

JUN 22 2004

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503.

1. AGENCY USE ONLY (Leave blank) 2. REPORT DATE 17.Jun.04 3. REPORT TYPE AND DATES COVERED THESIS

4. TITLE AND SUBTITLE
THE IMPACT OF A SELF MANAGEMENT ASTHMA EDUCATION PROGRAM ON HEALTH OUTCOMES AND QUALITY OF LIFE

5. FUNDING NUMBERS

6. AUTHOR(S)
CAPT HALL GERALD W JR

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)
ARIZONA STATE UNIVERSITY

8. PERFORMING ORGANIZATION REPORT NUMBER
CI04-372

9. SPONSORING/MONITORING AGENCY NAME(S) AND ADDRESS(ES)
THE DEPARTMENT OF THE AIR FORCE
AFIT/CIA, BLDG 125
2950 P STREET
WPAFB OH 45433

10. SPONSORING/MONITORING AGENCY REPORT NUMBER

11. SUPPLEMENTARY NOTES

12a. DISTRIBUTION AVAILABILITY STATEMENT
Unlimited distribution
In Accordance With AFI 35-205/AFIT Sup
DISTRIBUTION STATEMENT A
Approved for Public Release
Distribution Unlimited

12b. DISTRIBUTION CODE

13. ABSTRACT (Maximum 200 words)

20040706 096

14. SUBJECT TERMS

15. NUMBER OF PAGES
96

16. PRICE CODE

17. SECURITY CLASSIFICATION OF REPORT

18. SECURITY CLASSIFICATION OF THIS PAGE

19. SECURITY CLASSIFICATION OF ABSTRACT

20. LIMITATION OF ABSTRACT

**THE VIEWS EXPRESSED IN THIS ARTICLE ARE
THOSE OF THE AUTHOR AND DO NOT REFLECT
THE OFFICIAL POLICY OR POSITION OF THE
UNITED STATES AIR FORCE, DEPARTMENT OF
DEFENSE, OR THE U.S. GOVERNMENT.**

**IMPACT OF SELF-MANAGEMENT EDUCATION
ON HEALTH OUTCOMES AND QUALITY OF LIFE
IN CHILD ASTHMA**

by

Gerald W. Hall Jr.

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

DISTRIBUTION STATEMENT A
Approved for Public Release
Distribution Unlimited

ARIZONA STATE UNIVERSITY

May 2004

ABSTRACT

According to the National Center for Health Statistics (2001) in 1998, 3.8 million children aged 0-17 years had an asthmatic episode. Nationally the asthma population is 6.3%. Arizona has exceeded the national asthma rates for 1991-1998 with an incidence of approximately 7% of the population.

Asthmatic children require self-management instruction about asthma, medications, symptoms, and proper self-management. Poor self-management results from a lack of competence over asthma related self-management skills. This study defined self-management skill as those skills an asthmatic must have for competence in management. The purpose of this study was to test a self-management education program designed to enhance the self-management skill of inner city children with asthma in order to improve their health outcomes and quality of life. Measurement of effect in health outcomes and quality of life (QOL) were the indicators of competency in self-management skill. The pediatric asthma-specific questionnaire by Juniper and Guyatt (2001) examines QOL. Thurber and Blue (1994) developed the Asthma Self-care questionnaire to measure health outcomes.

The pilot study design utilized a quasi-experimental design with pretest/posttest and nonrandom assignment of subjects measured the differences in health outcomes and QOL of asthmatic children. Data collection was at three inner city Phoenix public schools. The analysis examined the independent variable influence of self-management education on the dependent variable impact on quality of life and health outcomes.

ACKNOWLEDGEMENTS

I am sincerely grateful for the wisdom and patience demonstrated towards me by my advisor and committee chair, Dr. Frances Thurber. In my work with her over the past two years, I am certain that I had a major part in causing her to retire. Humor aside, without you anchoring my insane drive for perfection I would have retired. I would also like to thank my committee members, Dr. Evelyn Cesarotti and Dr. Barbara Brillhart, for their support and assistance given to keep my proposal on course.

I would particularly like to thank the Phoenix Elementary School District number one. I especially want to acknowledge Dr. Deborah Jones and Principals Dr. Wendy Ong, Frank Tanori, and Alice Trujillo for their receptiveness into their schools. I would have made no progress at all without the support and dedicated effort of the school nurses. Sharon Laughlin and Elizabeth Hunter worked with me without complaint to gather the information and student support needed for my control group children. I especially am grateful for Lynette Cook. Her efforts in assistance with scheduling, child recruitment for the intervention, classroom support, and constant support were unmatched.

Finally, and most importantly I would like to express my love, accolades, and, gratitude to my wife and my four boys. Without your love, understanding, and support of "Dad's office time" and hours away from home I would have never managed to finish this thesis. I would like to especially acknowledge my wife [REDACTED], her love, commitment, and encouragement kept me going in the roughest of times. I love you.

TABLE OF CONTENTS

	Page
LIST OF APPENDICES.....	vii
LIST OF TABLES.....	viii
LIST OF FIGURES.....	ix
CHAPTER	
1 INTRODUCTION.....	1
Background or Need for the Study.....	2
Statement of the Problem.....	5
Purpose of the Study.....	7
Research Questions.....	9
Statement of Hypothesis.....	9
Theoretical or Conceptual Definitions.....	10
2 REVIEW OF LITERATURE.....	13
Deficit in Knowledge.....	13
Deficit in Self-management Skill.....	15
3 METHODOLOGY.....	22
Design.....	23
Protection of Human Subjects.....	28
Data Collection Plan.....	29
Instruments.....	30
Data analysis plan.....	33

CHAPTER		Page
4	FINDINGS.....	35
	Sample Characteristics.....	35
	Findings.....	37
	Summary of Findings.....	41
5	CONCLUSION AND RECOMMENDATIONS.....	43
	Summary of major findings.....	43
	Finding Interpretation Related to Previous Studies.....	44
	Implications of Findings to Theory.....	48
	Implications of Findings to Practice.....	50
	Limitations on the Generalizability of the Findings.....	51
	Further Research.....	52
	REFERENCES.....	54

LIST OF APPENDICES

Appendix	Page
I. PARENT CONSENT AND ASTHMA HISTORY FORMS.....	58
II. CHILD ASSENT FORMS.....	62
III. HANDOUT MATIERIALS.....	65
IV. ASTHMA SELF-CARE QUESTIONNAIRE.....	77
V. PEDIATRIC ASTHMA QUALITY OF LIFE QUESTIONNAIRE WITH STANDARDIZED ACTIVITIES.....	80

LIST OF TABLES

Table	Page
1. Sample population statistics for the PAQLQ(S).....	39
2. Descriptive statistics of posttest scores by group.....	40
3. Univariate Test of Within Subjects.....	42

LIST OF FIGURES

Figure	Page
1. Proposal Model.....	9
2. Proposal Framework.....	11

CHAPTER 1

Introduction

Asthma ranks among the most common pediatric chronic conditions in the United States, and is reported to affect nearly 5 million people who are younger than 18 years of age (Center for Disease Control (CDC), 2002). A study by Robertson, Rubinfeld, and Bowes (1992) found that pediatric asthma deaths frequently occur in children with mild asthma. Among 51 asthma deaths reported in patients younger than 20 years in Victoria, Australia, 17 (33%) occurred in patients classified with mild asthma. According to US asthma surveillance data from 1980 to 1999, asthma mortality rates have continually increased in the United States, children also had 3.5 million physician visits in 1999; 658,000 emergency department visits in 1999 and 203,000 hospitalizations in 2000; and 14 million missed school days, on average, annually from 1994 to 1996 (CDC, 2002). In the treatment of asthma, children with asthma are required to self-manage complex medication regimens that include adjustment of medications as symptoms increase or decrease. Patient's underestimation of their acute asthma symptoms has been associated with deaths and acute episodic care or emergent visits. This failure to acknowledge symptoms has caused not only delays in starting treatment of exacerbations, but also demonstrates poor knowledge of medication use and self-management skill. However, a review of literature shows that children with asthma can increase self-management skills and

improve health outcomes through education (Diette, 2000; Kelly, 2000; Lahdensuo, 1996; Lukacs, 2002).

Background or Need for the Study

According to the National Center for Health Statistics (2001) in 1998, 53 per 1,000 children 0-17 years (3.8 million) had an asthma episode or attack. Asthma is a major public health problem, the prevalence of asthma has increased 75% overall and 74% among children 5 to 14 years of age. Health care utilization for asthma includes outpatient visits to doctors' offices and hospital outpatient departments, visits to hospital emergency departments (EDs), and hospitalizations. Asthma occurs in approximately seven percent of the population, and is higher in the inner city populations. Nationally the incidence of the asthma population is 6.3%. Asthma occurs in approximately seven percent of the population in Arizona and may be higher in Phoenix due to the increase in prevalence with inner city populations. The population of Arizona is at risk for asthma. The risk of the population in Arizona and Maricopa County has equaled or exceeded the United States mortality rates from 1991 through 1998. The incidence is expected to increase with the rapid growth of the Phoenix Metropolitan area (University of Arizona Health Sciences Center, 2002).

The Arizona Hospital Discharge Dataset (includes length of stay and cost of care while hospitalized) and Arizona Mortality Data, available from the Arizona Department of Health Services (ADHS), can characterize serious asthma attacks and fatalities by age, sex, race, and regions of residence. This database reflects

45,988 asthma admissions to Arizona hospitals for the years 1999-2002 with 13,992 occurring in Maricopa County (ADHS, 2003). The Maricopa County admission rate for asthma accounts for approximately 31% of the entire state total. This does not include emergency room or outpatient visits for Arizona. This is not surprising when considering that the population density of Maricopa County is roughly 60% of the population in Arizona. Population density is one barrier of many common barriers to good asthma care (University of Arizona Health Sciences Center, 2002).

In addition to population density, common barriers to good asthma care encountered are poverty level, single-parent family, multiple caregivers, limited or no health insurance, and multiple parental responsibilities (American Academy of Allergy Asthma, and Immunology (AAAAI), 1999). In the United States, more than one in every five children live in poverty. Children who are under the age of 18 accounts for over 33% of medically underserved persons in the United States. The highest morbidity and mortality from asthma has been reported for inner-city populations for whom it is difficult to separate economically related factors. The economic factors include low education levels, sub optimal environmental characteristics, and inconsistent access to health care (Nelson, Johnson, Divine, & Strauchman, 1997). The inner-city child not only has increased morbidity and mortality, but also usually resides in a medically underserved area (Robinson, 1999). Jaing, Sepulveda, and Casillas, (2001) confirm that inner city children's lack of resources to prevent or avoid airway irritant exposures, antiquated and

substandard living arrangements, poor domesticated animal control, lack of health-care, population density, and patterns of viral illness contribute to the elevated risk of asthma. The increased incidence of asthma is mostly related to increased exposure to airway irritants that cause acute symptoms and exacerbations.

Patients with asthma have historically been particularly vulnerable to medication adherence problems because of the chronic nature of the disease, use of multiple medications, and periods of symptom remission. Rates of non-adherence in the treatment of asthma may vary from 20 to 80%, (Cochrane, 1992). Poor adherence with the asthmatics' complex medication regimen is a major problem in pediatric asthma management and leads to negative outcomes (Kemp, 2001).

In an adult self-management pilot study, Schott-Baer and Christensen (1999) realized that a self-management program is a pressing priority. They felt that most efforts to improve patient self-management had focused on patient education about the disease and its treatment. They also concluded that recent research had recognized the need to develop programs that first enhance a patient's willingness and abilities to participate actively in self-management. However, few research efforts that focus on children's self-management strategies that promote problem solving and prevent high-risk exposures to acute asthma symptoms are available.

Statement of the Problem

In the treatment of asthma, patients are required to self-manage complex medication regimens that include adjustment of medications as symptoms increase or decrease. Poor medication adherence can be the result of any number of causes, but asthmatics' lack of competence in self-management skills may be one cause that can be positively impacted through an education program. Self-management skill, for the purpose of this study, is defined as those learned skills that an asthmatic requires to have optimal control over one's disease.

Poor self-management skill has been correlated to variables in quality of life studies. In one study, low-income minority children were evaluated with the pediatric asthma quality of life tool (PAQOL) and consistently children with asthma and/ or their parents rated the four domains (activity limitations, symptoms, emotional status, and overall health) at significantly lower levels than children without asthma. A clinically significant improvement was measured in each category after the self-management education program was concluded (Kelly, et al., 2000). Treatment of asthma of a greater than mild intermittent disease state, as defined by current guidelines, consists of a combination of quick relief and long term control medications (NIH, 1997). Frequent adjustments are required due to exposure to asthma triggers like allergens, seasonal changes, and cold symptoms. Many times, even while under treatment, patients may fail to adjust long-term medication or they stop

maintenance medications on their own during periods of symptom remission resulting in eventual exacerbation (NIH, 1997). Further, Yoos and McMullen (1999) found that both children and parents missed early symptoms or waited too long prior to intervening in an exacerbation. For this study, a proactive approach in self-management education will be utilized with the child intervening before symptoms would normally appear.

It has been noted in published studies that supervised self-management using self-management skills education, which includes self-adjustment of long term or anti-inflammatory treatment improved quality of life. The improvements of one study documented an exchange of the negative health outcome measures of low peak expiratory flow, hospitalizations, acute episodic visits, and antibiotic courses for improved quality of life among adults (Ladensuo, Haahtela, Herrala, Kava, & Svahn, 1996). Much of the research on the effects of asthma education has demonstrated reduction in multiple negative health outcomes including reduction in asthma severity, school absenteeism, and Emergency Department visits as well as improved quality of life and control over asthma symptoms (Canadian Asthma Consensus report (CACR), 1999). Further, it has been suggested that poor self-management is evidenced by symptoms that are allowed to appear due to poor adherence or lack of knowledge in self-management. These symptoms often require the asthmatic child to utilize higher doses of anti-inflammatory medication and more frequent use of bronchodilator medication, (Kemp, 2001). A similar Canadian study of self-

management education conducted in the children's schools found a clinically important effect of improved quality of life (Young, et al., 2001).

The design of the proposed self-management education program is hypothesized to positively impact quality of life and decrease negative health outcomes by improving knowledge and self-management among asthmatic children.

Purpose of the Study

The purpose of this study was to test a self-management education program designed to enhance the self-management skill of inner city children with asthma in order to decrease their negative health outcomes and thus improve their quality of life. Evidence of improved quality of life will be measured as a decrease in activity, emotional, and symptomatic limitations. Successful asthma education should be aimed at altering behaviors that produce negative health outcomes. A diverse range of strategies was important to ensure that the self-management program was not totally reliant on written and videotaped material. The success of self-management education is dependent upon good communication with the educator, effective asthma therapy, and a written action plan for guided self-management (CACR, 1999). The self-management skill education program developed emphasized accurate symptom perception, prevention, and recognition of symptoms that worsen asthma. This study employed measures of health outcomes and quality of life as the primary indicators of improved medication adherence and self-management skill. Health

outcomes were monitored by use of the Asthma Self-care Questionnaire (Thurber and Blue, 1994), which included perceived self-management competence with the medication regimen. Additionally, parents were asked to report measures for number of acute episodic care visits, Emergency Department (ED) visits, and hospital admissions. Quality of life was assessed utilizing the Pediatric Asthma Quality of Life Questionnaire (PAQLQ) (Juniper, 2001). Self-management skill, for the purpose of this study, was defined as a set of learned skills that the asthmatic required to have optimal control over the disease. The self-management program included asthma education related to the skills of self-monitoring for symptoms, knowledge of airway irritants, regular medical follow-up, control of factors that contribute to or aggravate symptoms, and a written action plan that detailed routine and optimal use of quick relief and long-term medication.

There have been many validated and successful programs that are effective in impacting asthma health outcomes. The National Asthma Education and Prevention Program has outlined key educational messages for program design that reinforce the Expert Panel Report 2, Guidelines for the Diagnosis and Management of Asthma (1997). The study's self-management educational program was designed to improve knowledge and ability to assess and self-manage asthma. The short-term effect will be improved knowledge, by participation in the asthma education program. The long-term effect of competence in self-management will be measured by changes in the pediatric

asthmatic quality of life. See proposal model figure 1.

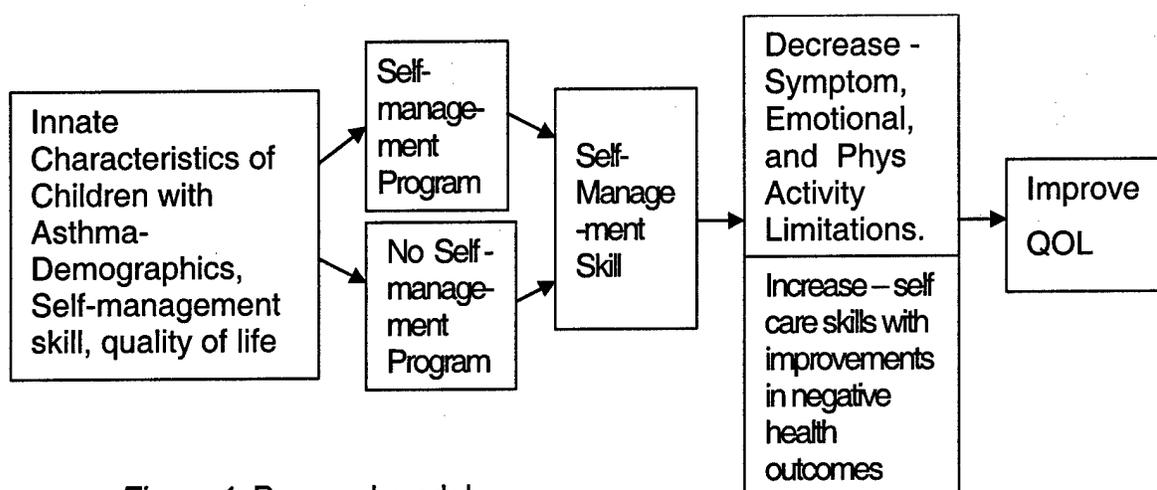


Figure 1. Proposal model

Research Questions

Will an asthma self-management educational program improve pediatric asthma health outcomes?

Will an asthma self-management educational program improve pediatric asthma quality of life?

Statement of Hypothesis

Children with asthma will demonstrate improved quality of life and health outcomes after completion of a self-management focused education program.

Theoretical or Conceptual Definitions

The essence of this asthma education program is the possession of the ability and knowledge needed to make planned changes in behavior that are related to improvement in health. The framework utilized to guide the asthma education outlined in this study is Nola Pender's Health Promotion Model. In her model, health promotion consisted of those activities that are directed toward increasing the level of well being and actualizing the health potential of individuals. She also emphasized the use of preventive efforts to minimize the occurrence of disease and its complications as well as promote health restoration and greatly enhance quality of life (Pender, 1982). In Pender's health promotion model she believed that a child's understanding of their own health and illness influences their health promotion behaviors. The goal of use of the health promotion model with this study was to understand how children could be motivated to attain personal health. The relevance for application is the emphasis placed on the importance of the individual's assessment of the factors believed to influence their health promoting behavior. This framework flows from the influences of the individual's characteristics and behaviors, individualizes to their perceptions, and attains commitment to a plan of action that works towards a health promoting behavior (Tomey & Alligood, 1998). The framework has been modified from Nola Pender's health promotion model (figure 2).

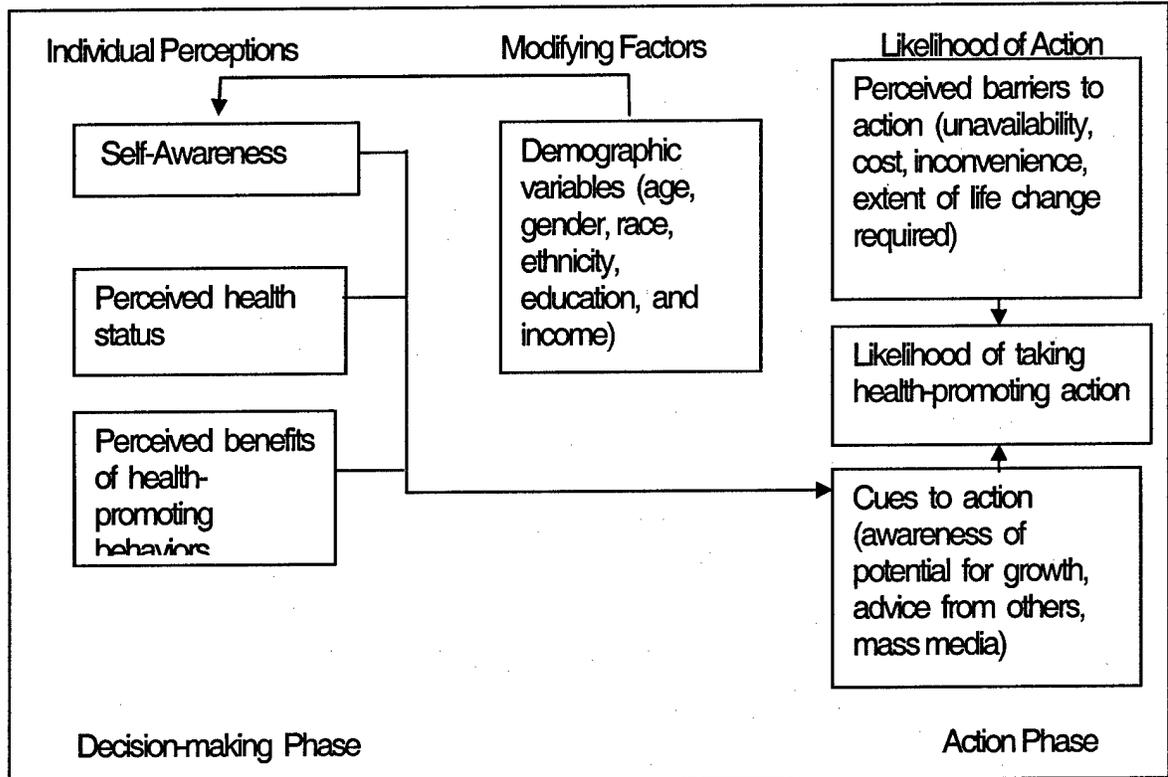


Figure 2. Proposal framework

The model has determinants of health-promoting behavior (dependent variable) categorized into individual perceptions, modifying factors, and variables affecting likelihood of action (independent variables). It is a holistic model that looks at infusing the perceived benefits of health promotion into everyday life and therefore is more inclined to begin or continue the health-promoting behaviors. The two most powerful components to this model that will affect the intervention are perceived health status and perceived barriers to action. These portions of Pender's Model will be evaluated by defined measures in the pre- and post-tests of the PAQOL and health outcomes. The school-age child may retain less information or poorly attend the intervention if the child feels their asthma is

under control. If barriers to action exist with the study population and are not eliminated, the child may not attend the program.

CHAPTER 2

Review of Literature

The review of literature focused on the two deficits that effect quality of life and health outcomes of asthma. These two deficits are a lack of knowledge of asthma and a lack of the skills required for self-management.

Deficit in Knowledge

A knowledge deficit exists in relation to self-management in the asthmatic child population that has been associated with evidence of poor medication adherence, symptom management, and understanding of the disease process. The outcomes of these deficits are increased use of rescue medications, acute episodic visits and emergency room visits, admissions to hospitals, and mortality. Deficiencies have been identified in all areas of self-management including proper technique with medications, self-management education, and control of factors contributing to asthma severity. In asthmatic children with the greatest severity of symptoms, knowledge gaps have been reported for many aspects of asthma care. Deficient areas included instruction on how to adjust medications, written instructions for management of asthma attacks, incorporation of pulmonary function and allergy testing, and regular use of long-term control medication (Diette, et al., 2000).

A comprehensive asthma intervention program for low-income pediatric clients in a Virginia study had the objective to improve quality of life (Kelly et al., 2000). Low-income, minority children were believed to lack the effective outpatient care required to decrease adverse outcomes due to their caretakers

relying heavily on acute episodic care instead of routine preventive care. The resulting program was designed to educate low-income, minority children who had poor knowledge about asthma because their primary health care was associated with only emergent care. The researchers organized a controlled clinical trial set in an urban pediatric allergy clinic. Eighty low-income minority children on Medicaid were alternately divided into intervention and control groups. The primary care providers (PCP) were aware that the study was being conducted, but not if any of their patients was a participant in the study. The control group received routine care from their PCP. The intervention group and their caretakers participated in a standardized curriculum one-on-one asthma education session in the clinic. The session was tailored to meet the needs of each of the children and their caretakers. The patients were given a written action plan for exacerbations. The entire program conformed to the standards set by the National Heart Blood and Lung Institute (NHBLI) asthma guideline. The researcher contacted each intervention family monthly over a year to inquire about the child's asthma, medications, and follow-up visits needed.

The results indicated the intervention group had a decrease in the health outcome measures of PCP visits, hospitalizations, and mean total charges for asthma-related health care utilization. Pediatric asthma-specific quality of life (PAQOL) was measured on children of 7 years of age and up and with the younger children's caretakers. A clinically important change was noted in each domain tested (see instrument description, Ch. 3). The researchers concluded

that a comprehensive intervention program including education, medical management of asthma in accordance with the NHBLI guidelines and an effective outreach component could improve negative health outcomes for low-income children with asthma with a level of significance (P) at $<.05$ and improve quality of life (Kelly et al, 2000).

Gallefoss and Bakke (1999) organized a randomized controlled study to compare the effects that the intervention of a standardized self-management education program and a self-management plan could have on the skills of steroid inhaler adherence and rescue medication utilization in patients with asthma and chronic obstructive pulmonary disease (COPD). They investigated if a lack of knowledge about the medication was a contributing factor that led to the poor adherence prevalent in this population. The premise for this study was that these patients are particularly vulnerable to self-management problems because of the chronic nature of their disease, the use of multiple medications, and the periods of symptom remission. The sample was 140 consecutive patients with age range of 18-70 years. They were randomly assigned equally into intervention or control groups after referral on a routine consult to an outpatient pulmonary clinic. The control group was then released to be followed by their general practitioner and the intervention group received the education program. The intervention group received educational handouts, two group educational sessions two hours in length and two individual 40-minute sessions. The educational intervention consisted of a specially designed handout, the sessions

concentrated on pathophysiology, use and function of medications, symptom awareness, asthma treatment plans and physiotherapy. Each one of the Intervention group members received an individualized asthma treatment plan. After one year, analyses were performed on steroid inhaler adherence (>75%) and adherence to the prescribed defined daily dosage. The study results indicated that self-management education gave 57% of the patients a better steroid inhaler adherence score when compared with traditional treatment by a general practitioner. Also, that double the amount of short-acting beta-2 agonists were being dispensed to the uneducated patients. The researchers concluded that self-management education can change medication habits by reducing the amount of short-acting inhaled beta-2 agonists and improved steroid inhaler adherence.

Deficit in Self-Management Skill

Yoos and McMullen (1999) organized a pilot study to explore how the inaccuracies in symptom perception contributed to morbidity and mortality in childhood asthma. They evaluated the asthmatics' ability to manage asthma and recognize symptoms, realize the need to interpret the symptoms, and then decide on the course of management. The hypothesis for the study was that an accurate symptom perception was the most important component of self-management. The authors proposed that symptom perception and evaluation on the part of children and their families is a multidimensional construct consisting of: accuracy, discrimination, evaluation, and negotiation. A convenience sample

of 28 child/parent pairs from both suburban and underserved urban pediatric populations with a mixture of age, race, and socioeconomic status was obtained. Both subjective and objective assessments of asthma severity were obtained in a five-week protocol. Subjective assessment was obtained by utilization of a visual analog scale. Objective measures were determined by home and office peak flow readings, office spirometry and by use of a validated Functional Assessment Scale to evaluate overall disease severity. Families were given careful oral and written instruction and asked to keep an asthma diary for two weeks.

Correlating the subjective rating with the objective peak flow reading derived the findings for perceptual accuracy. It was found that both parent and child thought that the child was asymptomatic when there was a decrease in pulmonary function. Twenty-seven of the 28 children spent the majority of the study period with pulmonary function of 50-80% of normal. In terms of symptom discrimination, children and parents most commonly reported wheezing and rarely associated cough and shortness of breath as a symptom.

The evaluative component was to assess to what extent the child needed to be symptomatic before they would initiate a change in therapy. Only 14.8% of the children and 33.3% of the parents thought change was needed while the child was at 50-80% of normal peak flow range. Further, only 79% of the children and 59% of the parents felt that change was necessary at less than 50% of normal. The families varied considerably in negotiation of a plan of care. The parents had a high correlation for agreement that the child to take the most

responsibility for self-management. The findings support the conclusion that despite careful instruction that this pilot group failed to recognize serious signs and symptoms and did not negotiate a self-management plan. This supports the proposal for study that an education method that uses prevention and anticipation of symptoms that the asthmatic child self-manages is necessary.

Another study was conducted that explored deficits in knowledge and the impact of self-management education on self-management of asthma over one year in the adult population (Lahdensuo, et.al., 1996). The author's objective was to compare the efficacy of self-management education to traditional treatment. The preventable factors that are common to deaths from asthma and 73% of asthma admissions are postulated to be manageable at home. The trial consisted of 115 patients from three health care centers with mild to moderate asthma who were randomly assigned into self-management or traditional treatment groups. The patients recruited for self-management were given personalized education. During these sessions, they received basic information about asthma and its causes, lung anatomy and physiology, the effect and purpose of asthma drugs, and the principles of self-management by specially trained nurses.

The following incidents caused by asthma were recorded for one year: admissions to hospital, unscheduled visits to ambulatory care facilities (outpatient clinics or primary care), days off work, courses of oral antibiotics, and courses of oral prednisolone. Quality of life was evaluated at the start of the trial and

thereafter during scheduled outpatient visits every fourth month using selected components (part 3) of the St George's respiratory questionnaire focusing on the symptoms of asthma and the sickness impact caused by asthma.

Admissions for asthma were rare in both groups: two patients in the self-management group and three in the traditionally treated group were admitted once during the study year because of deterioration of asthma. After the 12 months, when quality of life was compared to the baseline of the study, the quality of life score increased more in the self-management group than in the traditional treatment group. The study showed that guided self-management reduced by half or more the number of incidents caused by asthma when compared with traditional treatment.

A self-management study with asthma symptoms as the indicator of deterioration was conducted (Linna, 1996). The study used peak expiratory flow measurements for assigning definitive intervention levels by relying only on symptoms. As many as 60% of patients exhibited poor judgment of their dyspnea, plus poor perception of pulmonary function that could not be altered through training in peak expiratory flow measurements. It was found that the patients' adherence to the self-management instructions was strongly related to the severity of symptoms.

The positive impact of self-management education has been better documented than the use of peak expiratory flow measurements (PEFM), although not without controversy. Clear and definitive instructions in self-

management and good general self-management education must be considered fundamental for a successful self-management program that does not use PEFM. The author suggested that the adherence of patients to self-management instructions has not been thoroughly studied and should be emphasized in any further analysis.

Kropfelder and Winkelstein (1996), two health department nurses, developed a program in response to a random records review that revealed a high percentage of asthmatic children were receiving more urgent than routine care. The children also had the highest hospitalization rate and lowest follow-up rate in the region. The nurses designed a program with the over all goal of empowerment to the patient and family and to provide them with the tools needed for asthma self-management. The six-step program consisted of identifying patients at risk, gathering data, devising a plan, getting attendance to the asthma education class, developing a care plan, and following-up with visits and telephone calls. The initial contact and development of a database was the starting point of their interaction with the families. At this stage, a complete medical history was taken, an assessment of needs completed, and a teaching plan developed. The children and their families were then invited to the asthma information class. The class reviewed all aspects of asthma, its management, and prevention of exacerbations. Asthmatic children 6-12 years of age were also encouraged to attend an interactive class that explored these topics in a hands-on environment. The nurse then covered specific instructions outlining

what needs to be done by peak flow reading or symptoms at each level of the written plan. The final step was ongoing follow-up. The nurse conducted all other education necessary based on needs identified during this time.

This program was implemented and the data have shown a dramatic decrease in hospitalizations and ED utilization with an increase in routine office visits. Moreover patient feedback has voiced improvement in quality of life, fewer work/school days missed, and improved knowledge about the disease process.

Summary

It has been demonstrated in the literature that self-management education can have an impact on children with asthma. The conclusions of these studies support that a self-management deficit and knowledge deficit does exist in this population. The research supports that an improvement in knowledge through a standardized self-management asthma education program is necessary. The self-management skill education program should emphasize accurate symptom perception, prevention, and recognition of symptoms that worsen asthma. The studies have concluded that this approach may stimulate adherence of asthmatic children to self-management instructions, and improve both quality of life and health outcomes. The limitations of these studies support a study structured for the asthmatic child that includes various income levels, medical insurance coverage, and severity of asthma. A low-income, inner city sample population has been targeted because these children are at highest risk. Success in this

sample population is theorized to infer success with those having higher income level, cleaner environment, and better health care coverage. The gaps from previous studies include a need for effective tools that measure changes in pediatric quality of life and changes in symptoms that include more than wheezing. The issue of a standardized education programs impact on ability of children with asthma to self-manage has had limited study. Therefore, this study was designed to evaluate the impact of a self-management education on quality of life and health outcomes of the pediatric asthma population. This study utilized a program designed emphasize accurate symptom perception, prevention, and anticipation of symptoms that worsen asthma. The adherence of asthmatic children to self-management instructions will promote self-management skill and improve quality of life in the pediatric asthma cohort and its tested health outcomes.

CHAPTER 3

Methodology

There are essential elements to the self-management focused education program design that are important in the effective management of asthma. The emphasis of the asthma education program elements were: (1) communication with the asthmatic child and family in such way as to make learning optimal (incorporation of multiple learning styles); (2) insurance of an adequate therapeutic regimen (AAP); and (3) deliverance of core asthma messages (education), the self-management skills required for patients to understand and act on the regimen prescribed. These elements incorporated the key educational points outlined by the Expert Panel report 2 - Guidelines for the Diagnosis and Management of Asthma (NHLBI, 1997). Similar interventions have historically caused a decrease in patient visits, increase in control over symptoms, and a decrease in over and under use of medication (Kemp, 2001).

The proposed self-management plan was developed and laid out in specific steps that allowed the child to take guided control of symptoms and manage themselves to symptom free levels. The asthma plan included the child and family in order to incorporate patient goals and daily activities. Lastly, the asthma action plan was chosen because of its convenient design for practical use and simplicity for understanding symptoms associated with each level of severity of symptoms. The action plan was provided in the form of a daily self-management plan and Asthma Action Plan (AAP)(NHLBI, 1997) to the intervention group. It was necessary to provide adequate instruction to assure

understanding of asthma pathophysiology, medications, symptoms from mild to acute exacerbation, and proper self-management. The asthma plan used was designed utilizing the NHLBI asthma guidelines so that accurate symptom perception, daily medication dosages, and anticipation of symptoms that change the asthma levels for intervention are consistent with known methods (NHLBI, 1997).

Design of the Study

A design to capture the data necessary to test the effect of the intervention was required. A quasi-experimental design with nonrandom assignment of subjects was used to allow evaluation of program impact on the proposed health outcomes and quality of life changes of children with asthma. The design of the intervention was the control group design with pretest and posttest.

Experimental designs facilitate the search for knowledge and examination of causality in situations with control over as many variables as possible (Burns and Grove, 2001). It is proposed that the intervention of a self-management education program would meet the criteria as the treatment needed for a control group design with pretest and posttest. Threats to validity were controlled for the intervention with emphasis in the program design in order to ensure consistent implementation.

Internal and external threats to validity of the research design included selection bias, mortality, testing, instrumentation, and absence of randomization. The threats to validity were controlled through selection of subjects, control of the

environment, administration of the education program, and reliable and valid measurements of the dependent variables. A threat to testing may have contributed to design limitations related to the inconsistency of environment between the three tested populations. The different environments were three elementary schools and with students from multiple classroom settings and grade levels. The selection of tested tools used consistently throughout the study limited the threat of instrumentation.

The intervention took place in the late summer during the latent asthma period. The self-management principles were taught in three weekly visits and completed before the onset of fall. The intervention was based on the NHLBI approved asthma awareness curriculum for the elementary classroom (1993) course. Interactive and supplemental activities and materials were used to reinforce each lesson to the child and bilingual handouts to reinforce the lesson for the parents were also approved by the NHLBI. The intervention group's education program included three sessions on self-management education of asthma as a condition, symptoms, drug therapy, trigger avoidance, and self-management under normal circumstances and in crisis. The intervention was conducted in three weekly group sessions for approximately 50 minutes at a time that met the children's and school's schedule. The intervention group was further divided by age to allow for improved age-appropriate understanding of materials. Two groups were decided to optimally meet the needs of the children,

the age ranged from 2nd through 4th grades in group one and 5th through 8th grades in group 2.

The first education session included a power point lesson on normal respiratory anatomy and the asthmatic anatomy to include triggers. An interactive video game, Quest for the Code (2002), tour of anatomy was then used to reinforce the lesson. Two hands-on activities were accomplished. The first included a simulation with drinking and coffee straws to illustrate normal verses constricted airways each child had to blow raisins across their desk with each straw and state which one was harder. The second used glow germ © to show how germs are spread by touch and poor hand washing. Lastly, all concepts were reinforced with the viewing of the "what is asthma?" portion of the Wheeze World video. At the conclusion of the session handout materials were given for the children and bilingual handouts for the parents to reinforce the lesson (Appendix III).

The second education session included power point lessons on the symptoms and triggers of asthma. The children were educated on the warning signs of worsening asthma. The triggers of asthma portion of the Wheeze World video was used to reinforce the lesson. The video game and various graphics were used for the children to properly identify triggers and asthma symptoms. At the conclusion of the session handout materials were given to the children and bilingual handouts sent to the parents to reinforce the lesson (Appendix III).

The last education session included power point lessons on asthma medications and management to include proper use of the asthma action plan. Hands-on session included proper technique with asthma medications and devices. The asthma medication portion of the Wheeze World video was viewed. The portions of the video game were used to reinforce the lesson. The children's asthma action plans were handed out and reviewed. The session handout materials were given to the children and bilingual handouts for the parents to reinforce the lesson (Appendix III). At the conclusion of the final session the American Red Cross booklet, *Asthma Basics* (2001), was given to the children and the bilingual booklet, *Controlling Your Asthma* (1999) was given for the parents.

The control group's education was to be by the standards already in place for asthma education at their primary care clinics. The control group was measured at the onset of the program and at sixteen weeks utilizing the same format for follow-up as the self-management program. The final visit and post-test was during the highest risk for exacerbation period (late winter) in order to evaluate the effects of the intervention.

Setting

The environment setting was three Phoenix metropolitan elementary schools. School-age children were the primary subjects because they are more able to identify and understand their own asthma triggers and risks.

Sample

The attention spans for the proposal school-age children has been found to be about 50 minutes, this places the target population at an age appropriate level to tolerate an education session. The sample criteria was set to consist of children aged 7-14, with a positive past medical history of asthma of any severity, and with self-management and medication adherence needs as defined by the study guidelines for school nurse referral. Piagetian theory confirmed the readiness of the school age child because of the ability to reason through real and mental action. The sample criteria were nonexclusive to gender, ethnic background, income, or medical coverage.

The sample was divided into traditional care and intervention groups by school group. The schools were educated prior to the study of the population of interest and how to refer the children into the program. The request for inclusion criteria were to refer patients seen in the nursing office for acute or routine asthma management within the past year with documented or suspected self-management and medication adherence issues. The population required for moderate effect to be measured by power analysis was 100 children (Cohen, 1988). Each school submitted children to be consented. Consents and assents (Appendix I and II) were sent to 137 students. The children were given 48-72 hours to return the consents, with 50 returned within the requested time frame. It was decided than effect would not be measurable and the study was reformed to a pilot analysis of those consented.

Method for Protection of Human Subjects

The study and review board was fully informed of the details for the sample and data collection sites and of all interactions with the sample population. The school district board and principals of the schools were contacted and informed of the study for asthmatic children in three of their inner city elementary schools. The school district board was contacted by way of the executive director of student services. A proposal was sent and was reviewed and accepted by the school district board as submitted. The three respective principals of the targeted schools were contacted and approval of the research project received for being carried out on their campuses. The school nurses were then contacted and a plan developed for the 16-week program. Consent was then obtained from the parents and assent from the children by handouts given to the prospective children as identified by the school nurses (Appendices I and II). There was minimal risk present to potential subjects in loss of confidentiality. The measures carried out to protect confidentiality included assigning identification numbers, and access to raw data was secured and coded to protect the identities of the children, and limited to the researcher and faculty. The results were reported in aggregate. The children received at minimum the care they are accustomed to by their primary care giver. There are no tangible benefits to the subjects, but may have satisfaction of the contribution made to further the understanding of this disease process and its management. The rights of both the adults and children were protected at all times in accordance

with the federal regulations set forth by the National Institutes of Health's, Office of Human Subjects Research. The name of these subjects are known only to the author and not released for any purpose.

Data Collection Process for Each Individual

The school district board and principals of the schools were contacted and informed of the study for asthmatic children in three of their inner city elementary schools. The school district board and the respective principals approved the research project (Appendix IV). Initial meetings were set-up at each school. The emphasis of these sessions was school nurse identification and recruitment of the potential population for referral. The first step of the program was identification of the children with a known diagnosis of asthma in the public school system. The school nurse then referred the children known to be asthmatic by a chronic disease identifier on the children's medical history card. Referral into the program was based on the criteria of past asthma history, self-referral, and knowledge deficit. Parents were then informed and consent requested for their child's participation. The consent process was bilingual to meet the demands of the largely Hispanic population. The consents were translated and back-translated for a fee by professional interpreters. The children were asked to assent to their participation in the study. Parents were encouraged to participate in the education sessions if desired.

Data collection took place at each of the schools in order to allow the children to have the advantage of a familiar environment and the added control

for subjects that the familiarity of environment implies. The pretest data was completed using the instruments, outlined in the proposal model and detailed in the instrument section, at the initial meeting before the first education session. The instructions were carefully covered for consistency in test technique. The parent was allowed to be present during the interview if desired, but could not coach or answer questions for the child. The parent educational handouts were all bilingual for the largely Hispanic inner city population of Phoenix, Arizona. After sixteen weeks following the education of the intervention group, the posttest data was collected for both groups at the last encounter with utilization of the same pretest instruments.

Instruments

Historically, physiologic and clinical values are the outcome measures that providers have been the most concerned with in asthma. In outcomes analyses, the major focus has been on the effect health has on quality of life, with the assumption that health improvement has a linear relationship with the patient's ability to cope socially and physiologically. The bilingual instruments used in this study measured the effect that a self-management education intervention will have on health outcomes and quality of life.

To assess the outcome of an asthma education program an Asthma Self-care Questionnaire (ASCQ) was selected (Appendix V). In a previous study, Thurber and Blue (1994) developed the tool to measure key asthma-related processes and health outcome measures. The fourteen-item self-care posttest

demonstrated a Cronbach's alpha of .78. The test-retest reliability for the self-care scale was ($r=.72$, $p,.001$). This type of questionnaire relies on patient-centered information to evaluate the outcomes of the asthma self-management education program. The questionnaire has fourteen questions about functional status of asthmatics related to health outcomes. The following outcome measures would be assessed by questionnaire: medical system use, competence with asthma symptoms, asthma medication adherence, physical functioning, psychosocial functioning, and knowledge of and satisfaction with asthma care.

Specific health-related quality-of-life questionnaires can be used to evaluate specific aspects of asthmatic patients' functioning and well-being, as well as symptoms that may not be evaluated in depth in generic instruments. The pediatric asthma-specific questionnaire by Juniper and Guyatt (2001) examines these aspects with the Pediatric Asthma Quality of Life Questionnaire with standardized activities(PAQLQ(S))(Appendix VI). Juniper and Guyatt have confirmed reliability and validity in original research in 1993, 1994, 1996 and 1997. In a 52-patient validation study (Juniper, Guyett, Feeny, Ferrie, & Griffith, 1996, 1997), the questionnaire demonstrated good measurement properties as both an evaluative and a discriminative instrument. In stable asthmatic children, it has very acceptable reliability ($ICC=0.95$). It has also shown good responsiveness in being able to detect changes in patients whose health state changed ($p<0.0001$). Good cross-sectional and longitudinal validity were

supported by correlations between the PAQOL and other measures of asthma severity and health-related quality of life that were close to predicted. Numerous studies have continued to validate the original findings. The 2000 study by C.S. Kelly et al. used the PAQOL tool to evaluate the impact of a comprehensive intervention program on quality of life. The reliability test demonstrated retest and reproducibility as well as internal consistency. Construct validity has demonstrated significant correlations between domains and clinical measures (FEV₁, PEFR, B-agonist use) and domains and feeling thermometer scores by the author's original work.

The PAQOL asks the child to evaluate symptoms (10 items), activity limitations (5 items--3 are individualized), emotional functions (8 items) indicating that his or her asthma interferes with life in a negative way. These activities are then reevaluated when the questionnaire is re-administered. The responses of the children may differ, partly depending on the age, developmental level, and reading ability of the child. The researcher was present for all sessions with the children and the interviewer-administered version (1999) of the PAQLQ(S) tool was used to reduce dependence on reading or interpretation of items. Age-specific range for the questionnaires has been well tested and is within the range of this study.

The questionnaire has been validated for children aged 7 to 17 years of age. The standardized activity version has the three patient-specific responses removed to assist with long-term studies. The PAQLQ has four standardized

activities that replace the patient-specific ones. The questionnaire has demonstrated the ability to detect significant differences in individual asthmatic child's' perception of their quality of life, even when these individuals are receiving the same therapy and have the same physiologic measurements. This tool was used methodologically in an effort to preserve any previous results or validity.

Data analysis plan

The data were collected and analyzed utilizing the Statistical Package for the Social Sciences (SPSS) version 12.0. The statistical tests utilized were to analyze the research questions as stated and to test the proposal model (figure 1). The analysis needed to analyze the impact of an asthma self-management education program on self-care and quality of life. The data were analyzed and transformed into information for decision support for future asthma education efforts in outpatient care. Descriptive analysis of pre-test and post-test were conducted on the demographic data for age, years in school, and asthma severity using the mean, standard deviation, and range. Frequency count and percentages were obtained for differences in gender. Posttest asthma severity was not included in analysis due to lack of completion of the parent medical history forms at the close of the intervention. Data from each visit were collected and analyzed for impact. Composite scores were tabulated in SPSS for the total self-care score pretest and posttest of the ASCQ. An all items mean of the PAQLQ and the means for the three subscales of activity, symptoms, and

emotion. Descriptive statistics were included on all analysis variables, including test of normality and correlations among all dependent variables. Reliability analysis was also conducted (Cronbach's alpha) on pretest scale items, including item-total statistics. The hypothesis was tested for the impact of self-management education on the four dependent variables self-care, activity, symptoms and emotion by a multivariate analysis of variance (MANOVA) for pretest-posttest by group. The analysis examined the independent variable influence of asthma self-management education on the four dependent variables. T-tests were also analyzed to compare the differences between the means of the control and intervention groups with ratio and interval data. Alpha was set at 0.05 in this two-tailed analysis.

Potential extraneous variables were the differing environments, ages, and gender percentages of the three schools. Any patterns that emerged in analysis of the data were addressed through group ancillary analysis. The number of years and severity of asthma were considered and included in the health history questions. In the inner city population language and economics are also a potential extraneous variable, however all of the materials were bilingual and written to a sixth grade reading level.

CHAPTER 4

Findings

Introduction

The purpose of this study was to determine the impact that an age-specific educational intervention for children with asthma can have on ability to self-manage their asthma as measured by an increase in self-care and a decrease in the limitations for quality of life (figure 1). Included in this chapter are a description of the sample characteristics, findings related to each research question, any ancillary findings that emerge from the data, and a summary of findings.

Sample Characteristics

This was a convenience sample including children from three inner city Phoenix public schools. The schools were defined as an asthma high-risk population by diagnosis and location. The school nurses were oriented to the study and the children to be identified and then referred to the study. The children referred to the researcher were known to be asthmatic by a chronic disease identifier on the children's medical history card. Each school nurse submitted names of children to be contacted by the researcher. Once all of the children with a known diagnosis of asthma in the three public schools were established, the children and their parents were contacted. A power analysis indicated that the sample size required for moderate effect would be 100 children (Cohen, 1988). Consents and assents were sent to 137 students at the three schools. The children were given 48-72 hours to return the consents, with 50

returned within the requested timeframe. It was then decided that effect would not be measurable and the study was reformed to a pilot analysis of those who had consented.

The participants were assigned to either intervention or control groups by school which resulted in 29 individuals in the intervention group and 18 individuals in the control group with an overall attrition rate of 6%. Three members of the control group dropped out of the program due to change in residence. There were no members lost in the intervention group. The remaining 47 children completed the study. The participants gender, grade, and asthma severity were collected as demographical information used to define and stratify the sample population. The research was completed with the 47 children, 27 were males and 20 females. The sample population gender within assigned group was control group 10 males and 8 females, and intervention group 17 males and 12 females. The participants were also stratified by grade level. Only children above the age of 7 years were permitted to participate as determined by the reliability of testing with the PAQOL tool. The grade range of the study was first to eighth grade with 87% of the participants between the second and seventh grades. The majority (61.8%) of participants ($n = 29$) were in third through fifth grade. The sample group means for grade level were 4.7 ($SD = 1.87$) for the intervention group and 3.3 ($SD = 1.45$) for the control group. The severity range was assessed for normality and percentages. There were four (8.5%) participants that had severe asthma, 17 (36.2%) participants had

moderate asthma, and 26 (55.3%) had mild asthma. SPSS version 12.0 was utilized to determine all reported findings. The Kolmogorov-Smirnov test (D) for normality was significant (.000) for both groups.

Findings

The first research question addressed was; will an asthma self-management educational program improve pediatric asthma health outcomes? The asthma self-care questionnaire developed by Thurber and Blue (1994) was the tool selected to measure the difference. The range of scores can be from a low of 14 to a high of 56 points, one score per child. Scoring is determined by sum of all the scores for the fourteen questions on the questionnaire. The sample population ($N = 47$) mean scores of the pretest intervention ($n = 29$) and control ($n = 18$) groups were 37.5 ($SD = 7.2$) and 34.8 ($SD = 6.8$) respectively with an overall sample mean of 36.5 ($SD = 7.1$). The mean scores of the posttest for the intervention and control groups were 38.5 ($SD = 7.2$) and 36.7 ($SD = 8.0$) respectively with an overall sample mean of 37.8 ($SD = 7.5$). The Cronbach's α for the 14 item ASCQ pretest was 0.744, indicating acceptable internal reliability. To examine differences in self-care scores for children in the control and intervention pretest groups, an independent t-test was used. The significance (two-tailed) with equal variances assumed was 0.217. The t value for the ASCQ was 1.253. It was then decided that in order to optimize the MANOVA results that correlations were needed to see how closely the four variables were. There was poor correlation (significance at the 0.05 level) by

Pearson Correlation (r) of .305 and significance (two-tailed) of $p = .218$ for test retest reliability. No further t-tests were completed due to the lack of significance with both equal variance and test retest procedures. Item total statistics were run to determine which items poorly correlated within the ASCQ. There were four items within the corrected item-total correlation that scored less than ideal (less than .3), and were viewed as the source of error for significance. However, individual item statistics were examined to assess medication knowledge as a health outcome measure. The pretest sample mean for the intervention and control groups were 3.48 and 3.39 respectively with a posttest mean of 3.52 and 3.00 respectively.

The second research question addressed was; will an asthma self-management educational program improve pediatric asthma quality of life? The PAQOL questionnaire with standardized activities (PAQLQ(S)) was used to determine quality of life changes within the three domains of activity limitations, emotional function, and symptoms. Individual items within the PAQLQ(S) are equally weighted and the scores recorded are expressed as the mean score per item for each of the three domains. Each item is presented with a range of 1 to 7 on a Likert scale. The results from a domain can be expressed as a score from 1 to 7 as well. Overall quality of life is estimated from the mean score of all of the items (Juniper, 1996).

The sample population ($N = 47$) mean scores of the pretest intervention ($n = 29$) and control ($n = 18$) groups means and standard deviations for pre-

overall score and pre-domain score demonstrated a normal distribution (see table 1).

Table 1

Sample population statistics for the PAQLQ(S).

	Group	N	Mean	Std. Deviation	Std. Error Mean
PAQLQ Mean pre	1 Intervention	29	4.7811	1.23782	.22986
	2 Control	18	5.2729	1.11994	.26397
Emotion pre	1 Intervention	29	4.7802	1.42899	.26536
	2 Control	18	5.6042	1.32998	.31348
Symptoms pre	1 Intervention	29	4.7862	1.35929	.25241
	2 Control	18	5.1167	1.08641	.25607
Activity pre	1 Intervention	29	4.7724	1.27473	.23671
	2 Control	18	5.0556	1.37166	.32330

The mean scores of the descriptive statistics for the three domains at posttest for the intervention and control groups (Table 2) and overall were significant in pre-posttest analysis of correlations. According to Juniper (1994) a mean difference of 0.5 or greater correlates to a clinically significant change. Correlation was again examined to determine the closeness among the variables for the MANOVA (significance at the 0.05 level) by Pearson Correlation (r) of pretest total score to posttest total score of .532 and significance (two-tailed) of .02 for test retest reliability. Emotion pre-post was also significant ($r = .605$) with two-tailed t-test significance of .008. Similar pre-post test findings for symptoms and activity were found ($r = .476, .395$) and significance at .04 and .10 respectively. All three domains also correlated with each other as expected for a

tool that would measure overall quality of life.

Table 2

Descriptive Statistics of posttest scores by group

	Group	Group	Mean	Std. Deviation	N
Emotion post	1	Intervention	5.5819	1.14480	29
	2	Control	4.9583	1.75943	18
		Total	5.3431	1.42676	47
Symptoms post	1	Intervention	5.2172	1.20388	29
	2	Control	4.5111	1.37878	18
		Total	4.9468	1.30581	47
Activity post	1	Intervention	5.5517	1.04970	29
	2	Control	4.7667	1.48918	18
		Total	5.2511	1.28026	47

Based on the reported findings a MANVOA procedure was determined to be the best measure used to test over time the differences among the four dependent variables.

The repeated-measures MANOVA were utilized to compare questionnaire subscale scores of children in the control group to children in the intervention group from pretest to sixteen weeks later at the posttest. The MANOVA analyzed the statistical differences between the means of the three subscales of the PAQOL and the ASCQ. The MANOVA allowed for simultaneous control over the subscales for type 1 error. The correlations needed to demonstrate closeness of the variables for the PAQOL subscales were strong enough that the loss of power from the MANOVA was not significant. Results of the MANOVA revealed no significant differences in the responses to the three PAQOL subscales of the tests for any disease category ($p < 0.05$). However the

differences with the ASCQ were not significant ($p = 0.715$). A MANOVA also indicated that the two groups differed significantly within subjects pretest and posttest by group. The results of the study demonstrated that control for demographic and the interrelationships among the groups by gender, age, and severity as covariates in MANOVA and correlations were not significant enough to change the conclusions. MANOVA procedures were examined, the Wilks' Lambda multivariate test of the group by prepost interaction was significant, $F(4, 42) = 3.01, p = .025$.

Univariate analysis was used to explore the relationship with the significant effect from items on the MANOVA to determine which dependent measures reflects the effect. Univariate analyses confirmed that differences were not significant for pretest posttest by group (see table 3).

Summary of Findings

Improvements were noted in the asthma quality of life. The three domains of activity limitations, symptoms, and emotional function all demonstrated improvement in the areas measured with the quality of life questionnaire (PAQLQ(S)). The improvement favored the intervention group after completion of a developmentally appropriate self-management educational curriculum. The asthma self-care questionnaire failed to measure a significant difference by MANOVA and Univariate analysis.

Table 3

Univariate Test of Within Subjects

Source	Measure		<i>df</i>	<i>F</i>	Sig.
prepost * group	selfcare	Sphericity	1	.135	.715
		Assumed			
		Greenhouse-Geisser	1.000	.135	.715
		Huynh-Feldt	1.000	.135	.715
	emotion	Lower-bound	1.000	.135	.715
		Sphericity	1	13.1	.001
		Assumed			
		Greenhouse-Geisser	1.000	13.9	.001
	symptom	Huynh-Feldt	1.000	13.9	.001
		Lower-bound	1.000	13.9	.005
		Sphericity	1	8.58	.008
		Assumed			
	activity	Greenhouse-Geisser	1.000	8.577	.005
		Huynh-Feldt	1.000	8.577	.005
		Lower-bound	1.000	8.577	.005
		Sphericity	1	7.652	.008
Assumed					
Greenhouse-Geisser		1.000	7.652	.008	
Huynh-Feldt		1.000	7.652	.008	
Lower-bound		1.000	7.652	.008	

CHAPTER 5

Conclusion and Recommendations

Summary of major findings

The knowledge level and self-management skill of asthmatic children has been demonstrated by literature review to commonly be deficient in the inner-city population. This research combined the use of two tools to measure changes with this deficiency. The quality of life and health outcomes questionnaires (ASCQ and PAQLQ(S)) were selected in order to obtain an understanding of the effect an asthma education program can have on a targeted high-risk population. The major finding in this study was that the developmentally appropriate asthma education program targeted at inner city children would improve pediatric asthma quality of life. The MANOVA was used once the relationships of the correlations was established and Univariate procedures were used to explore the relationship of the significant items from the MANOVA to see which dependent measures reflect the significant effect. There was significant differences in the pre-test, post-test by group comparisons in the PAQLQ(S) overall and within the three domains. There was no significance by Bivariate correlations, MANOVA, or Univariate procedures in the ASCQ. The initial intention of the ASCQ use was to measure differences in health outcomes. It was determined that the ASCQ is not suited for measurement of health outcomes in this pilot study. An additional finding is particularly important to note in this pilot study of asthma education in the inner city child population.

An additional finding was the sample mean improvement of asthma-related quality of life found in this sample of inner city children. The overall sample mean scores on the PAQLQ(S) improved in all three domains. Juniper, et. al. (1996) concluded that a mean difference of 0.5 was sufficient to indicate a clinically significant change had taken place in the population. Pretest-posttest change in the three domains of the PAQLQ(S) in the intervention group displayed significant change by this standard in emotional function and activity limitations. Interestingly noted is a sample mean change of .43 in the domain of symptoms. The interesting fact was the study design post-test session took place at the most symptomatic time of year in the asthma population. While a 0.43 sample mean increase may not meet the Juniper criteria in the intervention group, a significant sample mean decrease of 0.61 was noted in the control group.

Finding Interpretation Related to Previous Studies

The results of the findings of this study are consistent with similar study findings using the PAQOL as a tool of measurement. The review of literature focused on the two deficits that have affected quality of life and health outcomes of asthma. The two deficits of knowledge and the skills required for self-management were reviewed.

The knowledge deficit in self-management with the asthmatic child was investigated in the Kelly, et al. (2000) study which had the objective to improve quality of life. Designed to educate low-income, minority children who had poor knowledge about asthma, the researchers organized a controlled clinical trial set

in an urban pediatric allergy clinic. Some similarities exist with the intervention groups of this study and the Kelly study. The asthma education with Kelly was one-on-one and standardized and given to child and caretaker versus age-appropriate groups. The Kelly study children also were given a written action plan for exacerbations, however daily management emphasis was unknown. Both programs conformed to the standards set by the National Heart Blood and Lung Institute (NHBLI) asthma guideline. Similarly, the results from the Kelly study indicated the control group had a decrease in the PAQOL scores. The Kelly study also concluded that a comprehensive intervention program including education, medical management of asthma in accordance with the NHBLI guidelines and an effective outreach component improved quality of life (Kelly et al, 2000).

The Gallefoss and Bakke (1999) study compared the effects that the intervention of a standardized self-management education program and a self-management plan could have on the skills of steroid inhaler adherence and rescue medication utilization in patients with asthma and chronic obstructive pulmonary disease (COPD). They investigated each disease separately and concluded that in the asthmatic adult benefited from the intervention with medical adherence to prescribed inhaled corticosteroids. The premise for this study was that these patients are particularly vulnerable to self-management problems because of the chronic nature of their disease, the use of multiple medications, and the periods of symptom remission. The study was included due to the fact

that asthma is a chronic disease for all ages and the assumption that children can be educated to be compliant with their asthma management. Their educational intervention similarly consisted of a specially designed handout, the sessions concentrated on pathophysiology, use and function of medications, symptom awareness, asthma treatment plans and physiotherapy. Also, each one of the Intervention group members received an individualized asthma treatment plan. The researchers concluded that self-management education can change medication habits by reducing the amount of short-acting inhaled beta-2 agonists and improved steroid inhaler adherence. The study medication adherence was emphasized in the educational sessions and measured with the ASCQ and implied with improved asthma perception by the three domains of the PAQOL. The ASCQ demonstrated a sample mean improvement in knowledge of asthma medicines when compared pre and post-test by group.

The deficit in self-management skill was examined in the literature with the Yoos and McMullen (1999) pilot study to explore how the inaccuracies in symptom perception contributed to morbidity and mortality in childhood asthma. In their study families were given careful oral and written instruction and asked to keep an asthma diary for two weeks. The parent and child both thought that asymptomatic was when there was an actual decrease in pulmonary function. The correlation between the parents and their child was high in terms of wanting the child to take the most responsibility for self-management. The findings support the conclusion that despite careful instruction that this pilot group failed

to recognize serious signs and symptoms and did not negotiate a self-management plan. This supported the intervention of a child self-management education intervention that emphasized prevention, asthma action plan use, and recognition of symptoms. In the intervention children were found to improve all scores as measured by the PAQOL included the domains of symptoms, emotions, and activity limitations.

The Lahdensuo, et.al. (1996) study demonstrated that a comparison of quality of life with a self-management educational intervention can measure asthma skill in adults. The patients recruited for self-management were given personalized education. During these sessions, they received basic information about asthma and its causes, lung anatomy and physiology, the effect and purpose of asthma drugs, and the principles of self-management by specially trained nurses. Quality of life was evaluated at the start of the trial and thereafter during scheduled outpatient visits every fourth month. Similar to the study findings, the quality of life score improved in the self-management group.

The Kropfelder and Winkelstein (1996) study designed a program with the over all goal of empowerment to the patient and family and to provide them with the tools needed for asthma self-management. The six-step program reviewed all aspects of asthma, its management, and prevention of exacerbations. The study also used a individualized written action plan. The final step was ongoing follow-up. The nurse conducted all other education necessary based on needs identified during this time. Their data reflected a decrease in measurable

negative health outcomes and an increase in routine office visits. Similarly an improvement in quality of life, and improved knowledge about the disease process was measured.

Implications of Findings to Theory

The education of children about their asthma and the importance of health promotion activities was the priority of study design. The framework utilized to guide the asthma intervention outlined in this study was Nola Pender's Health Promotion Model. The Health Promotion Model (HPM) addresses making choices about one's own health and stresses the importance of incorporation of strategies to promote health. As illustrated in the study HPM model (figure 2), her model consisted of activities that are directed toward increasing the level of well being and actualizing the health potential of individuals. The interventions impact on the pertinent components used for each determinant of individual perceptions, modifying factors and likelihood of action will be discussed.

The study HPM supports that health promotion practices are partially determined by the individual perceptions of self-awareness, the perception of health status, and the benefits of health-promoting behaviors. The intervention emphasis was on activities that improve asthma awareness and wellness behaviors. The need for greater self-awareness was emphasized with the intervention with the goals of raised consciousness of asthma, clarified health perception, and increased awareness of environment. In Pender's book (1982), she asserted that the health-promoting potential of increased self-awareness has

played an important role in motivating continued practice of health-promoting behavior. The component perception of health status has played a role in the frequency and intensity of health promoting behaviors. The intervention group reinforced that the feelings of well-being and improved health status would reinforce the value of good health with improvements in quality of life scores in the midst of the most asthmatic time of year. The individual perception of benefits of health-promoting behaviors facilitates continued practice of newly required behaviors. This was illustrated again by consistent improvements in PAQOL scores, which reinforced that the more independent that a child can be with asthma-management the better their asthma and quality of life are long term.

The second determinant of the study model was the modifying factors. The component of this determinant utilized was the demographic factors. These are the characteristics as illustrated in figure 2. The impact of demographic variables on health promoting behaviors in inner city children has been addressed in the literature. Interestingly the age-appropriate approach to the intervention group benefited the children. This is illustrated by the absence of withdrawals from the intervention and the significant improvements of the PAQOL scores.

The final determinant of likelihood of action was the most critical component of the intervention. The study findings reinforce that children with asthma in their lives need self-management education that emphasizes their

ability to control their environment and, thus improve asthma symptoms and eliminate barriers to health. Pender (1982) emphasized the use of preventive efforts to minimize the occurrence of disease and its complications as well as promote health restoration and enhance quality of life. The goal of use of the health promotion model with this study was to understand how children could be motivated to attain personal health. The relevance for application is the importance the individual believed the education influenced their health promoting behavior. If a barrier to action was perceived it was believed that the children would not value the intervention and not attend. The entire intervention group attended the complete intervention course and improved their PAQOL scores from baseline in a time of the year when one would expect them to be lowest.

Implications of Findings to Practice

Improvement in PAQOL decreases cost, workload in the asthma population, and improves health outcomes. For success in self-management of asthma in childhood, definitive instructions in self-management and self-management education are fundamental to the clinical setting. Disease management of asthma is achievable. This study determined that a self-management education and self-management program did positively impact the asthmatic child's quality of life in all three domains of the PAQLQ(S). A change of the asthma population mindset to a preventative and proactive role is necessary. The literature demonstrated that the heightened adherence from an

self-management intervention concluded that asthmatics were two times more likely to be compliant with long-term medications, (Gallefoss and Bakke, 1999). The objective of this study was to produce a measurable outcome with desired goals of increased adherence with optimal and current asthma treatment regimens, increase patient knowledge of disease process and contributing factors, and improved competence with asthma self-management skill. The child asthmatic competence with self-management skill was concluded to be one cause that a nurse can positively impact through a self-management education program.

Limitations on the Generalizability of the Findings

This study utilized a program designed to emphasize accurate symptom perception, prevention, and anticipation of symptoms that worsen asthma. The adherence of asthmatic children to self-management instructions will promote self-management skill and improve quality of life in the pediatric asthma cohort and its tested health outcomes. The sample population tested was a convenience sample that consisted of volunteers in three areas characterized as inner city, but geographically separated. Limitations to gender, age, education, and income existed and may not accurately reflect and have inference to the normal distribution of the general population. Limits to the responses of the children and parents existed, partly depending on the age, developmental level, ability to meet date requirements, and reading ability of the parent and child. In regards to the self-care questionnaire findings further analysis would need to be

accomplished on individual items to establish what items were effecting the results. Culture may have been an issue in that self-care is may not be acceptable among children in the studied population. Control over this limitation was attempted through the two separate age appropriate education programs for the intervention group. All questionnaires, consents and medical history letters were bilingual and written at the 4th grade level and were developed to facilitate the task of instrument completion for the child. However, parental biases, language barriers, and task time requirements may have conceivably influenced the poor return of posttest health history parent questionnaires.

A threat to testing may have existed with design limitations related to the inconsistency of the environment. The different environments will be the three elementary schools and variations were controlled as much as possible. The selection of tested tools used consistently throughout the study limited the threat of instrumentation.

Further Research

Therefore, to improve the asthma self-management skill of inner city children a focused educational curriculum will improve health outcomes and quality of life. Further research is needed to broaden the findings of this pilot study. A recommendation to continue to focus on one geographical area is needed. Utilization of the school system proved efficient, but the pretest scores varied widely between the intervention and control groups. Location is theorized to have impacted the finding related to all other known demographics were

examined. Inclusion of the entire typical asthmatic season of September through March may demonstrate even greater findings. An improvement in the system of obtaining health outcome measures will allow for inclusion of medication use, acute or urgent visits, and admissions. This researcher suggests phone contact of all the children's parents.

The effort of empowering asthmatic children through a developmentally appropriate educational curriculum that teaches patients about the rationale and skills required for understanding and treating asthma as a chronic inflammatory process rather than an acute episodic, emergent process is necessary. The content and methods of conducting asthma education programs have varied considerably, as have the outcome measures used to evaluate the efficacy of these programs. Nevertheless, it appears that educational programs that emphasize the educational goals set by the NHLBI will improve the pediatric asthma quality of life in inner city population.

References

- American Academy of Allergy, Asthma, and Immunology. (1999). Guide for managing asthma in children. *Pediatric Asthma: Promoting best practices*, pp. 102-135.
- Arizona Department of Health Services (2003). Hospital inpatient discharge statistics for asthma. *Arizona Vital Statistics*. Retrieved February 20, 2003, from <http://www.hs.state.az.us/plan/asthma/htm>.
- Blaiss, M. (1997). Asthma outcome measurement. *Journal of American Medical Association*, 278(22), 1874-1880.
- Canadian Asthma Consensus Report. (1999). Asthma education and patient monitoring. *Journal of Canadian Medical Association*, 161(11), 15-32.
- Centers for Disease Control and Prevention (2002, March 29). Surveillance for asthma -- United States 1980-1999. *Morbidity and Mortality Weekly Report*, 51(SS-1).
- Charlton, I., Charlton, G., Broomfield, J., & Mullee, M. (1990). Evaluation of peak flow and symptoms only self-management plans for control of asthma in general practice. *British Medical Journal*, 301, 1355-1359.
- Cohen, Jacob (1988). *Statistical analysis for the behavioral sciences* (2nd ed.). Lawrence Erlbaum Association: Hillsdale, N.J.
- Diette, G., Skinner, E., Markson, L., Algatt-Bergstrom, P., Nguyen, T., Clark, R., & Wu, A. (2000). Consistency of care with national guidelines for children with asthma in managed care. *American Family Physician*, 61, 2003-2016.

- Gallefoss, F. & Bakke, P.S. (1999). How Does Self-management education and Self-Management among asthmatics and patients with chronic obstructive pulmonary disease affect medication? *American Journal of Respiratory Critical Care*, 160, 2000-2005.
- Jaing, J., Sepulveda, J., & Casillas, A. (2001). Novel computer based assessment of asthma strategies in inner-city children. *Annals of Allergy, Asthma, and Immunology*, 87(3).
- Juniper, E., Guyatt, G., Feeny, D., Ferrie, P., Griffith, L., & Townsend, M. (1996). Measuring quality of life in children with asthma. *Quality of Life Research*, 5(1), 35-46.
- Juniper, E., Guyatt, G., Feeny, D., Ferrie, P., & Griffith, L. (1997). Minimum skills required by children to complete health-related quality of life instruments for asthma: comparison of measurement properties. *European Respiratory Journal*, 10(10), 2285-2294.
- Kelly, C., Morrow, A., Shults, J., Nakas, N., Strobe, G., & Adelman, R. (2000). Outcomes evaluation of a comprehensive intervention program for asthmatic children enrolled in medicaid. *Pediatrics*, 105(5), 1029-1035.
- Kemp, J. & Kemp, J. (2001) Management of asthma in children. *American Family Physician*, 63(7), 1341-1348.
- Kropfelder, L. & Winkelstein, M. (1996). A case management approach to pediatric asthma. *Pediatric Nursing*, 22(4), 291-295.

- Lahdensuo, A., Haahtela, T., Herrala, J., Kava, T., & Svahn, T. (1996).
Randomized comparison of guided self-management and traditional
treatment of asthma over one year. *British Medical Journal*, 312, 748-752.
- Linna, O. (1996). Spirometry, bronchodilator test or symptom scoring for the
assessment of childhood asthma. *Academy of Pediatrics*, 85, 564-569.
- Lozano, P., & Lieu, T. (1999). Asthma is managed care. *Pediatric Annals*, 28(1),
74-88.
- Lukacs, S., France, E., Baron, A., & Crane, L. (2002). Effectiveness of an asthma
management program for pediatric members of a large health
maintenance organization. *Archives of Pediatrics and Adolescent
Medicine*, 156(9), 872-891.
- National Heart, Lung and Blood Institute (1993). Publication number 93-2894,
Asthma Awareness: Curriculum for the Elementary Classroom
- Nelson, D.A., Johnson, C.C., Divine, G., and Strauchman, C. (1997). Ethnic
differences in the prevalence of asthma in middle class children. *Annals of
Allergy, Asthma, and Immunology*, 78(1), 21-31.
- Pender, N. (1982). Health promotion in nursing practice. Norwalk, CT: Appleton-
Century Crofts.
- Robinson, L. (1999). Pediatric asthma self-management: Current concepts.
Journal of the National Medical Association, 91(8), Supplement p.40-51.
- Robertson, C., Rubinfeld, A., & Bowes, G (1992). Pediatric asthma deaths in
Victoria: The mild are at risk. *Pediatric Pulmonology*. 13, 95-100.

- Schott-Baer, D. & Christensen, M. (1999). A pilot program to increase self-care of adult asthma patients. *Medsurg Nursing*, 8(3), 178-183.
- Thurber, F. & Blue, B. (1994). Asthma Self Care Questionnaire (ASCQ). University of Arizona, Health Sciences Center. (2002). *Allergy and Asthma in the Southwestern United States*. Retrieved January 30, 2003, from <http://www.peds.arizona.edu/allergyimmunology/southwest/prevalence.htm>
- Wagner, E., Austin, B., & Korff, M. (1996). Improving outcomes in chronic illness. *Managed Care Quarterly*, 4(2), 12-25.
- Yoos, H.L. & McMullen, A. (1999). Symptom perception and evaluation in childhood asthma. *Nursing Research*, 48(1), 2-7.

APPENDIX I

PARENT CONSENT AND ASTHMA HISTORY FORMS

Dear Parent/Caregiver,

I am a graduate student and registered nurse under the direction of Professor Frances Thurber in the College of Nursing at Arizona State University. I am conducting a research study to learn more about the effect that a well-structured asthma self-management education program can have on the quality of a child's life. This is important because we now know that children with a higher quality of life will be more likely to follow their asthma management plan and benefit from better asthma control.

I am requesting your child's attendance in this study, it is completely voluntary, and you or your child may withdraw at any time without influence on their grades. The program will follow guidelines that have been recommended by asthma specialists world-wide and the National Heart, Blood, and Lung Institute. I will teach your children about asthma, how to recognize symptoms and irritants, and how to manage their asthma when well and when having problems. This type of program has resulted in fewer school absences, improved sleep, urgent care appointments, and emergency room visits. It will consist of an initial and final questionnaire. As the parent or caregiver you are encouraged to be present, but your presence IS NOT required. The questionnaires will take approximately 20 minutes to fill out, and will be accomplished in the 1st and 16th week of the study. The three asthma education sessions will take place in the environment of your child's school during school hours at a prearranged time with the school faculty.

The medical care your child receives will not be affected in any way. There are no known risks associated with participation in this program. All of the information obtained from the questionnaires will have special precautions taken to protect the identity of your child and assure complete privacy. A number, rather than a name will identify all information obtained by the questionnaire and everything will be locked in a separate location. The results of the study will be used only in scientific papers where confidentiality is fully protected.

If you have any questions concerning the research or your child's participation in this study, please feel free to call Dr. Thurber or me at (480) 965-7230. You may contact the Chair of the Human Subjects Institutional Review Board, through Karol Householder at (480) 965-6788.

Very Respectfully,

Gerald W. Hall, R.N., B.S.N.
Certified Pediatric Nurse

Signature on this form grants permission for you child to participate in the study.
I give consent for _____ (Child's Name) to be in this study.

Signature

Date

Printed Name: _____

Asthma Information

CHILD'S NAME: _____ DATE: _____

CHILD'S SCHOOL: _____

PARENT'S NAME: _____

ADDRESS: _____

PHONE: HOME: _____ WORK: _____

DOCTOR'S NAME: _____ OFFICE NUMBER: _____

1. When did your child begin to have symptoms of Asthma?
(give the age symptoms started) _____
2. How often does you child have an asthma attack?
 - 1) 1 – 2 times each week
 - 2) 1 – 2 times each month
 - 3) Seasonal attacks during one to two months per year
 - 4) Occasionally when ill
3. How many times has your child been hospitalized for an asthma attack? _____
4. When was your child last hospitalized for an asthma attack?
(give month, day, and year if possible) _____
5. How many times during the last year have you had to take your child to the
Emergency Room for asthma related problems? _____
6. When was your last visit to the Emergency Room for your child's asthma related
problems? _____
7. How many times during the last year have you had to take your child to his/her Doctor
for an urgent or same day appointment for asthma related problems? _____
8. What medications does you child take for his/her asthma? (List name of medication,
how much, and how often medication is taken) _____

9. Does your child have a personalized Asthma Action Plan? Yes _____ No _____
Dear Parent/Caregiver,

I am a graduate student and registered nurse under the direction of Professor Frances Thurber in the College of Nursing at Arizona State University. I am conducting a research study to learn more about the effect that asthma self-management can have on the quality of a child's life. This is important because we now know that children with a higher quality of life will be more likely to follow their asthma management plan and benefit from better asthma control.

I am requesting your child's attendance in this study, it is completely voluntary, and you or your child may withdraw at any time without influence on their grades. The program will follow guidelines that have been recommended by asthma specialists world-wide and the National Heart, Blood, and Lung Institute. The program will consist of an initial and final questionnaire. As the parent or caregiver you are encouraged to be present, but your presence IS NOT required. The questionnaires will take approximately 20 minutes to fill out, and will be accomplished in the 1st and 16th week of the study. The questions will be asked in the environment of your child's school during school hours at a prearranged time with the school faculty.

The medical care your child receives will not be affected in any way. There are no known risks associated with participation in this program. All of the information obtained from the questionnaires will have special precautions taken to protect the identity of your child and assure complete privacy. A number, rather than a name will identify all information obtained by the questionnaire and everything will be locked in a separate location. The results of the study will be used only in scientific papers where confidentiality is fully protected.

If you have any questions concerning the research or your child's participation in this study, please feel free to call Dr. Thurber or me at (480) 965-7230.
Very Respectfully,

Gerald W. Hall, R.N., B.S.N.
Certified Pediatric Nurse

Signature on this form grants permission for you child to participate in the study.

I give consent for _____ (Child's Name) to be in this study.

Signature

Date

Printed Name: _____

If you have any questions regarding you child's rights as a research subject, or if you feel your child has been placed at risk, please contact the Chair of the Human Subjects Institutional Review Board, through Karol Householder at (480) 965-6788.

APPENDIX II
CHILD ASSENT FORMS

CHILD ASSENT

My name is Gerald Hall and I am a nurse trying to figure out if learning more about asthma and how to care for it will make you feel better and allow you to be sick less and not have to see your Doctor or Nurse Practitioner.

I have given a letter to your parents and they have given permission for me to ask you questions and teach you about your asthma and skills to make it better. It will take about 20 minutes to ask you the questions. Then we will have 3 weekly (once a week) classes that will be almost an hour. Then before your Christmas break I will come back and ask you the questions again. My teacher and I will review your answers to the questions.

If you choose to answer my questions and come to the asthma classes, do it because you want to. You can stop at any time and have no problems with school grades or anything else.

Your signature below means that you understand that your parents have given permission, you agree to participate, and understand that you can stop at any time.

Signature

CONTROL CHILD ASSENT

My name is Gerald Hall and I am a nurse trying to figure out if learning more about asthma and how to care for it will make you feel better and allow you to be sick less and not have to see your Doctor or Nurse Practitioner as much.

I have given a letter to your parents and they have given permission for me to ask you questions. It will take about 20 minutes to ask you the questions. Then before your Christmas break I will come back and ask you the questions again. My teacher and I will review your answers to the questions.

If you choose to answer my questions, do it because you want to. You can stop at any time and have no problems with school grades or anything else.

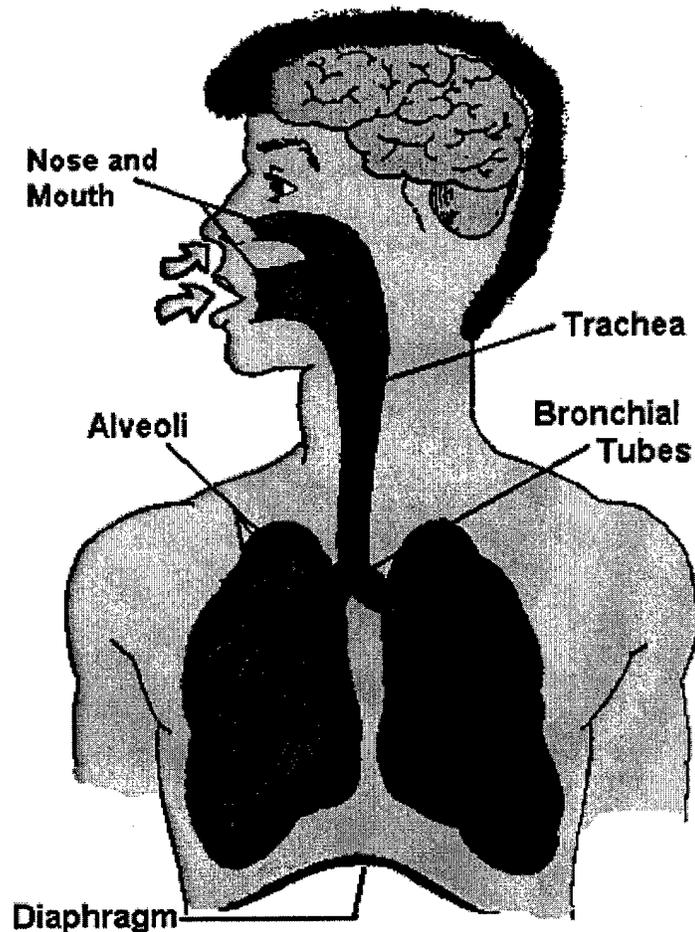
Your signature below means that you understand that your parents have given permission, you agree to participate, and understand that you can stop at any time.

Signature

APPENDIX III
HANDOUT MATERIALS

Respiratory System

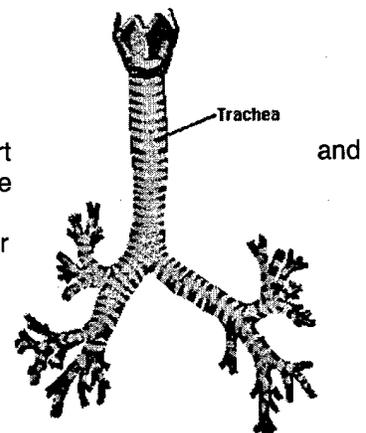
Your lungs are amazing machines that give your body all the oxygen it needs to live. Your lungs are made up of many parts, and they are all important for your lungs to work right.



Your mouth and nose are very important, because they let air into your body. The air you breathe in goes from your mouth and nose down to your trachea and into your lungs.

Your nose is really neat, because it is able to block some of the dirt germs in the air. Your nose has hair in it that can block some of the stuff, but the most amazing part is the mucus that your nose makes. The dirt and germs in the air get stuck in the mucus in your nose, and they can't enter your lungs. When you blow your nose, you're getting rid of all the bad germs and dirt that your nose stopped from getting into your body!

Your trachea is the tube that connects your mouth and nose to your lungs. You can also call it the **windpipe**. It is in the front of your neck, and is very hard with tough rings around it.



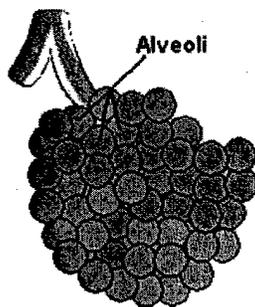
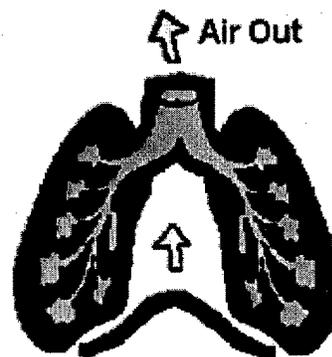
Only air goes into your trachea. When the air you breathe in goes down your trachea, it comes to a fork in the road. These are the bronchial tubes. One tube goes into your right lung, and the other goes into your left lung. The bronchial tubes go into your lungs and keep branching off into smaller and smaller tubes until the sacs at the end called alveoli are reached.

Your bronchial tubes not only bring the air from your trachea to your alveoli, they also help clean your lungs. Your bronchial tubes are covered with mucus, which sticks to dirt and germs that get into your lungs. Next, millions of tiny hairs called **cilia** act like tiny brooms to sweep out the bad stuff caught in the mucus. They do this to keep your lungs clean.



When air enters your lungs, it goes through a maze of smaller and smaller tubes until it reaches tiny sacs called **alveoli**. The sacs look like bunches of grapes at the end of the bronchial tubes. The alveoli are where the oxygen from the air enters your blood, and the carbon dioxide from your body goes into the air. Alveoli are very tiny, but you have a lot of them in your lungs.

The diaphragm is a big sheet-like muscle that's at the bottom of your chest cavity. The diaphragm helps you get air in and out of your lungs by moving up and down. When your diaphragm moves down, you breathe in. When your diaphragm moves up, you breathe out!



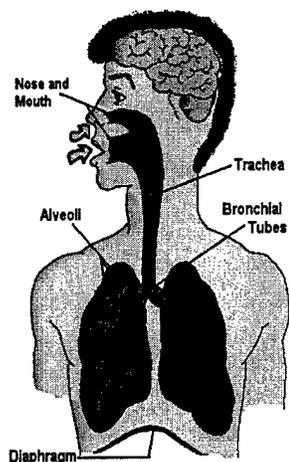
Asthma: A sickness or disease that affects the airways in the lungs causing difficulty with children when they are very young, and others do not have the signs and symptoms of asthma for many years. People can control their asthma and live active, healthy lives. Asthma cannot be caught like a cold.

What part of the respiratory system (or body) is affected during an asthma episode? The airways in the lungs.

In what way? The airways get swollen and filled with mucus, and squeezed. The narrow airways make it hard to breathe in and out.

- If you feel wheezy, go to a grownup;
- If you have your medication, take it;
- If you don't take your medications, you'll be wheezing a lot more and things like cat hair can trigger an attack;
- Take a peak flow if you're running around. If the peak flow shows green, you're OK. If it's yellow, take it easy. If it's red, sit down. Take your inhalers right away;
- Be glad that you're still alive. You've had bad asthma attacks before and didn't die.

Worksheet No. 1



Asthma is a chronic lung disease that lasts a long time. It cannot be cured only controlled.

- Airways are inflamed. That is, airway lining are swollen.
- Airways narrow and breathing becomes hard to do. This narrowing gets better (but not all the way in some patients), sometimes by itself, some times with treatment.
- Airways are super sensitive. They react to many things, such as cigarette smoke, pollen, or cold air. Coughing, wheezing, tight chest, difficult breathing, or an asthma episode may result. A more complete list of things that can

cause some people's airways to react is given later (see, "What Causes Asthma Episodes").

- **What Are the Symptom of Asthma?**

The main symptoms of asthma are:

- Shortness of breath,
- Wheezing,
- Tightness in the chest, and
- Cough lasting more than a week.

Not all people with asthma wheeze. For some, coughing may be the only symptom of asthma. Coughing often occurs during the night or after exercise.

It's important to know that treatment can reverse asthma symptoms. And it's important to treat even mild symptoms of asthma so that you can keep the symptoms from getting worse.

Normal Breathing

When you breathe in, air is taken in through the nose and mouth. it goes down your windpipe, through your airways, and into the air sacs. When you breathe out, stale air leaves the lungs in the reverse order.

What Happens During an Episode of Asthma?

Asthma affects the airways in your lungs. During an episode of asthma:

- The lining of the airways becomes swollen (inflamed).
- The airways produce a thick mucus.
 - The muscles around the airways tighten and make the airways narrower.



These changes in the airways block the flow of air, making it hard to breathe.

You need to know the ways that asthma affects the airways SO You can understand why it often takes more than one medicine to treat the disease. Very simply, some medicines relax the airways and others reduce (and even prevent) the swelling and mucus.

What Causes Asthma?

The basic cause of asthma is not yet known. What we do know is that asthma is not caused by emotional factors such as a troubled parent-child relationship. In short, asthma is not "all in one's head." It is instead a chronic lung disease.

What Causes Asthma Episodes?

People with asthma have airways that are super sensitive to things that do not bother people who do not have asthma. These things are called triggers because when you are near or come in contact with them, they may start an asthma episode. Your airways may become swollen, produce too much mucus, and tighten up. Common triggers for asthma episodes include the following:



strong smells

- Dander (or flakes) from the skin, hair, or feathers of all warm-blooded pets (including dogs, cats, birds, and small rodents)
- House dust mites
- Cockroaches
- Pollens from grass and trees and mold
- Molds (indoor and outdoor)
- Cigarette smoke; wood smoke; scented products such as hair spray, cosmetics, and cleaning products; strong odors from fresh paint or cooking; automobile fumes; and air pollution
- Infections in the upper airway, such as colds (a common trigger for both children and adults)
- Exercise
- Showing strong feelings (crying, laughing)
 - Changes in weather and temperature.



dust

Is There a Cure for Asthma?

Asthma cannot be cured, but it can be controlled. You should expect nothing less.

How Can Asthma Episode Be Prevented?

To prevent asthma episodes you will have to work closely with your doctor to:

- Develop a medicine plan that keeps you from getting symptoms.
- Plan ways to avoid or reduce contact with your triggers.

How Are Asthma Episodes Controlled?

To control asthma episodes when they occur, you will have to work out a medicine plan with your doctor that includes:

- Treating symptoms early,
- Doing the right things for any changes in symptoms, and
- Knowing when a doctor's help is needed and seeking help right away.

What Can a Patient with Asthma Expect From Treatment?

With proper treatment most people will be able to:

- **Be active without having symptoms. This includes participating in exercise and sports.**
- **Sleep through the night without having asthma symptoms.**
- **Prevent asthma episodes (attacks).**
- **Avoid side effects from medicines.**

Here are the most important times to wash your hands:

Before:

- touching or serving food
- performing first aid
- touching your eyes, nose or mouth

After:

- using the rest room
- diapering a baby
- coughing or sneezing
- wiping anyone's nose
- playing with pets
- handling raw meat, poultry or fish
- handling garbage



Do a good job, follow these steps:

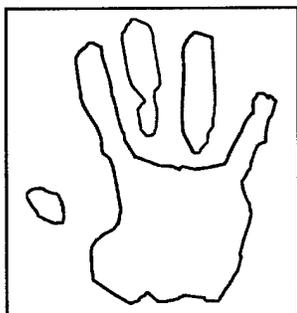
1. Wet your hands.

2. Apply soap

(liquid soap is less messy, but bar soap is fine if it is in a dish that drains well.)

3. Lather and wash for at least 10-15 seconds. Say your A,B,Cs or sing a little jingle. Pay attention to all surfaces of the hands, especially between fingers, under nails and under and around jewelry.

4. Rinse and dry. If using a public rest room, turn the faucets off with a paper towel, if available.



If hand washing is done correctly, both viruses and bacteria (germs) will go right down the drain and won't get you or anyone else sick.

Other things we can do:

Use tissues -- not their sleeves or bare hands -- to wipe their noses and eyes. Of course, those tissues should be thrown away immediately.

NO sharing water bottles and other drinks.

Worksheet No. 17
Warning Signs of Asthma Episodes

Asthma episodes rarely occur without seaming. Most people with asthma have warming signs (physical changes) that occur hours before symptoms appear. Warning signs are not the same for everyone. You may have different signs at different times. By knowing your warming signs and acting on them, you may be able to avoid a serious episode of asthma.

- Think back on your last asthma episode. Did you have any of the signs below?
- Check your warning sign(s). Show them to your doctor and family.
- Remember to follow your asthma control plan as soon as these signs appear.

Check here

- _____ Drop in peak flow reading
 _____ Chronic cough, especially at night
 _____ Difficulty breathing
 _____ Chest starts to get tight or hurts
 _____ Breathing faster than normal
 _____ Getting out of breath easily
 _____ Tired, itchy, watery, or glassy eyes
 _____ Itchy, scratchy, or sore throat
 _____ Stroking chin or throat
 _____ Sneezing, Head stopped up
 _____ Headache, Fever
 _____ Restless
 _____ Runny nose
 _____ Change in face color
 _____ Dark circles under eyes

_____ Other: _____

My most common warning signs of an asthma episode are:

1. _____
 2. _____
 3. _____

Worksheet No. 19
Summary of Steps to Manage Asthma Episodes

- Know your warning signs so you can begin treatment early.
- Take the correct amount of medicine at the times the doctor has stated. Follow the asthma control plan (increase dosage or add a second medicine) during episodes, take medicines as prescribed. Always call your doctor if you need to take more medicine than the doctor ordered.
- Remove yourself or the child from the trigger if you know what it is. Treatment does not work as well if you stay around the trigger.
- Keep calm and relaxed. Family members must stay calm and relaxed too.
- Rest
- Observe yourself or the child by noting changes (better or worse) in body signs such as wheezing, coughing, trouble breathing, and posture. If you have a peak flow meter, measure peak flow number 5 to 10 minutes after each treatment to see if peak flow is improving.
- Review the list below for signs to seek emergency medical care for asthma. They include:
 - Your wheeze, cough, or shortness of breath gets worse, even after the medicine has been given and had time to work. Most inhaled bronchodilator medicines work within 5 to 10 minutes. Discuss the time your medicines take to work with your doctor.
 - Your symptoms or peak flow number do not improve after treatment with bronchodilators, or drops to 50 percent or less of personal best. Discuss this peak flow level with your doctor.
 - Your breathing gets difficult. Signs of this are:
 - Your chest and neck are pulled or sucked in with each breath.
 - You are hunching over.
 - You are struggling to breathe.
 - You have trouble walking or talking.
 - You stop playing or working and cannot start again.
 - Your lips or fingernails are gray or blue. If this happens, Go to the Emergency Room Now!
- Keep your important information for seeking emergency care handy.
- Call a family member, friend, or neighbor to help you if needed.
- Immediately call a clinic, doctor's office, or hospital for help if needed.

Do Not Do the Following:

- Do not drink a lot of water. Just drink normal amounts.
- Do not breathe warm moist air from a shower.
- Do not rebreathe into a paper bag held over the nose.
- Do not use over-the-counter cold remedies without first calling the doctor.

Avoiding Asthma Triggers

Home Environment

For patients with asthma, the ideal atmosphere is as free as possible of asthma triggers. While it may be impossible to remove every trigger from your home, you can alter some things to provide cleaner and healthier air.

Air-conditioning may offer relief from some airborne triggers. If air-conditioning every room is not an option, then a window unit for your bedroom is a smart alternative. And, in houses with forced-air heat, a filter or damp cheesecloth over vents can trap airborne particles.

The simpler your decor, the better. Remove as many dust-trapping items as possible. Ornate and upholstered furniture, knickknacks, draperies, and floor coverings are notorious collectors of dust. Opt for furnishings that are easily cleaned, such as vinyl-covered couches, washable shades, and wood or linoleum flooring. And, when cleaning your home, a dampened dust cloth will attract particles and keep them from becoming airborne.

In your bedroom, choose Dacron or other synthetic pillows. Cover mattress and box spring with allergen-proof covers for additional protection. Use washable cotton or synthetic bedding.

Prevent situations that encourage mold to form. Keep bathrooms clean and dry. Install a dehumidifier. Check foods for spoilage. Dry your freshly laundered clothes promptly. And, don't cultivate a lot of houseplants since moist potting soil can be a haven for mold.

Avoid exposure to pets, particularly cats. Animal dander and animal saliva are known allergens. Do not smoke, and initiate a no-smoking policy in the home. If these efforts are not possible, designate pets and smokers to areas outdoors or at least to rooms in the house that are far removed from your bedroom. This will ensure that you have a healthy retreat when needed.

Work Environment

Air-conditioning may be effective in the workplace for reducing the number of airborne allergens. Air filtration systems are an additional help, provided they are used properly and maintained.

When you identify triggers that may provoke an asthma episode, minimize your exposure to them. Heavy scents,

smoke, and fumes may aggravate asthma symptoms. Investigate the possibility of relocating your work area or, at the very least, modifying working conditions. For example, you might ask your supervisor to initiate a no-smoking policy or to limit smoking to designated areas of the building.

Stress can also be a contributor to asthma episodes. Tension and anxiety cause your airway muscles to tighten, making breathing more difficult. Try stress reduction techniques to help you relax and to put you more in control of your asthma.

Foods and Drugs

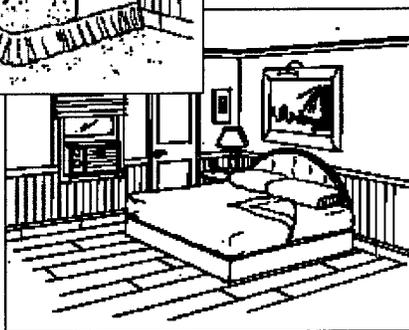
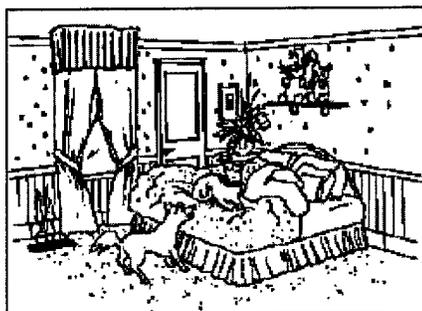
An asthma episode can also be triggered by things you eat or medicine you take.

Processed foods contain chemicals, called sulfiting agents, which are added as preservatives. Foods that may contain these chemicals include dried fruits, fruit juices, vegetables, and wines. Many patients may need to avoid sulfiting agents because these chemicals may initiate an asthma episode. Other foods can cause you to experience an allergic reaction that may trigger an asthma

episode. The most common culprits are cheese and dairy products, citrus fruits, tomatoes, seafood, and corn.

Certain drugs have been identified as asthma triggers. Aspirin and aspirin-like medicines are likely to instigate the occurrence of symptoms in those who encounter recurring sinusitis and have nasal polyps. Beta-adrenergic blocking agents, which are used to treat migraines, rapid heart rate, congestive heart failure, tremor, and glaucoma, are also known to provoke asthma episodes.

It is important to always follow the advice of your doctor. Be sure to ask if there are any foods or drugs you should avoid. Don't take any medications other than those for your asthma without first asking your doctor. And, be sure to notify your doctor when you experience any unusual reactions to foods or drugs.



Asthma Medications

What they are and how they work

Understanding your bronchodilator

As part of the plan for managing your asthma, your doctor has prescribed a bronchodilator to relieve your asthma symptoms. One of two types of medications used to treat asthma, bronchodilators relax the muscles surrounding your airways, or bronchial tubes, so that they open more fully and allow you to breathe more freely. When these muscles contract and cause bronchospasm, your airways narrow considerably. While short-acting bronchodilators are successful in relieving your symptoms by opening airways during an episode, they do not reduce or inhibit the inflammation and swelling within your airways.

Your doctor will prescribe a form of bronchodilator that is most likely to be effective for you. Bronchodilators are available in several different forms. Pills, liquids, inhalants, and injections can be prescribed. However, inhaled medication is usually preferred to oral medication.



Commonly used bronchodilators are inhaled β_2 -receptor stimulants (agonists). As you breathe in, these medications go directly into your lungs and deposit on the restricted airways. There are two types of inhaled β_2 -agonists — short-acting and long-acting. The short-acting β_2 -agonist acts almost immediately to relieve symptoms. The long-acting β_2 -agonist is intended to be used to help prevent asthma symptoms. It should never be used to treat sudden symptoms.

Short-acting β_2 -agonist bronchodilator

For persons who encounter only an occasional episode of asthma, for instance, less than once or twice a week, a short-acting bronchodilator may be prescribed. This provides quick relief for the episodes experienced by the person who is otherwise free of symptoms most of the time. The most common side effects of this medication are tremor, cough, and headache.

Short-acting bronchodilators begin acting quickly and reach their peak of relief within two hours of ingestion and can be taken every four hours as needed.

Long-acting β_2 -agonist bronchodilators

For persons who suffer from chronic episodes of asthma, a long-acting bronchodilator can be prescribed. This is part of a stabilizing maintenance program. The medication is taken regularly to constantly maintain airway opening. Long-acting bronchodilators are commonly taken twice daily, approximately 12 hours apart. The most common side effects of this medication are tremor, cough, and headache. A commonly used oral medication for asthma is theophylline.

It is available in a wide range of strengths and dosage forms. The many different dosages allow for a more exact prescription to treat a person's individual symptoms with the least amount of side effects. Theophylline can be prescribed as a short-acting or a long-acting medication. It is also part of a stabilizing maintenance program. The most common side effects of this medication are nausea, headache, restlessness, and rapid heartbeat. Blood tests should be taken periodically to ensure that the correct dosage is maintained.

Understanding your anti-inflammatory agent (Cromolyn, Nedocromil)

Cromolyn or nedocromil may be used as a part of a regular maintenance plan for controlling asthma by helping prevent sudden asthma attacks. They are inhalants taken regularly as a preventive measure. They work to prevent the swelling within your bronchial tubes when you come in contact with an asthma trigger. These agents calm hypersensitive airways to ensure easier breathing, and may be used to reduce the reaction to those triggers that are known but unavoidable. They may also be helpful when taken before exercise or activity. They are neither intended nor useful for providing relief of symptoms once an attack has begun. The most common side effects of these medications are throat irritation, bad taste, cough, and nausea.

Corticosteroids

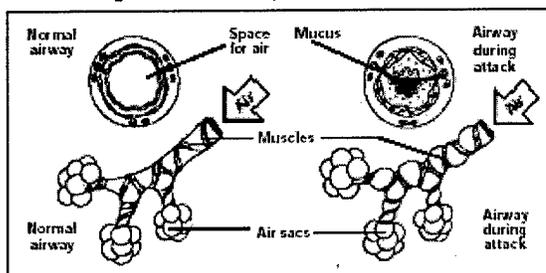
Corticosteroids are anti-inflammatory medications that reduce the swelling and hypersensitivity of the airways. Corticosteroids are available as an inhalant, tablet, suppository, liquid, or injection. They are very effective in the regular maintenance of asthma control and provide treatment of the underlying problem, inflammation. While inhaled corticosteroids cannot treat a sudden episode, they are the most effective medicines used to reduce airway inflammation that can contribute to symptoms. Corticosteroids are derived from a natural hormone already produced in your body. They are in no way related or similar to the anabolic steroids that are sometimes misused by athletes to increase muscle mass.

If you have been prescribed a long-acting, inhaled β_2 -agonist in addition to a corticosteroid, do not discontinue your corticosteroid without consulting your doctor, even if you feel better. The most common side effects of these medications when taken orally are increased appetite, fluid retention, and weight gain. When inhaled, the most common side effects of these medications are yeast infections in the mouth, sore throat, hoarseness, and coughing. You can minimize your risk of yeast infections by rinsing your mouth with water after every use.

Understanding Asthma

What is asthma?

Asthma is a chronic lung disease that makes breathing difficult. During an episode of asthma, the lining of the airways, or bronchial tubes, becomes inflamed and swollen. Surrounding muscles become tighter so that the airways are even narrower. A thick mucus is also produced, which further blocks breathing. Although asthma cannot be cured, its symptoms can be controlled with the help of your doctor and a manageable treatment plan.



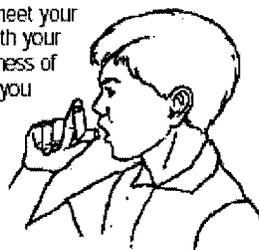
What are the symptoms of asthma?

Typical symptoms include shortness of breath, tightness in the chest, wheezing, and coughing.

How is asthma diagnosed and treated?

Asthma is best diagnosed with a visit to your doctor, who will evaluate your medical and family history. A physical exam will also be necessary, during which your doctor will listen to your breathing. Certain lab tests are also helpful in diagnosing asthma. These tests determine pulmonary function, blood counts, and allergies.

While there is no cure for asthma, there are a number of ways to control asthma symptoms. Your doctor will prescribe asthma medications to meet your needs. You should work closely with your doctor and report on the effectiveness of the medicine and any side effects you may experience. You should also try to discover what triggers an asthma attack. Together, you and your doctor can develop a medication plan and treatment plan that work best for you.



Two kinds of medicines are prescribed to treat asthma — bronchodilators and anti-inflammatory agents. One kind of bronchodilator acts quickly to relax the muscles that tighten around airways. They are available to provide rapid onset of relief. These are referred to as short-acting bronchodilators. There are also long-acting bronchodilators that help prevent episodes of asthma. This type of bronchodilator should not be taken for treatment of sudden symptoms. Anti-inflammatory medicines, such as corticosteroids and cromolyn, take longer to work than bronchodilators. However, they are important in preventing and reducing inflammation and swelling of the airways.

What causes asthma?

The exact cause of asthma is not known, but it does seem to run in families.

Patients with asthma may be supersensitive to various substances and environmental conditions that are normally harmless. Some common triggers may include allergens such as pollen, animal dander, dust, and dust mites as well as irritants such as smoke, fumes, and strong odors. Other triggers can be changes in the weather or temperature, certain drugs, and food additives.

Nocturnal asthma, or asthma symptoms that occur at night, can be related to a number of factors including allergens in the bedroom, late responses to triggers exposed to during the day, heartburn, and even the drop in body temperature that occurs during sleep.

Exercise-induced asthma involves asthma symptoms that occur during or immediately following activity.

Take an active role in your own therapy. What you can do —

Managing your asthma correctly is the most important effort you can make to ensure that you lead a normal and healthy life. Your best start is forming a strong partnership with your doctor. Together you can develop a personalized treatment plan to help control your symptoms.

Eat right, exercise, and get enough rest. Know your asthma triggers and ways to avoid contact with them. Watch for warning signs of an episode so that you can begin treatment quickly and effectively with the proper dose of prescribed medicine. Stay calm when symptoms do arise and ask for help from family, friends, or your doctor when you need it.

If your medication does not seem to alleviate your symptoms, seek the medical care you need immediately. Be sure those around you are aware of your condition and teach them ways they can assist you when urgent help is needed. Keep emergency information and important phone numbers handy.

What you should avoid —

Preventing episodes of asthma becomes easier and more manageable when you know your triggers. Make some practical changes in your environment by removing as many irritants as you can. Asthma is a controllable disease that should not prevent you from enjoying a healthy and active life. See your doctor regularly and use your medications properly. Remember that you're in control!

ASTHMA MANAGEMENT PLAN Patient Name _____ Date of Birth _____ Best Peak Flow _____

Health Center/Office _____ Phone Number _____ Provider Name _____



#1 Medication _____ Dose _____ How to take? _____ When to take? _____

#2 Medication _____ Dose _____ How to take? _____ When to take? _____

#3 Medication _____ Dose _____ How to take? _____ When to take? _____

Which medications are ordered for the school nurse to give? Med.#1: time _____ Med.#2: time _____ Med.#3: time _____

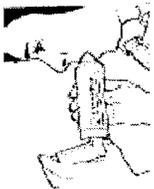
Common side effects: _____

Coughing, Wheezing, Shortness of Breath



SLOW!

OR



OR



Call the Health Center/Office if there is no improvement!

Rescue Medication _____ Dose _____ How to take? _____ When to take? _____

Is rescue medication ordered for the school nurse to give PRN? Yes No

Anti-inflammatory _____ Dose _____ How to take? _____ When to take? _____

Peak Flow: _____



Extreme Trouble Breathing, Cannot Walk or Talk!

Give Rescue Medication!

OR



OR



Call Health Center/Office Now! Call 911 if Condition Worsens!

FOR SCHOOL OR AFTER SCHOOL PROGRAMS

I have instructed _____ in the proper way to use his/her medications.

In my professional opinion this child should not be allowed to carry and use these medications.

Comments/Special Instructions _____

Physician signature _____

Emergency parent/guardian phone # _____

Parent/Guardian signature _____

Other Important Instructions:

- No smoking in your home or car.
- Remove known triggers from your child's environment.

APPENDIX IV

ASTHMA SELF-CARE QUESTIONNAIRE

	Never	Sometimes	Most of the time	Always
1. I can tell if I'm about to have an asthma attack.	_____	_____	_____	_____
2. I stay away from things that cause me to have breathing problems.	_____	_____	_____	_____
3. I take my asthma medicines the way my Doctor tells me.	_____	_____	_____	_____
4. I let my parents/teacher know when I'm having trouble breathing	_____	_____	_____	_____
5. I learn about asthma by talking or reading about it or having someone read to me.	_____	_____	_____	_____
6. I chart and graph my peak flow reading everyday.	_____	_____	_____	_____
7. I know when I need to take my medicines	_____	_____	_____	_____
8. I stop playing and take it easy when I start to have trouble breathing	_____	_____	_____	_____
9. I talk to my Doctor about my asthma when I visit the clinic.	_____	_____	_____	_____
10. I stay calm and relaxed when I have trouble breathing.	_____	_____	_____	_____
11. I change my medicines if my breathing gets worse	_____	_____	_____	_____
12. I check my peak flow reading without being reminded	_____	_____	_____	_____

13. I do breathing exercises
to help control my asthma _____

14. I avoid things that
cause breathing problems _____

APPENDIX V
PEDIATRIC ASTHMA QUALITY OF LIFE QUESTIONNAIRE WITH
STANDARDIZED ACTIVITIES

PAEDIATRIC ASTHMA QUALITY OF LIFE QUESTIONNAIRE WITH STANDARDISED ACTIVITIES (PAQLQ(S))

INTERVIEWER-ADMINISTERED

© 1999

QOL TECHNOLOGIES LTD.



For further information:

Elizabeth Juniper, MCSP, MSc
Professor
20 Marcuse Fields,
Bosham,
West Sussex,
PO18 8NA, UK
Tel: + 44 (0) 1243 572124
Fax: + 44 (0) 1243 573680
E-mail: juniper@qoltech.co.uk
Web: www.qoltech.co.uk

© The PAQLQ(S) is copyrighted. It may not be altered, sold (paper or electronic), translated or adapted for another medium without the permission of Elizabeth Juniper.

I want you to tell me how much you have been bothered by your asthma during the past week. I will tell you which card to use. Pick the number that best describes how much you were bothered by your asthma during the past week.

- A 1. How much have you been bothered by your asthma in **PHYSICAL ACTIVITIES** (such as running, swimming, sports, walking uphill/upstairs and bicycling) during the past week. [BLUE CARD]
- A 2. How much have you been bothered by your asthma in **BEING WITH ANIMALS** (such as playing with pets and looking after animals) during the past week. [BLUE CARD]
- A 3. How much have you been bothered by your asthma in **ACTIVITIES WITH FRIENDS AND FAMILY** (such as playing at recess and doing things with your friends and family) during the past week. [BLUE CARD]
- S 4. How much did **COUGHING** bother you in the past week? [BLUE CARD]
- E 5. How often did your asthma make you feel **FRUSTRATED** during the past week? [GREEN CARD]
- S 6. How often did your asthma make you feel **TIRED** during the past week? [GREEN CARD]
- E 7. How often did you feel **WORRIED, CONCERNED, OR TROUBLED** because of your asthma during the past week? [GREEN CARD]
- S 8. How much did **ASTHMA ATTACKS** bother you during the past week? [BLUE CARD]
- E 9. How often did your asthma make you feel **ANGRY** during the past week? [GREEN CARD]
- S 10. How much did **WHEEZING** bother you during the past week? [BLUE CARD]
- E 11. How often did your asthma make you feel **IRRITABLE** (cranky, grouchy*) during the past week? [GREEN CARD]
(*use only if patient does not understand the word "irritable")
- S 12. How much did **TIGHTNESS IN YOUR CHEST** bother you during the past week? [BLUE CARD]

- E 13. How often did you feel **DIFFERENT OR LEFT OUT** because of your asthma during the past week? [GREEN CARD]
- S 14. How much did **SHORTNESS OF BREATH** bother you during the past week? [BLUE CARD]
- E 15. How often did you feel **FRUSTRATED BECAUSE YOU COULDN'T KEEP UP WITH OTHERS** during the past week? [GREEN CARD]
- S 16. How often did your asthma **WAKE YOU UP DURING THE NIGHT** during the past week? [GREEN CARD]
- E 17. How often did you feel **UNCOMFORTABLE** because of your asthma during the past week? [GREEN CARD]
- S 18. How often did you feel **OUT OF BREATH** during the past week? [GREEN CARD]
- A 19. How often did you feel **YOU COULDN'T KEEP UP WITH OTHERS** because of your asthma during the past week? [GREEN CARD]
- S 20. How often did you have trouble **SLEEPING AT NIGHT**, because of your asthma, during the past week? [GREEN CARD]
- E 21. How often did you feel **FRIGHTENED BY AN ASTHMA ATTACK** during the past week? [GREEN CARD]
- A 22. Think about all the activities that you did in the past week. How much were you bothered by your asthma doing these activities? [BLUE CARD]
- A 23. How often did you have difficulty taking a **DEEP BREATH** in the past week? [GREEN CARD]

DOMAIN CODE:

- S = Symptoms
A = Activity Limitation
E = Emotional Function

RESPONSE SHEET

NAME: _____ NUMBER: _____

DATES OF COMPLETION:

1st: _____ 2nd: _____

3rd: _____ 4th: _____

ITEM	RESPONSES			
	1st	2nd	3rd	4th
1. Physical activities	_____	_____	_____	_____
2. Being with animals	_____	_____	_____	_____
3. Activities with friends and family	_____	_____	_____	_____
4. Cough	_____	_____	_____	_____
5. Frustrated	_____	_____	_____	_____
6. Tired	_____	_____	_____	_____
7. Worried/concerned/troubled	_____	_____	_____	_____
8. Asthma attacks	_____	_____	_____	_____
9. Angry	_____	_____	_____	_____
10. Wheezing	_____	_____	_____	_____
11. Irritable	_____	_____	_____	_____
12. Tightness in chest	_____	_____	_____	_____
13. Feeling different or left out	_____	_____	_____	_____
14. Shortness of breath	_____	_____	_____	_____
15. Frustrated can't keep up with others	_____	_____	_____	_____
16. Wake up during the night	_____	_____	_____	_____
17. Uncomfortable	_____	_____	_____	_____
18. Out of breath	_____	_____	_____	_____
19. Can't keep up with others	_____	_____	_____	_____
20. Trouble sleeping at night	_____	_____	_____	_____

ITEM	RESPONSES			
	1st	2nd	3rd	4th
21. Frightened by asthma attack	—	—	—	—
22. Bothered in activities overall	—	—	—	—
23. Deep breath	—	—	—	—

RESPONSE OPTIONS**GREEN CARD**

1. ALL OF THE TIME
2. MOST OF THE TIME
3. QUITE OFTEN
4. SOME OF THE TIME
5. ONCE IN A WHILE
6. HARDLY ANY OF THE TIME
7. NONE OF THE TIME

BLUE CARD

1. EXTREMELY BOTHERED
2. VERY BOTHERED
3. QUITE BOTHERED
4. SOMEWHAT BOTHERED
5. BOTHERED A BIT
6. HARDLY BOTHERED AT ALL
7. NOT BOTHERED