE MOST OF THE TIME

2=TRUE SOME OF THE TIME

1= TRUE NONE OF THE TIME

1. Family members are concerned with each other's welfare.
2. Family members feel free to say what's one their mind.
3. We don't have spur of the moment guest at mealtime.
4. It is hard to know who the leader is in our family.
5. It 's difficult for family members to take time away from the family
6. Family members are afraid to tell the truth because of how harsh the punishment will be.
7. Most personal friends are not family friends.
8. Family members talk a lot but nothing ever gets done.
9. Family members feel guilty if they want to spend some time alone.
10. There are times when other family members do things that make me unhhappy.
11. In our family we know where all family members are at all times.
12. Family members have some say in what is required to them.
13. The parents in our family stick together.
14. I have some needs that are not being met by family members.
15. Family members make the rules together.
16. It seems like there is never any place to be alone in our house.
17. It is difficult to keep track of what other family members are doing.
18. Family members do not check with each other when making decisions.

19. My family completely understands and sympathizes with my every mood.

20. Family ties are more important to us than any friendship could possible be.

21. When our family has an argument, family members just keep to themselves.

22. Family members often answer questions that are addressed to another person.

23. The parents check with the children before making important decisions in our family.

24. Family members like to spend some of their free time with each other.

25. Punishment is usually pretty fair in our family.

26. Family members are encouraged to have friends of their own as well as family friends.

27. Family members discuss problems and usually feel good about the solutions.

28. Family members share almost all interest and hobbies with each other.

29. Our family is not a perfect success.

30. Family members are extremely independent.

31. No one in our family seems to be able to keep track of what their duties are.

32. Family members feel it's "everyone for themselves."

33. Every new thing I've learned about my family has pleased me.

34. Our family had a rule for almost every possible situation.

35. We respect each other's privacy.

36. Once our family has planned to do something, it's difficult to change it.

37. In our family we are on our own when there is a problem to solve.

38. I have never regretted being with my family, not even for a moment.

39. Family members do not turn to each other when they need help.

40. It is hard to know what other family members are thinking.

41. Famly members make visitors feel at home.

42. Parents make all of the important decisions in our family.

43. Even when everyone is home, family members spend their time separately.

44. Parents and children in our family discuss together the method of punishment.

45. Family members have little need for friends because the family is so close.

46. We feel good about our ability to solve problems.

47. Although family members have individual interest, they still participate in family activities.

48. My family has all the qualities Iv'e always wanted in a family.

49. Family members are totally on their own in developing their ideas.

50. Once a task is assigned to a family member there is no chance of changing it.

51. Family members seldon take sides against other members.

52. There are times when I do not feel a great deal of love and affection for my family.

53. When rules are broken, family members are treated fairly.

54. Family members don't enter each other's areas or activities.

55. Family members encourage each others efforts to find new way of doing things.

56. Family members discuss important decisions with each other, but usually make their own choices.

57. If I could be apart of any family in the world I could not have a better match.

58. Home is one of the loneliest places to be.

59. In our family, it's important for every one to express their opinion.

60. Family members find it easier to discuss things with persons outside the family.

61. There is no leadership in our family.

62. We try to plan some things during the week so we can all be together.

63. Family members are not punished or reprimanded when they do something wrong

64. In our family we know each others close friends.

65. Our family does not discuss its problems.

66. Our family doesn't do things together.

67. If my family has any faults, I am not aware of them.

68. Family members enjoy doing things alone as well as together.

69. In our family, everyone shares responsibilities.

70. Parents agree on how to handle the children.

71. I don't think any one could possibly be happier than my family and I when we are together.

72. It is unclear what will happen when rules are broken our family.

73. When a bedroom door is shut, family members will knock before

entering.

74. If one way doesn't work in our family, we try another.

75. Family members are expected to have the approval others before making decisions.

76. Family members are totally involved in each others lives.

77. Family members speak their mind without considering how it will affect others.

78. Family members feel confortable inviting their friends along on family activities.

79. Each family member has at least some say in major family decisions.

80. Family members feel pressured to spend most free time together.

81. Members of our family can get away with almost anything.

82. Family members share the same friends.

83. When trying to solve problems, family members jump from one attempted solution to another without giving any of them time to work.

84. We have difficulty thinking of things to do as a family.

85. Family members understand each other completely

86. It seems as if we agree on everything

87.It seems as if males and females never do the same chores in our family.

88. Family members know who will agree and who will disagree with them on most family matters.

89. My family could be happier than it is.

90. There is strict punishment for breaking rules in our family.

91. Family members seem to avoid contact with each other when at home.

92. For no apparent reason, family members seem to change their minds.

93. We decide together on family matters and separately on personal matters.

94. Our family has a balance of closeness and separateness.

95. Family members rarely say when they want.

96. It seem there are always people around home who are not members of the family.

97. Certain family members order everyone else around.

98. It seems as if family members can never find time to be together

99. Family members are severly punished for anything they do wrong.

100. We know very little about the friends of other family members

101. Family members feel they have no say in solving probelms.

102. Members of our family share many interests.

103. Our family is as well adjusted as any family in their world can be.

104. Family members are encouraged to do their own thing.

105. Family members never know how others are going to act.

106. Certain individuals seem to cause most of our family problems.

107. I don't think any family could live together with greater harmony than my family.

108. It is hard to know what the rules are in our family because they always change.

109. Family members find it hard to get away from each other.

110. Family members feel that the family will never change.

111. Family members feel they have to go along with what the family decides to do.

APPENDIX B

ASTHMA SELF MANAGEMENT INDEX

APPENDIX B

ASTHMA SELF-MANAGEMENT INDEX FOR ADULTS CARING FOR CHILDREN WITH ASTHMA

1. Would you say you ask the doctor questions about asthma
a) often b) sometimes c) rarely d) never

2. In the last year, have you tried to find information about asthma in:
a)Newspaper
b)Magazine
c)Pamphlet
d)Book
e)TV/Radio
f)School
g)Special Program for asthma children

3. In the last year, have you ever discussed your child's asthma with his/her teacher. Yes_____No_____

4. Recall your child's last asthma attack which resulted in a trip to the emergency room or a doctor. Once you noticed that your child was having symptoms, what did you do?
Did you give asthma medicine : yes_____
no_____

5. Did you have the child do breathing or relaxation exercises? yes_____
no_____

6. Did you have the child rest? yes_____
no_____

7. Did you do postural drainage or productive cough? yes_____
no_____

8. Are there any other measures that you did during an attack? yes_____
no_____

9. When you child has mild wheezing, what do you usually do for it?
Did you give fluids? yes_____
no_____

10. How much confidence do you feel in your ability to handle your child's asthma? a) Complete b) Alot c) A little d) None

11. What makes you decide when to give those medicines which are not given on a fixed time schedule.
a) when your child has a cold/infection
b) when overtired
c) before exercise
d) before exposure to allergens
e) during bad weather

12. Do you give fluids regularly? Yes_____
No_____

13. Do you have your child do breathing or other exercises to relax?
Yes_____
No_____

14. Do you keep your child away from other children who have colds or infections? Yes_____
No_____

15. Do you clean house in a special way? Yes_____
No_____

16. Do you keep your child away from allergens or irritants? Yes_____
No_____

APPENDIX C

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

APPENDIX C

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

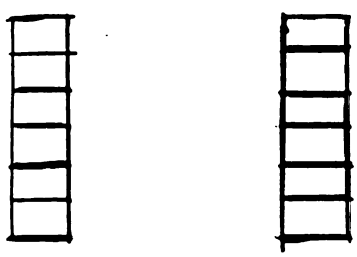
1. Name of parent_____ 2. Code no_____
3. Address_____ 4. Telephone_____
5. Sex of child_____ 6. Age of child_____
7. Is there a history of asthma in family?_____
8. When did you first find out about childs asthma?_____ 9. How long ago_____
10. Number of asthma attacks/wheezing symptoms last week?_____
11. last month?_____ 12. last year?_____

13. Has child spent night in hospital because of asthma?_____
14. if yes, how many times?_____
15. How many times during the last year have you been a doctor's office or hospital for an emergency visit due to child's asthma?_____
16. Number of school absenses since September due to asthma?_____

17 Are you currently participating in any other program for families with asthmatic children?_____ if yes, please explain_____

18. Check the box for the highest number of years completed for yourself and your spouse

	18. YOURSELF	19. YOUR SPOUSE
Some high school		
High school graduate		
Technical/business school		
Some college		
Completed college		
Graduate school		
Post graduate school		



20. Do you rent?_____ 21. Do you own a home?_____
22. Do you/your spouse have a job?_____ 23. How many children do you have_____ 24. Are you (check one) married____ divorced____ separated____ widowed____ single____

25. Income Level
less than 10,000 ____
10,000-19,000 ____
20,000-30,000 ____
30,000-40,000 ____
40,000 or more ____

26. Do you consider yourself
white ____
black ____
native american ____
hispanic ____
other____

APPENDIX D

ASTHMA ACTIVITY AND MEDICATION

ASTHMA ACTIVITY AND MEDICATION USAGE

		* of wheezing symptoms	* of asthma attacks	taken prescribed medications (yes or no)
WEEK ONE	SUNDAY			
	MONDAY			
	TUESDAY			
	WEDNESDAY			
	THURSDAY			
	FRIDAY			
	SATURDAY			

		* of wheezing symptoms	* of asthma attacks	taken prescribed medications (yes or no)
WEEK TWO	SUNDAY			
	MONDAY			
	TUESDAY			
	WEDNESDAY			
	THURSDAY			
	FRIDAY			
	SATURDAY			

		* of wheezing symptoms	* of asthma attacks	taken prescribed medications (yes or no)
WEEK THREE	SUNDAY			
	MONDAY			
	TUESDAY			
	WEDNESDAY			
	THURSDAY			
	FRIDAY			
	SATURDAY			

		# of wheezing symptoms	# of asthma attacks	taken prescribed medications (yes or no)
WEEK FOUR	SUNDAY			
	MONDAY			
	TUESDAY			
	WEDNESDAY			
	THURSDAY			
	FRIDAY			
	SATURDAY			

		# of wheezing symptoms	# of asthma attacks	taken prescribed medications (yes or no)
WEEK FIVE	SUNDAY			
	MONDAY			
	TUESDAY			
	WEDNESDAY			
	THURSDAY			
	FRIDAY			
	SATURDAY			

		# of wheezing symptoms	# of asthma attacks	taken prescribed medications (yes or no)
WEEK SIX	SUNDAY			
	MONDAY			
	TUESDAY			
	WEDNESDAY			
	THURSDAY			
	FRIDAY			
	SATURDAY			

APPENDIX E

PARENTS ASTHMA KNOWLEDGE QUIZ

PARENTS ASTHMA KNOWLEDGE QUIZ

True/False: Place a T for true and an F for false in the space provided.

_____ 1. Coughing is frequently a symptom of asthma

_____ 2. At present there is no cure for asthma

_____ 3. Swimming is good exercise for those with asthma.

_____ 4. Certain medications taken before exercise can help prevent an attack.

_____ 5. Asthma medications have no side effects.

_____ 6. Becoming emotional may cause an asthma attack to worsen

_____ 7. Children with asthma should be disciplined differently from other children

_____ 8. Most every one with asthma needs psychological help

_____ 9. There are usually other physical symptoms before wheezing is heard

_____ 10. Children with allergies to animals usually show symptoms the first time they are exposed.

_____ 11. Children with asthma have strict limits on all physical activities.

_____ 12. Parents can teach a child to relax by relaxing themselves.

Circle the correct word(s) in each statement.

13. During an asthma attack air gets trapped (INSIDE, OUTSIDE) the lungs.

14. A severe attack rarely comes on (WITH, WITHOUT) warning.

15. It appears that the occasional short term use of steroids (DOES, DOES NOT) serious,immediate side effects.

16. Laughing (CAN, CANNOT) be a cause of an asthma attack.

Choose as many phrases as are correct in each of the following items.

There may be several for each item. (Circle the letter next to each correct phrase.)

17. Asthma:
a. Is sometimes outgrown
b. Is a reversible condition
c. Is the same as emphysema
d. Can safely be ignored except when symptoms occur

18. A bronchodilator is:
a. A machine used in the hospital to force into the bronchial tubes
b. Any medicine that is prescribed for asthma
c. Any medicine that helps open the bronchial tubes
d. Any bronchial medicine that can be used in an aerosol form

19. The changes that take piece inthe lungs during an asthma attack include:
a. Swelling of tissues in the bronchial tubes
b Extra mucous is produced
c. The bronchial tubes are narrowed
d. Drying out the mucous membrances

20. Important treatment steps to following during an asthma attack include:
a. Immediately calling a physician
b. Drinking fluids
c. Continuing or beginning vigorous activity
d. Resting

21. Medicines your doctor may prescribe for asthma includes:
a Steroids
b. Bronchodilators
c. Aspirin
d. Sleeping pills

22. Some early warning signs of asthma are
a. Coughing
b. Hunched over posture
c. Paleness
d. Weight gain

23. Using more medicine then prescribed:
a. Cannot be harmful
b. Can be used in place of environmental control
c. May mean that hte asthma is not under control
d. Is the patient's choice

24. Theophylline is an asthma medicine:
a. Whose side effects are similar to steroids
b. The amount of which can be measured in the blood
c. That can be affected by smoking
d. That is the primary one used in the United States

APPENDIX F

ADULT ATTITUDE SURVEY

APPENDIX F

ADULT ATTITUDE SURVEY

DIRECTIONS: Please answer every questions, even though it may be difficult in some cases. Put a check beneath how you feel about each statement. Remember, please be as honest as possible and answer every question.

	STRONGLY AGREE	AGREE	UNCERTAIN	DISAGREE	STRONGLY DISAGREE
1. My observations of my child's asthma are important in helping to get the asthma under control.					
2. Missing a dose of medications won't hurt					
3. My child needs to be watched over almost all the time.					
4. My child can do a lot to control his/her asthma					
5. My child's like most other kids except he/she has asthma.					
6. It's hard for me to ask my doctor questions about asthma.					
7. It's important to take asthma medicine on time.					
8. My child's observations about his/her asthma are important in getting it under control					

9. The way I raise my child has little influence on his/her asthma

10. Because of asthma my child has to be more responsible than other kids his/her age.

11. My child's asthma is under control

12. There is nothing my child can do to relieve an asthma attack before it gets bad.

13. Eating healthy food can help my child's asthma

14. My child makes his/her asthma worse than it really is.

15. People with asthma can be successful.

16. My child's asthma is not affected by my attitude toward it

17. The more I know about asthma, the better I can help my child.

18. The child can't do well in school because of asthma

19. Children with asthma should be disciplined pretty much like other children

20. The more medication my child could take the better off he/she'd be

---

21. I try to be as calm as I can during my child's asthma attack.

---

22. My child uses asthma to get out of things

---

23. I cannot help my child in any way when he/she is having an asthma attack

---

24. Adults don't like my child because of asthma

APPENDIX G

SATISFACTION WITH HOME VISIT

APPENDIX G

SATISFACTION WITH HOME VISIT
(For questions 1-10 rate each statement, where 1=not true, 2= somewhat true, 3=true, 4=very true)

1. Did you learn from the home visitor	1 2 3 4
2. Would like her to return	1 2 3 4
3. Did you wish she had spent more time	1 2 3 4
4. Did it seem like you wasted your time	1 2 3 4
5. Would you like to visit other parents yourself	1 2 3 4
6. Would you recommend another parent to the program	1 2 3 4
7. Did she treat you like an equal	1 2 3 4
8. Did you feel she understood you	1 2 3 4
9. How satisified were you with the visit	1 2 3 4
10. Rate your buddy trainer (1=poor, 5=excellent)	1 2 3 4 5

What would you like to change about the content covered in the visit?_____

_____

What would like to change about the visitor? _____

_____

_____

Any other comments _____

_____ _____

APPENDIX H

SATISFACTION WITH HOME VISIT FROM TRAINER

APPENDIX H

SATISFACTION WITH HOME VISIT FROM BUDDY TRAINER

(1=not true, 2=somewhat true, 3=basically true, 4=very true)

1, Did you enjoy the time spent with your parents 1 2 3 4

2. Were you able to cover the content as specified 1 2 3 4

3. Did you think the content was relevant to the parents you visited 1 2 3 4

4. Did you feel prepare to make the home visit 1 2 3 4

5. Were the parents receptive to you 1 2 3 4

6. Do you wish somehone had visited you during your early times with your asthmatic child 1 2 3 4

7. Do you wish someone had visited you now, instead of your visiting them 1 2 3 4

8. Did you spend alot of time on things not covered in the manual 1 2 3 4

9. How would you rate the overall program of home visits for parents of asthmatic children (1=poor, 5=excellent) 1 2 3 4 5

COMMENTS_____

APPENDIX I

CASE NOTES

APPENDIX I

CASE NOTES

This is mainly for follow-up (2nd visit or phone calls). It is important that you **jot down information immediately after each contact.** This will include any requests or needs expressed by the parent and anything you considered noteworthy.

You also want to include the folowing kinds of issues or problems if they arise - parent is a smoker, feelings about Asthma Parents Support Group, issues/concerns regarding project, stated psychological needs, financial needs and anything outstanding that occurred during the visit (eg. wheezing symptoms). If any of these things come up be sure to state what action was taken (mostly this will be referral).

Please Sign and Date your entries.

APPENDIX J

FOLLOW-UP TELEPHONE SURVEY

APPENDIX J

FOLLOW-UP TELEPHONE SURVEY

Protocol
Hello my name is Joyce Nix may I speak with_____

After desired party is reached proceed with the following:

About one and one half years ago you agreed verbally to be involved in a home visitation program for families with asthmatic children. Soon after you were sent three questionnaires.

Questions
1. Do you recall the situation?

2. According to our records you never completed the questionnaires
   Wait for a response

3. What was your primary reason for dropping out of the study at that time?

4. What did you think of the questions?

5. Were the questions what you expected?

6. Did you need more prodding - if someone called you to remind you to return the questionaire do you think you would have returned them?

7. How would you have felt if someone interviewed you in your home instead of the mail-in questionnnaire?

8. What did you think of the number of questions to be answered?

APPENDIX K

MANUAL FOR HOME VISITS

APPENDIX K

MANUAL FOR HOME VISITS TO PARENTS OF ASTHMATIC CHILDREN

Prepared by Joyce Nix

"Buddy Trainer"

Please keep the following information in mind.

Each visit should be one and one-half hours long. You are making this visit for a purpose. The overall purpose is to help these parents become better managers of their child's asthma. There are guidelines you must stick *to* in order to make the program effective. These are specifically outlined in this booklet on the following pages. Try to follow these guidelines as closely as possible. We should also keep in mind that each parent is an individual.

Remember that your are/were in their same situation. Before you appoach them, think about how you would like to have been/be approached.

* The underlined sentences represent the content which is to be directly communicated to the parent

HOME VISIT 1

Introduction

You are a parent with an asthmatic child who can identify with the parent whom you are visiting. Your approach should be as nonthreatening and informative as possible. You are not there to lecture, evaluate, diagnose, treat, psychologize or chit chat. One way to open the conversation might be to give your name_____
then proceed to describe the program and be sure to cover the following points:

*we are trying to establish positive communication among families with asthmatic children in the Greater Lansing Area.

*we will do this by making two one and one half hour home visits to those families assigned to this aspect of the study

*I am a "buddy trainer". A "buddy trainer" is a parent like yourself who has an asthmatic child and has received some extra training in order to help other parents in managing their asthmatic child

*during this first home visit we will first go over some general information about asthma, treatment for asthma, expectations during medical visit and EMR visit. We will also discuss some ideas for effective self management behavior before an attack, during an attack and in the medical care

facility. An appointment for a second visit will be made, no more than two weeks away from first visit.

*be sure to ask if they have any questions

Do not spend too much time on the introduction. There is alot more to cover during this one and one-half hour visit.

****
****

Asthma- Incidence/Prevalence

This part is to remind them that they are not alone in dealing with this condition. Alot of other people and parents of asthmatic children are dealing with this. Your can read this directly or just relay this information in your own way. The major point is that they are in good company.

There are about 6 million people with asthma in the United States. It is particularly common among children. Some estimates range from 5 to 15 percent of the children have asthma. It is one of the most common conditions of childhood and is a major cause of school absenteeism. There are probably several hundred asthmatics in the Lansing area. We were able to identify about 150 families with asthmatic children with this project alone.

Be sure to give time for questions, comments or conversation around this issue if it arises.

Asthma - What is it

Show them this picture on the last page to give them a visual idea of what is happening to the lung during an attack. This is a simplistic representation of the physiology of the lung before and during an attack. Remember your are not an expert, you are there to help them understand the condition with the hope of increasing their self management skills.

What Triggers an Asthma Attack There are many different things that can trigger the occurence of an asthma attack.

You can go over with them the following list consisting of some of the things that are known to cause an attack in other asthmatics
Trees, Grass, Weeds, Pollen, Mold, Fungi, Animal Feathers, Aspirin, Exercise, Infections and Emotions

You want to stress that these are just some of the things that may cause an attack. There are lot of other things that may cause an attack. And, these particiular things may not cause an attacks in your child's case. In many cases what causes an attack remains unknown.

What can be done to help prevent an attack- Some parents may feel overwhelmed with the possibility of an attack at every turn. To take the child out could bring on an attack since trees and grass can be found every where. This is where sensibility, your experience, their experience, their physician's advice needs to be solicited. The main thing you want to accomplish in this section is to determine what are the identifiable precipitants This will be accomplished by looking at the events surrounding the asthma attack

Think back to the last asthma attack/or wheezing episode your child had.
Where was he/she_____
What was the environment like_____
What was he/she doing_____
What can you conclude was the possible cause(s)_____

Have the Parent go through this process again by remembering the asthma attack/wheezing episode before this one. Maybe they can begin to recognize a pattern of precipitants. Or perhaps they already know the preciptants in their child's asthma.

The Parent may have concluded we should /we do limit this activity_____and /or that activity_____ because of our child's asthma.

The parent may have several different activities that they would like to do but they do not do because of their child's asthma. Give the parent time to include as many as they want to.

Treatment

This is the most important aspect of a self care program; following the medical regiment prescribed by the physician. The more closely this is followed, the more likely the child is able to avoid/prevent an attack. As the 'buddy trainer' it is your job to find out what the child is currently taking.

What medication is your child currently taking for his/her asthma?
How long has he/she been taking this medication?
Do you find that you are able to insure that he/she takes his/her medication regularly (or when prescribed)?

There are some things that you can do to encourage your child to take his/her medication. You can give him verbal or material reinforcement when he/she take his/her medi cation. The type of reinforcement may vary depending on the age of the child. The point is to make notice of the positive behavior with some positive response, an expression of praise. Or, you can give a privilege, a gift, money for his/her proper medication taking. This accomplishes the same thing. The key in both the verbal and material reinforcement is to be consistent. In other words, give the reinforcement regularly in response to the positive behavior

Medication

At this point you want to describe what the medication is doing to the lungs. The parent can get a visual idea of what the medicine is doing to the body in treating the asthmatic condition. You may use the figure on the last page to explain this. This, it is hoped, can act as an incentive for the parent to encourage his/her child to take the medication.

Generally The Medicine does.....

Bronchodilators are.....and they do.....

The Shots can.....

Most asthmatics are suppose to either take their medication regularly or when they feel an attack coming on.

My child takes _____ about _____ (name of medicine)

every _____

For those asthmatic children on a regular medication schedule the following comments maybe helpful

It is helpful to focus on the particular time of day your child is suppose to take the medicine. You can help him/her stick to taking the medicine at this time by associating it with some other event like a meal.

It is important to remember that although your child

may be symptom-free at times, he/she still needs to continue with the medical regiment as prescribed by the doctor (unless the doctor discontinues it). Even though your child still has symptom when he/she is taking the medication, don't be discouraged. Asthma symptoms are unpredictable at times.

If you have any particular fears of drug side-effects, or general questions about medications, be sure to talk to your doctor/medical professional about it. Many other parents have had the same concerns as you.

During The Asthma Attack

At this point you want the Parent to describe what they normally do when the child has an asthma attack or wheezing symptom. You do not want to tell these parents what to do, you merely want to determine their current behavior.

What do we do during an asthma attack.....
During the last asthma attack we did_____
And the asthma attack before that we_____

Did you go to the hospital/doctor's office or stay home_____

How did you feel about your response_____
Did you feel comfortable engaging in that behavior_____

There are often early signs of respiratory distress. Some of these signs are postural changes, a hunching over of the shoulders, itchiness around the nose, chin or throat, darkness around the eyes, changes in facial expressions, feelings of fatigue and signs of irritability and a low tolerance for frustration. A particular sign or combination of signs will be particular to your child. You can begin to learn your child's signs of respiratory distress .This will serve as cue for immediate symptom management efforts.

There are three self management steps during these initial states that the child can do. The first is to drink large amounts of liquid. Warm juices are better than cold. The next step is immediate rest and reduction of activity. Diaphragmatic breathing, in contrast to shallow breathing from the chest and shoulders, is a more effective use of breathing at this time. (As the "Buddy Trainer" you might briefly demonstrate this.) The third step is taking medication, if there is no relief from the first two steps. The medication at this time is usually the broncho dilators. But broncho dilators need to be taken cautiously and carefully. Consult with your physician for accurate knowledge of its uses and abuses .

If the parent felt comfortable with his/her behavior at home during an asthma episode, then you can go on to PROCEDURE IN MEDICAL CARE FACILITY. If the parent was uncomfortable , determine what they were particularly uncomfortable with during the episode of asthma.

What was particularly uncomfortable regarding the asthma episode_____

Do you have any ideas of what you can do to increase your confidence in being able to deal with this_____

Affirm those behaviors/attitudes that the parent feels may increase his/her confidence by nodding your head or elaborating on any particular point that has been especially helpful to you in coping with your asthmatic child. At this point it may also be helpful to stress the importance of time and experience in increasing the parents ability to cope with asthmatic episodes.

The more experience you have in dealing with your child's asthma the more competent you probably will become in handling your child's asthma and the better you will feel.

Procedure in Medical Facility

If the parent went to the medical facility to have their child treated for asthma, now is the time to go over briefly the procedure for a child brought in for an asthma attack.

You can expect that the medical professional in the hospital will respond immediately when they see your child come in with an asthma attack. Their main concern is to help your child breath normally as soon as possible.

In order to do this the medical person will give your child a bronchorelaxer. This could be administered orally or by an injection. There are many different kinds. The purpose of this is to relieve the constriction in the lungs thats causing the difficult breathing. If an asthma attack is untreated it could lead to death, although this is not very common.
If the attack is not too severe, the child will be treated and allowed to go home immediately. Sometimes it is necessary to keep the child in the hospital.

The medical person may ask you questions regarding events leading to the attack and/or medication usage. Since this is usually in a hurried situation, you can help their care by being mentally prepared with this information beforehand.

Not all physicians are alike. When receiving emergency care you can almost be sure that one doctor will not be as personable as the next. This calls for some flexibility when using emergency room service. This may also call for a toleration of frustration. In particular, some parents would like to stay with their child during the treatment, physicians vary on this.

But its up to you to make sure your questions are answered. If you must, while waiting for your child, jot down some questions to ask the physician. In the mist of a stressful situation its very easy to forget. Remember, this is your child, and you always have the right to know the facts regarding his/her condition.

Any questions/comments_____

****

Make an appointment for the second visit

Date_____Time_____

HOME VISIT 2

Visit 2 - The purpose of this visit is to reinforce the self management skills discussed in visit 1. At the same time, as the "buddy trainer" you will work at establishing a rapport with the parent and informing him/her of resources in the community.

Introduction

During this visit I would like you to get to know me better. I would also like to discuss some of the resources available in this community to parents of asthmatic children. At last,I would also like to review some of the self management skills we discussed at the first visit

****
****

Sharing Your Own Story

At this time you want to briefly discuss aspects of your experience that seem particularly similar to the parent you are with. You are attempting to find points of commonality with the hope of establishing a link. It's extremely important that you be honest about what you felt at those times earlier in your experience. You become a more effective coping model when the parent can see that you were at his/her same place but you were able to adapt, grow and become more competent.

In order to share your experience you may consider the following:

*a description of your earlier experience with your child's asthma attack
*feelings you had while your child was experiencing an episode
*lifestyle changes that you made to accommodate your child's condition
* how things have changed from those earlier days when you first found out about your asthmatic child

Resources in the Community

At this time you want to discuss three important resources available to parents of asthmatic children. These three community resources are: The Office of Crippled Children, The Superstuff Kit, and The Asthma Parents Support Group. You want to at least cover the following points for each of these resources.

The Office of Crippled Children

* it provides financial support to help eligible families pay for health care for their children.
*Asthma may be covered depending on the severity of the condition.
* You can call 371-5360 for more information

The Superstuff Kit

*This is a self help kit distributed primarily by The American Lung Association. You can get it by calling ALAM office (484-4541). Many people offer a donation when requesting it.
* It is geared toward parents and children from 6 to 12 years of age.

The Asthma Parent Support Group

* This is a self help group run by parents of asthmatic children in the Greater Lansing Area. There are similar groups getting together all over the country.
* The meetings are usually held monthly and the group is always interested in recruiting new members.
* They typically have a speaker to discuss some issue relevant to the parents. The format always provides for

discussion as well.
* The meetings are usually held at Ingham Medical Center
* Call Marilyn Parent for more information (655-2572)

The Review of Self Management Skills

You want to go over the major skills discussed in the first visit. You will tell the parent- since the purpose of these visits is to help you adapt/cope with your asthmatic child more effectively, we would like to stress the following points:

* determine the environment in which the asthma attacks/wheezing symptoms occurr.

* find the triggers and avoid them as much as possible.

* take medication as prescribed whether there are asthma symptoms or not. And, if you have questions about medications be sure to ask your physician

* begin to notice how your child looks before an asthma attack. You may notice changes in face, breathing, coughing etc.

* there are three simple things you can have your child do when you are anticipating an attack - these are: rest, drink warm juices and finally take medication if the first two do not reverse the symptoms.

* be prepared to answer questions related to the asthma attack when going to the emergency room for treatment.
* have the list of medications that your child is

discussion as well.
* The meetings are usually held at Ingham Medical Center
* Call Marilyn Parent for more information (655-2572)

The Review of Self Management Skills

You want to go over the major skills discussed in the first visit. You will tell the parent- since the purpose of these visits is to help you adapt/cope with your asthmatic child more effectively, we would like to stress the following points:

* determine the environment in which the asthma attacks/wheezing symptoms occurr.

* find the triggers and avoid them as much as possible.

* take medication as prescribed whether there are asthma symptoms or not. And, if you have questions about medications be sure to ask your physician

* begin to notice how your child looks before an asthma attack. You may notice changes in face, breathing, coughing etc.

* there are three simple things you can have your child do when you are anticipating an attack - these are: rest, drink warm juices and finally take medication if the first two do not reverse the symptoms.

* be prepared to answer questions related to the asthma attack when going to the emergency room for treatment.
* have the list of medications that your child is

currently taking when you go to the emergency room

* don't be afraid to ask the doctor any questions you may have.

* inform teacher about your child's asthma and be sure your child takes medication in school if he/she needs to.

Do you have any questions or comments_____

_____

_____

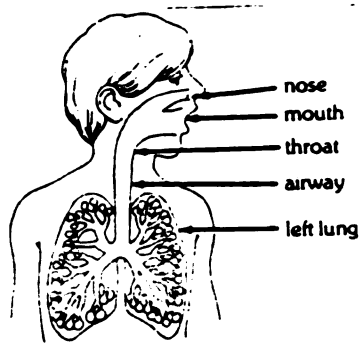
Conclusion

At this time you may want to say that you have personally enjoyed meeting with them. Please leave your personal phone number just to give the parent the opportunity to call you if they wish. You may also want to inform the parent that you will be calling them to follow-up on some of the things that were discussed.

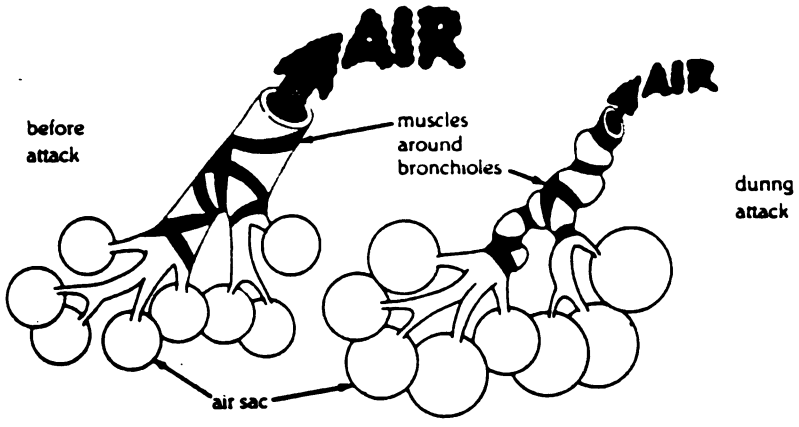
Three things happen when you have an Asthma Attack.

These three things make it harder for you to breathe.

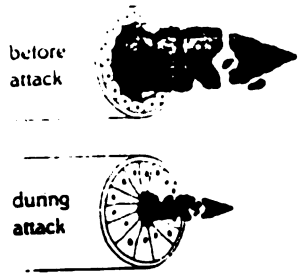
These three things make the space the air goes through get smaller.



1. The muscles in the bronchioles *tighten* up
   This makes it hard to get air out of the air sacs in the lungs.



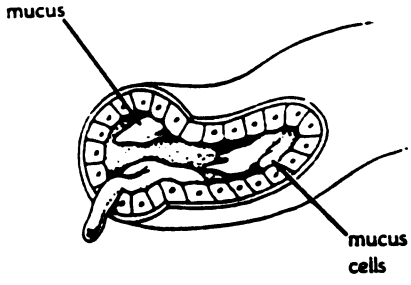
2. The cells inside the bronchioles become swollen
   Cells are small parts of the body



When something is *Swollen*, it is bigger than it should be.

This also makes it hard to get air out of the air sac.

3. The cells inside the bronchioles make *Mucus*.
   Mucus is watery. In your head it will give you a runny nose or make you feel stuffed up.



REPRINTED AND REVISED FROM, PARCEL/TIERNAN/NADER/WEINER's "TEACHING MYSELF ABOUT ASTHMA"

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