REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

1. AGENCY USE ONLY *(Leave blank)*	2. REPORT DATE	3. REPORT TYPE AND DATES COVERED
	2 October 1998	

4. TITLE AND SUBTITLE
QUALITY OF LIFE FOR ADULTS WITH ASTHMA IN A MILITARY SETTING

5. FUNDING NUMBERS

6. AUTHOR(S)
RHONDA RAE ADLER

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)
UNIFORMED SERVICES UNIVERSITY OF THE HEALTH SCIENCES

8. PERFORMING ORGANIZATION REPORT NUMBER
98-072

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 35-205/AFIT Sup 1

12b. DISTRIBUTION CODE

13. ABSTRACT *(Maximum 200 words)*

14. SUBJECT TERMS

15. NUMBER OF PAGES
61

16. PRICE CODE

17. SECURITY CLASSIFICATION OF REPORT	18. SECURITY CLASSIFICATION OF THIS PAGE	19. SECURITY CLASSIFICATION OF ABSTRACT	20. LIMITATION OF ABSTRACT

Captain Rhonda Adler
1024 Copperstone Court
Rockville, MD 20852

7 June 1998

Air Force Institute of Technology/CIMI
2950 P Street, Building 125
Wright-Patterson AFB, OH 45433-7765

Major Johnson,

I, Captain Rhonda Adler, NC, attended the Uniformed Services University of the Health Sciences and request reimbursement for my thesis. Enclosed is a copy of my thesis and the signed approval for the acceptance from the school. Please mail the reimbursement check to me in care of my sister:

Regina Steinhardt
1311 Maryland Avenue
Sheboygan, WI 53081.

Thank you.

Sincerely,

Rhonda R. Adler

Rhonda Adler, Capt., USAF, NC

QUALITY OF LIFE FOR ADULTS WITH ASTHMA IN A MILITARY SETTING

by

RHONDA RAE ADLER, RN, BSN

THESIS

Presented to the Graduate School of Nursing Faculty of

the Uniformed Services University of the Health Sciences

in Partial Fulfillment

of the Requirements

for the Degree of

MASTER OF SCIENCE DEGREE

UNIFORMED SERVICES UNIVERSITY OF THE HEALTH SCIENCES
May 1998

QUALITY OF LIFE FOR ADULTS WITH ASTHMA IN A MILITARY SETTING

Rhonda Rae Adler

APPROVED:

Barbara M. Sylvia — 1 May 98
Dr. Barbara Sylvia, Ph.D., R.N., Chair of Committee — Approval Date

Kenneth Miller — 1 May 98
Dr. Kenneth Miller, Ph.D., R.N., Member — Approval Date

Lorraine A. Fritz — 1 May 98
MAJ Lorraine Fritz, MSN, PNP, Member — Approval Date

APPROVED:

Faye G. Abdellah — 14 May 1998
F.G. Abdullah, Ed.D., ScD., RN, FAAN — Date
Dean

CURRICULUM VITAE

Name: Rhonda Rae Adler

Permanent Address: 1024 Copperstone Court, Rockville, MD 20852

Degree and date to be conferred: Master of Science in Nursing 1998

Data of Birth: August 14, 1954

Place of Birth: Chicago, Illinois

Secondary education: Howards Grove High School, Howards Grove, WI, June 1972

Collegiate institutions attended:	Dates	Degree	Date of Degree
Lakeshore Technical College Cleveland, WI	1978 - 80	Associate	June 1980
Marquette University Milwaukee, WI	1983 - 86	BSN	Dec 1996
Uniformed Services University of the Health Sciences Bethesda, MD	1996 - 98	MSN	May 1998

Major: Family Nurse Practitioner

Professional publications: None

Professional positions held:

Next duty assignment:	Family Nurse Practitioner	2nd Medical Group Barksdale AFB, LA
Feb 1995 - June 1996	Staff Development Officer	49th Medical Group Holloman AFB, NM
July 1992 - Feb 1995	Staff Nurse, Med-Surg	49th Medical Group Holloman AFB, NM
Aug 1990 - June 1992	Staff Nurse, ED and ICU	Community Health Center of Branch County, MI

Dec 1989 - Aug 1990	Staff Nurse, ED	Waukesha Memorial Hospital Waukesha, WI
Sep 1985 - July 1990	Staff Nurse, ED, Hospital & Shift Supervisor	St. Michael Hospital Milwaukee, WI
May 1884 - Sep 1985	Staff Nurse, ED	Family Hospital Milwaukee, WI
Dec 1982 - May 1984	Staff Nurse, Transplant	Froedtert Memorial Hospital Milwaukee, WI
June 1982 - Dec 1982	Staff Nurse, Dialysis	St. Mary's Hospital Milwaukee, WI
June 1980 - June 1982	Staff Nurse, Med-Surg	St. Nicholas Hospital Sheboygan, WI

DISCLAIMER STATEMENT

Department of Defense

"This work was support by the Uniformed Services University of the Health Sciences Protocol No. T06146-01. The opinions or assertions contained herein are the private opinions of the author and are not to be construed as official or reflecting the views of the Department of the Defense or the Uniformed Services University of the Health Sciences."

COPYRIGHT STATEMENT

The author hereby certifies that the use of any copyrighted material in the thesis entitled: "QUALITY OF LIFE FOR ADULTS WITH ASTHMA IN A MILITARY SETTING" beyond brief excerpts is with the permission of the copyright owner, and will save and hold harmless the Uniformed Services University of the Health Sciences from any damage which may arise from such copyright violations.

ABSTRACT

Asthma is a disease that affects millions of Americans. The financial, functional and emotional costs are substantial and have a significant impact on quality of life. The purpose of this study was to examine the relationship between the severity of asthma via clinical and functional parameters and the quality of life described by adults with asthma in the military health care system. A convenience sample of 39 subjects with the diagnosis of asthma at a major military medical center completed a self-administered survey which included demographic information and symptoms with measures of lung function. The survey included the Asthma Quality of Life Questionnaire (AQLQ) developed by E. Juniper and associates. Missing data for symptom frequency and lung function measures necessitated a revision in the question that related to nighttime symptoms after the first month of data collection. In the data collected prior to the revision a statistically significant correlation was seen in the four domains of activities, emotions, symptoms, and environment and in the overall score of quality of life with indices for symptom severity. There was nonsignificant correlation to lung function. After the revision of the tool, data correlated to lung function and not to symptom severity. Although the small sample size and the lack of adequate information relating to symptom severity may explain these findings, asthma may affect quality of life in ways that objective clinical measures cannot predict. This is consistent with the Conceptual Model of Symptom Management in which quality of life is one of ten interrelated dimensions of symptom outcomes. Providers should include assessment for quality of life to understand the patient's perspective and provide a comprehensive approach to asthma management.

Key Words: asthma, quality of life, military, outcomes evaluation, symptom management.

DEDICATION

To my husband, Gary, and my sons, Eric and Matt, I dedicate the creation of this thesis. Without their love, encouragement, and support the attainment of my goal and the creation of this thesis would not have been possible.

"A cheerful heart is good medicine." Proverbs 17:22.

ACKNOWLEDGMENT

The assistance, guidance and support of numerous people have contributed to making possible the attainment of this degree. I am especially grateful to Dr. Sylvia, and the members of the thesis advisory committee, Dr. Ken Miller and MAJ Lorraine Fritz. Their guidance, knowledge and support was invaluable.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1 - INTRODUCTION

Asthma is a major, chronic airway disease which is characterized by airway inflammation, hyperresponsiveness, and reversible obstruction. The operational description adopted by the National Asthma Education and Prevention Program (NAEPP)in the *Expert Panel Report II* (National Heart, Lung and Blood Institute [NHLBI], 1997) is that:

> Asthma is a chronic inflammatory disorder of the airways in which many cells play a role, in particular, mast cells, eosinophils, T lymphocytes, neutrophils, and epithelial cells. In susceptible individuals, this inflammation causes recurrent episodes of wheezing, breathlessness, chest tightness, and cough particularly at night and in the early morning. These episodes are usually associated with widespread but variable airflow limitation that is often reversible either spontaneously or with treatment. The inflammation also causes an associated increase in the existing bronchial hyperresponsiveness to a variety of stimuli. (p. 3-4).

The National Heart, Lung, and Blood Institiute (NHLBI) and the World Health Organization (WHO) reported that the prevalence of asthma is worldwide with over 100 million people affected with this disease (NHLBI/WHO, 1995, p. xiii). According to the 1997 *Expert Panel Report II* (NAEPP), 14 to 15 million Americans have asthma. Asthma affects all age groups, but the incidence is rising among children. According to the Centers for Disease Control and Prevention (CDC), (1996) the annual hospitalization

rate for persons younger than 25 increased by 28% since 1980 (p. 351). Death rates for this group have also increased over the last 15 years. This disease usually appears in childhood and produces lifelong consequences. These consequences are substantial in terms of cost of medical care and days lost from school and work, and add up to over $6 billion per year (Kropfelder & Winkelstein, 1996).

Statistics currently kept by the Military Health Services System show more than five thousand admissions per year for asthma at an estimated cost of $12 million annually (Collins, Goodman, & McQueston, 1995). The Department of Defense currently spends over $19 million per year on drug treatment for asthma (PharmacoEconomic Center, 1996, p. 1). Asthma is one of the conditions that, unless it is caused by a well defined and avoidable precipitant, is reason for exclusion from military service (Air Force Instruction 48-123, 15 November 94, p. 69). According to Lt. Col. John Mitchell, USAF, MC, consultant to the office of the Surgeon General for pulmonary medicine, 52% of medical discharge in the military are related to asthma. Exacerbation of asthma is the number one reason for air evacuation. Approximately one percent of our active duty troops have asthma (Lt. Col. J. Mitchell, MD, personal communication, April 29, 1997). If this proportion of our military cannot perform their jobs due to asthma complications, it will have a significant effect on the readiness of our forces.

Although asthma cannot be cured, it is a disease that can be controlled. Recent major advances in the understanding of this disease include: a) a new appreciation for the significant role of airway inflammation in the pathogenesis of asthma, b) a new emphasis on treatment, and c) a new focus on establishing risk factors for the development of

asthma and identifying appropriate prevention programs (NHLBI/WHO, 1995).

The National Asthma Education Program (NAEP) was developed at a workshop sponsored by the National Heart, Lung, and Blood Institute in 1988. The intent of the program is to enhance the quality of life for the asthmatic patient, as well as decrease morbidity and mortality through increased awareness and use of optimal therapeutic and management strategies. To accomplish these goals the NAEP planned to: (a) raise awareness of patients, health care providers and the public about the seriousness of asthma as a chronic disease, (b) ensure appropriate recognition and diagnosis, and (c) ensure effective control of asthma (NEAP, 1991). Their findings and recommendations represented a compilation of much research done in the past ten years. The NAEP published the *Executive Summary: Guidelines for the Diagnosis and Management of Asthma* in 1991 which includes background information, reference material, and discussion of specific considerations to assist health care providers with asthma management. These guidelines are based on four components: (a) objective measurement of lung function, (b) comprehensive medication therapy to treat narrowed airways and inflammation, (c) environmental controls and immunotherapy, and (d) patient education in order to form partnerships with patients to assist with self management (NEAP, 1991).

In 1992, the NAEP also published *Teach Your Patients about Asthma: A Clinician's Guide* that provides step-by-step assistance and teaching materials for patients with asthma. In 1992 , the WHO and NHLBI collaborated in a Global Initiative for Asthma to publish the *International Consensus Report of Diagnosis and Management of Asthma.* This report represented collaboration among medical leaders in eleven countries

who had developed national guidelines for asthma management. The *Global Strategy for Asthma Management and Prevention, NHLBI/WHO Workshop Report* was published in 1995 as a result of the international response to the *International Consensus Report.* More recently, February 1997 guidelines have been made available from the National Asthma Education and Prevention Program (NEAPP), formerly known as the NEAP, and are titled *Expert Panel Report II: Guidelines for the Diagnosis and Management of Asthma.* (NAEPP, 1997)

According to the 1995 and 1997 guidelines, asthma severity is classified into four steps. Step I is considered mild intermittent asthma and the steps continue to Step IV, in which the symptoms are severe and persistent. With each step level increase, the severity of the symptoms increase while the peak expiratory flow readings (PEF) and lung function measures decrease (See Table 1). Appropriate pharmacotherapy is based on this stepwise approach and is dictated by the level of severity, age, compliance, inhaler technique, and side effects. Control of environmental factors and patient education are integrated into every step of clinical asthma care.

Table 1.

Classification of Asthma Severity

	Symptoms	Nighttime Symptoms	Lung Function
STEP 4 Severe persistent	• Continual symptoms • Limited physical activity • Frequent exacerbations	• Frequent	• $FEV_1/PEF \leq 60\%$ predicted • PEF variability > 30%
STEP 3 Moderate Persistent	• Daily symptoms • Daily use of inhaled short acting beta agonist • Exacerbations affect activity • Exacerbations ≥ 2 times a week; may last days	• > 1 time a week	• $FEV_1/PEF > 60\%$ to <80% predicted • PEF variability > 30%
STEP 2 Mild Persistent	• Symptoms > 2 times a week but less than one time per day • Exacerbations may affect activity	• > 2 times a month	• $FEV_1/PEF \geq 80\%$ predicted • PEF variability 20 - 30%
STEP 1 Mild Intermittent	• Symptoms ≤ 2 times a week • Asymptomatic and normal PEF between exacerbations • Exacerbations brief (few hours to a few days); intensity may vary	• ≤ 2 times a month	• $FEV_1/PEF \geq 80\%$ predicted • PEF variability < 20%

Note: From National Asthma Education and Prevention Program; Expert Panel Report II: Guidelines for the diagnosis and management of asthma, 1997, p. 11a.

The goals of therapy are to improve the quality of life, as well as lung function, since this is a chronic disease that has no cure. However, the impact that a chronic

disease, such as asthma, has on patients' and their families' lives is often underestimated by health care providers. Asthma involves a permanent change in the individual's way of life with a reappraisal of what is optimal for both function and health. Patients are forced to pay attention to their bodies and manage the physical symptoms. Criteria that a health care provider uses to record successful treatment may not be seen as the most important or relevant to the patients. Therefore, it is important for the provider to understand the impact of this disease from the patient's perspective.

For the military community, uncontrolled asthma places considerable restrictions on the lives of all members of the family physically, emotionally, socially, and may even have impact on the careers of the active duty members. Dependents with asthma may need to be enrolled in the Exceptional Family Member Program. Once identified as someone with special medical needs which require continued assistance, reassignments are made to locations where the required services are available (Air Force Instruction 36-2110, 1994, Attachment 7). Families may be separated in order for the member with asthma to obtain services at another location. If the active duty member's presence is essential to handle the problem, this may have an impact on opportunities for promotion. Well controlled asthma in one location may be difficult to control in another geographic area. And finally, frequent moves, fragmented care, and separation from extended family all affect the quality of care and the quality of life as families move from location to location.

The changes that any patient undergoes evolve with the severity of asthma, grief adaptation, developmental stages, and stress management. Price (1996) describes the

problems that chronically ill patients face with these changes in their lives. The recurring themes are: dealing with uncertainty, reconstructing self, managing regimens, managing relationships, body as uncomfortable, body as disobedient, the vulnerable body, the violated body, and the enduring/resigned body. It then becomes the practitioner's challenge to not only assess and teach clients about asthma, but to understand the experience of the effects as described by the patient or their families.

Due to increasing incidence and prevalence (Hartert, Windom, Peebles, Freidhoff, & Togias, 1996; NHLBI/WHO, 1995), primary care providers devote much time to caring for patients with asthma. A comprehensive approach integrates the patient's experience into asthma management and is tailored to meet the needs of each patient. Emphasis is placed on evaluating the outcome of management in terms of the patient's perception of improvement, especially quality of life, and ability to engage in usual activities. According to the *Scope and Standards of Advanced Practice Registered Nursing*, Standard Vc, with respect to health promotion, health maintenance, and health teaching, the nurse practitioner bases measurement criteria on methods that are appropriate to developmental levels, learning needs, readiness and ability to learn, along with cultural health beliefs and practices (American Nurses Association [ANA], 1996). Nurse practitioners have a unique role in the care of these patients with the skills they possess to provide educational counseling and support for quality of life issues.

Historically, the majority of asthma related studies were conducted to determine physiologic measures, cost benefits, and frequency of use of hospital services. However, relatively little information has been collected on the way patients with asthma feel and

how they function in their day-to-day lives (Bousquet, et al., 1994; Jones, Quirk, Baveystock, & Littlejohns, 1992; Juniper, et al., 1992; Juniper, Guyatt, Ferrie, & Griffith, 1993; Juniper, Guyatt, Willan, & Griffith, 1994; Steinwachs, Wu, Skinner, & Campbell, 1995). The results of these quality of life studies were used along with clinical trials. Investigators recommended inclusion of quality of life questionnaires in future trials as well as follow up office visits to evaluate the components which the patient feels are the most important (Earwood, 1996, Rutten-Van Molken, Van Doorslaer, & Rutten, 1992).

Purpose of the Study

When patients clarify their perceptions of the effects of asthma, they may be better able to choose courses of action to enhance their health and future. In this manner, the nurse practitioner can begin to assist the patient toward achieving goals that the patient decides are important for his or her quality of life. A mutual effort is required to make the patient's life more meaningful and personally fulfilling when illness symptoms and physical restrictions cannot be removed entirely. Therefore, the purpose of this study was to describe the effect of asthma in adults within the military health care system on their quality of life. Data/results from this study can be used to facilitate a comprehensive, individualized approach to care. More specifically, the questions posed for this study were: What are the overall quality of life scores for individuals in the military health care system? What are the relationships between symptom severity of asthma, lung function, and the quality of life in each of the four domains of activities, symptoms, emotions, and environment?

Hypotheses

The following hypotheses were addressed in this study:

1. Adult asthma patients who have increased symptom severity and diminished lung function will have decreased quality of life overall.

2. Adult asthma patients who have increased symptom severity and diminished lung function will have decreased quality of life related to activity limitations.

3. Adult asthma patients who have increased symptom severity and diminished lung function will have decreased quality of life in emotional function.

4. Adult asthma patients who have increased symptom severity and diminished lung function will have decreased quality of life related to an increase in symptoms.

5. Adult asthma patients who have increased symptom severity and diminished lung function will have decreased quality of life with exposure to environmental stimuli.

CHAPTER 2 - REVIEW OF RELEVANT LITERATURE

This chapter begins with a discussion of the development of the current guidelines for management of asthma. Next, studies on the problems with adherence to the guidelines, education, and use of inhalers are analyzed. Finally, studies on the development and use of general and disease specific quality of life tools are included.

Guidelines

The 1995, publication of the *Global Strategy for Asthma Management and Prevention, NHLBI/WHO Workshop Report* (NHLBI/WHO) had become the accepted universal guideline for asthma management. This report is the work of 21 participants from 17 countries who met three times to develop information, recommendations, and tools to help public health officials and health care professionals to design and deliver effective asthma treatment and prevention programs. The Global Initiative for Asthma (GINA) was formed to prepare and disseminate such reports and to promote international collaboration on research.

This *NHLBI/WHO Workshop Report* (NHLBI/WHO, 1995) describes asthma as one of the most common chronic diseases worldwide. It occurs in all countries regardless of the level of development. The incidence is increasing throughout the world and, so far, there is insufficient data to determine the reasons. Some of the theories offered in this report are related to changes in indoor and outdoor environment and may involve aeroallergens, a synergistic action of air pollution and tobacco smoke, and increased urbanization. Other studies listed in the report are looking at socioeconomic factors,

appropriate medical care, housing environments, and dietary factors. Since asthma can impair the quality of life and is a major cause of absence from school and work, research needs to be conducted on effective treatment measures. Most of the existing data is biased toward the Western developed countries.

The *NHLBI/WHO Workshop Report* (1995) includes a comprehensive set of guidelines organized into ten chapters which discuss definitions, diagnosis, prevention, management, socioeconomics, and education. Each chapter represents a meta analysis of the studies done around the world on each of these topics. Key points are covered in depth along with future research recommendations and lists of references for each chapter. This report includes charts, tables, patient interviewing guides, and teaching aides.

Problems with Asthma Management

The incidence and mortality of asthma has increased in the United States over the last 20 years despite these discoveries and well-published guidelines for treatment (Hartert, et al., 1996; NHLBI/WHO, 1995). Studies conducted in both the private and military sectors reveal that the guidelines outlined in the Global Initiatives for Asthma (GINA) have not yet had the desired treatment effect (PharmacoEconomic Center, 1996; Hartert, et al, 1996; NHLBI/WHO, 1995). These studies found underutilization of inhaled anti-inflammatory therapy, overutilization of beta-agonists during exacerbations, inability of patients to use their metered dose inhalers properly, and inadequate communication between patient and provider for an action plan in the event of an exacerbation. The following are examples of such studies.

Hartert et al. (1996) conducted a study of 101 adult patients who were admitted to Johns Hopkins Medical Institutions in 1992 to assess adherence to the guidelines published by the NAEP. Using a cross-sectional survey, this descriptive study looked at the outpatient medical management as well as the actions of patients and their physicians during exacerbations leading up to the hospitalization. Hartert and colleagues found that the average admission rate for this group was 2.5 per year, which classified their asthma as moderate to severe. Also, less than 50% (45/101) of the patients had been prescribed inhaled anti-inflammatory medication, only 11% (11/101) could demonstrate proper use of the metered dose inhaler despite instruction, only 28% (28/101) had been given an action plan to use with exacerbations, and the average use of the beta-agonist inhalers was nearly twice that of the recommended dose. In 60% (60/101) of the patients who contacted their primary care provider prior to the admission, no change was made in the treatment plan (p. 393). The researchers felt that the patients were not receiving the appropriate medication regimens or the education recommended by the NAEP guidelines. Their findings are limited to the severity of this asthma population, and the urban environment in which this study was made.

Dales et al. (1992) also studied inadequacies of asthma management and control preceding emergency department visits. They used a standardized self-administered questionnaire to describe the usual level of disability, medications, self-management plans, and use of environmental control measures of 111 consecutive patients who presented to a hospital in Ontario, Canada. The data from this group was compared with non-participants based on information from the emergency room records. The data,

presented in tables and text to clearly show percentiles and correlation, indicated that 25% (27/111) had sleep disturbances greater than 15 days per month which indicates severe asthma, school and work attendance was affected more than 14 days per year, and the emergency department had been used twice in the past year. Thirty-seven percent (41/111) had no effective plan to manage exacerbations and 43% (47/111) continued to be exposed to smoke at home even though they claimed to have worsened symptoms due to cigarette smoke. The researchers also found that visiting a physician regularly did not necessarily have a positive effect on asthma control. As a result of these findings, Dales et al. suggest that health care workers at all levels receive education on the current asthma management guidelines so they in turn can educate patients to minimize the morbidity. Although this study is more representative of patients with severe asthma, the researchers felt that this group had more significant morbidity and potential mortality than those with minimal to moderate asthma.

Kropfelder and Winkelstein (1996) conducted a program evaluation in 1993 after a large inner-city health maintenance organization (HMO) developed a case management approach for asthma patients who were receiving urgent care rather than routine office visits. This descriptive evaluation looked at 114 pediatric patients in a case management program that identified the patients at risk, collected data on the patient and family, provided education for patients and family, and initiated written detailed plans for care. Follow up was done through phone and office visits. Their findings indicated that in the first year of this program, emergency visits decreased by 50%, office visits increased by 25%, and hospital admissions were decreased by 66% (data for n = not available).

Anecdotal reports of patient satisfaction indicated that those families involved in this program appreciated the efforts of these providers. This evaluation did not include any mention of how the data was collected and analyzed. The focus was mainly on the development of the program and its components.

A study of 323 adult patients with moderate to severe asthma in the Kaiser Permanente health system in California was conducted by Wilson and colleagues (Wilson, et al., 1993). They compared the effectiveness of individual and group education programs on cognitive, behavioral, and clinical outcomes. The patients were randomly assigned to small-group education, individual teaching, or one of two control conditions. The control conditions were a self-paced instructional workbook and the usual care, which was no formal asthma education. Data was collected by questionnaire, diary, and physical exam at intervals over a two year period. Medical record data was collected for three years and included the year prior to enrollment. Their findings indicated that a self-management education program was associated with significant improvements in control of symptoms, use of a metered dose inhaler, control of environmental triggers, and the patient's level of activity. Comparison of the educational programs showed that small-group education and individual education were associated with the greatest significance of improvement. The time frame of this study allowed for effects of behavioral changes. Other findings of the education program included little effect regarding change in smoking or pet ownership patterns. There was also little improvement noted in the lung function parameters; however, there was no spirometry data available after the first year. The authors' conclusions can be generalized to most

asthmatic adults, with providers taking caution to look at the individual needs and actual problems of each patient for compliance issues.

Two studies of technique for metered dose inhalers (MDIs) were conducted on medical personnel with very similar results. Guidry, Brown, Stogner, and George (1992) used a questionnaire and observation of physicians, nurses, and respiratory therapists (RTs) use of MDIs. They found that 92% (11/12) of the RTs, 65 % (15/23) of house staff physicians, 57 (8/14) percent of nurses, and 50% (6/12) of nonpulmonary faculty physicians performed at least 4 of the 7 steps correctly (p. 31). Most of the participants followed the package instructions. This study was conducted in one facility and the 61 subjects were randomly selected. Most of the physicians were selected from Internal Medicine, and the rest were selected from specialties other than pulmonary disease. The nurses were selected from a group that was involved in some way with outpatient care involving patient instruction of the MDI. All of the RTs were certified respiratory therapy technicians. Although this study brought to light the inadequacies of proper use of MDIs by health care providers in this particular facility, it also described how most of the providers followed the package inserts (p. 32). The findings are limited to this facility but do indicate that the package instructions need modification and medical personnel require instruction on the proper use of the MDI.

The other study on the use of MDIs was done by Interiano and Guntupalli (1993) to determine if the lack of proficiency by health care providers contributed to improper use of MDIs by patients. They looked at 100 adults with asthma recruited from the clinics of BenTaub General Hospital in Houston, Texas. They also studied 100 internal

medicine residents, 6 pulmonary medicine fellows, 20 respiratory therapists, and 50 nursing staff. The patients and providers were observed for technique by evaluating 6 essential steps, ability to estimate amounts of medication left in the canister, and whether they rinsed the mouth after use of steroid inhalers. Patients in pulmonary clinics performed better than those in general clinics. The RTs were more proficient in the use of MDIs than physicians or nurses. The researchers concluded that RTs should be used more to instruct patients since teaching of the proper technique takes 10-28 minutes. They also concluded that health care providers needed core training in the proper use of MDIs.

Quality of Life

Quality of life studies have evolved over the last ten years with the use of general health surveys such as the Sickness Impact Profile, the Inventory of Subjective Health, the Nottingham Health Profile, and the Short-Form Health Survey (SF-36). One such study by Bousquet et al. (1994) looked at quality of life in asthma with the SF-36 Questionnaire. They studied 252 patients with asthma of variable severity and the correlation to clinical scores. The SF-36 is a self-administered questionnaire and is of a general nature with 9 different categories, which took approximately ten minutes to complete. The SF-36 correlated well ($p< 0.0007$ to $p< 0.0001$) with severity of clinical measures as the higher score on the SF-36 related to a lower severity of asthma. This quality of life tool, along with other clinical parameters, was used by Noonan and associates (1995) in a clinical trial with inhaled fluticasone. It is currently in use by the Managed Health Care Association in their Asthma Patient Outcomes Study (1995). Its

general nature may not be sensitive to determine differences in quality of life for patients with mild to moderate levels of impairment.

Van Schayck et al. (1995) conducted another study that used general health surveys and measured the influence of inhaled steroid on quality of life. He and his colleagues used the Inventory of Subjective Health (ISH) and the Nottingham Health Profile (NHP) on 56 patients with asthma and COPD over four years to look at the effects that beclomethasone dipropionate had on quality of life, symptoms, and lung function. Quality of life was measured at the start and at 2 year intervals. Although the medication improved lung function, the researchers found that it did not improve general well-being as measured by the instruments they used. Since they concluded that the symptom severity decreased and the lung function improved, they felt a disease-specific health instrument would have better detected the changes in quality of life.

However, a very limited number of quality of life instruments are specific to asthma. One example is the 76-item St. George's Respiratory Questionnaire developed by Jones and colleagues to measure health in chronic airflow limitation (Jones, Quirk, Baveystock, and Littlejohns, 1992). Symptoms, activity, impacts on daily life, and a total score were calculated from 141 patients with asthma and chronic obstructive pulmonary disease (COPD) to determine a correlation between airflow limitation and impact on health and well-being. The subjects were recruited from six different countries and had a mean age of 44. This study found that the instrument was valid, results were repeatable, and sensitive enough to respond to changes in asthma over the age of 20. Limitations of this study were related to questions surrounding the demographics of the subjects and the

amount of time needed to administer the questionnaire.

The Asthma Quality of Life Questionnaire (AQLQ) is a disease specific questionnaire developed by Juniper and colleagues in 1991. Since that time they have conducted tests on this questionnaire for reliability and validity and found that it is an accurate way to measure the way patients feel and how they function in their day-to-day lives. It consists of 32-items that are categorized into four domains: activity limitations, symptoms, emotional function, and exposure to environmental stimuli. One hundred and fifty patients with asthma were selected to represent a wide range of airway responsiveness. These patients were then asked to evaluate 152 items that related to asthma and their airway responsiveness was measured. The results of the study identified the items that were considered most important to the patients. These items were examined with respect to airway hyperresponsiveness, age, clinical asthma severity, and sex (Juniper, et al., 1992). The methods, characteristics of the sample, scoring, and correlations were all described well in the text and tables. The complete questionnaire was also included. Since 1992, the AQLQ has been used successfully in other studies that include clinical trials in both interviewer-administered and self-administered formats (Malo et al., 1993; Marks, Dunn, & Woolcock, 1993; Rowe & Oxman, 1993; Gibson, Talbot, Toneguzzi, & Population Medicine Group 91C, 1995; & Juniper et al., 1995; Boulet, Belanger, & LaJoie, 1996; Blixen, Tilley, Havstead, & Zoratti, 1997).

More recently, van der Molen, et al. (1997) conducted a study comparing discriminative aspects of two generic instruments (Short Form 36 and Psychological General Well Being index); and two asthma-specific instruments (Living with Asthma

Quality of Life Questionnaire and Asthma Quality of Life Questionnaire). The researchers looked at the relationship between symptoms, bronchodilator use and lung function in patients with mild asthma. They conducted a multicenter, randomized, placebo-controlled study to investigate the long-term effects of the long-acting beta-agonist, formoterol, in 110 asthma patients using inhaled corticosteroids and short-acting beta-agonists. The patients and methods were clearly described along with the four questionnaires that were used. A description of the methods for pulmonary function testing was also detailed. The results indicated that the correlations between the QOL scores and total symptoms scores were all strong. The highest correlation was found between the AQLQ and symptoms scores ($r = 0.65$ and $p < 0.001$). They also found that the SF-36 had significant and strong correlation in a broad range when compared to the general population.

In a recent discussion paper in the June 1997 issue of *British Journal of General Practice,* Dr. Kevin Gruffydd-Jones stressed the importance of inclusion of quality of life measurements to be used not only in clinical trails, but to be used in conjunction with clinical parameters for measuring effects of asthma treatment. He reviews the costs of asthma in categories of direct, indirect and intangible costs. He discussed the general types of health economic evaluation, the clinical parameters such as airflow measurements, use of bronchodilators, and frequency of exacerbations. He compared the three types of quality of life questionnaires and discussed the advantages and disadvantages of generic instruments, utility instruments and the disease-specific instruments. Of the questionnaires that he reviewed, the AQLQ was the one he felt most

responsive to change, simple and short to complete and reflected the significant effect of asthma on everyday life of the patient. Gruffydd-Jones stated that the quality of life measures should be important to the general practitioner to quantify the intangible costs to the patient and to assess the cost effectiveness of established and new asthma therapies.

Similarly, Dr. Michael S. Blaiss (1997) reviews outcomes analysis for asthma treatment. He categorizes the outcomes in relation to clinical, physiologic, humanistic and economic measures. The quality of life measures and patient satisfaction studies fall within the humanistic category. Some of the problems he identifies in clinical outcomes are the variability of the symptoms, and the reliability of the observation of symptoms by different observers or even the same observer on different occasions. Peak flow meters and spirometry are also good indicators of outcomes, but remain effort dependent. He briefly reviewed the generic and asthma specific quality of life questionnaires that were previously discussed. He stressed the need for improved measures of disease severity and patient-based quality of life. Blaiss feels that physicians should be educated to include collection of outcome data in their everyday practice as well as interpretation and implementation of the findings.

In summary, the findings of these studies are fairly consistent with the view that asthma management is often inappropriate due to lack of education of the health care providers as well as the patients. The understanding of the significance of the asthma restrictions in an individual needs to be addressed. A comprehensive treatment approach that includes quality of life perceptions along with the components of proper diagnosis, medication, education, and plans for exacerbation is needed and should be individualized

for patients with asthma. By using a quality of life questionnaire along with treatment, one can determine if the treatment approach will improve the patient's perception of their health status and its' effect on their daily life.

CHAPTER 3 - FRAMEWORK OF THE STUDY

The chronic nature of asthma necessitates a high degree of self-care abilities and symptom management. Patients must learn to recognize and treat exacerbations, understand and comply with medication regimens, control triggers in their environments, and make decisions about when to seek assistance with their health needs. Physicians and other providers have traditionally focused on the cause and cure of symptoms. Effective treatments can be initiated when the underlying cause is found. On the other hand, nurses have tried to assist patients and their families to cope with symptoms. They can provide teaching strategies and patient counseling for this purpose, but it is not comprehensive enough to actually lessen the symptomatology.

It is important to realize that a broader perspective is needed. When both the underlying causes and the symptoms are managed, patients are more likely to continue with the prescribed treatments and advise of healthcare professionals. If a comprehensive approach to the management of asthma is not used, patients may rely on their own or other lay persons' judgment that could seriously endanger themselves if the symptoms are not properly managed.

The Symptom Management Faculty Group (SMFG), (1994), at the University of California, San Francisco School of Nursing developed a model for symptom management which has three major dimensions: symptom experience, symptom management, and symptom outcomes. To effectively manage a symptom, all three of these interrelated dimensions should be considered. This generic symptom management

model can be used to direct care and research for a variety of diseases and conditions. This model or theoretical framework incorporates quality of life into the dimension of symptom outcomes for asthma management.

Other models have been developed to describe what occurs before, during, and after episodes of an illness. These models focus on the sick role, symptom definition, treatment considerations, and symptom appraisal and response (SMFG, 1994). They are based on the traditional physician-patient relationship in an acute care setting or they usually address only one aspect of the symptom management. They don't provide guidance for patients and nurses or practitioners for managing symptoms at home that are long term and of a chronic nature, such as asthma.

Dorothea Orem's nursing self-care theory focuses on the concept of assisting patients to care for themselves or act as an agent to care for others. Orem (1995) describes self-care as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (p. 104). To promote self-care, emphasis is placed on enabling patients to make decisions and perform actions for themselves except when this is impossible. This model however, does not address a patient's experience, the strategies the patient has tested and used, or the desired outcomes.

In the Symptom Management Model (SMFG, 1994), the primary focus is on symptoms because the subjective experiences usually cause the most patient distress. Clinical signs are incorporated to assess disease status and evaluate the effectiveness of management strategies. Patients will have to be taught the importance of signs to enable

them to understand the link to an underlying cause. The patients with asthma also need to be taught the meaning of their symptoms.

The model for Symptom Management (SMFG, 1994) has three dimensions and is illustrated as follows:

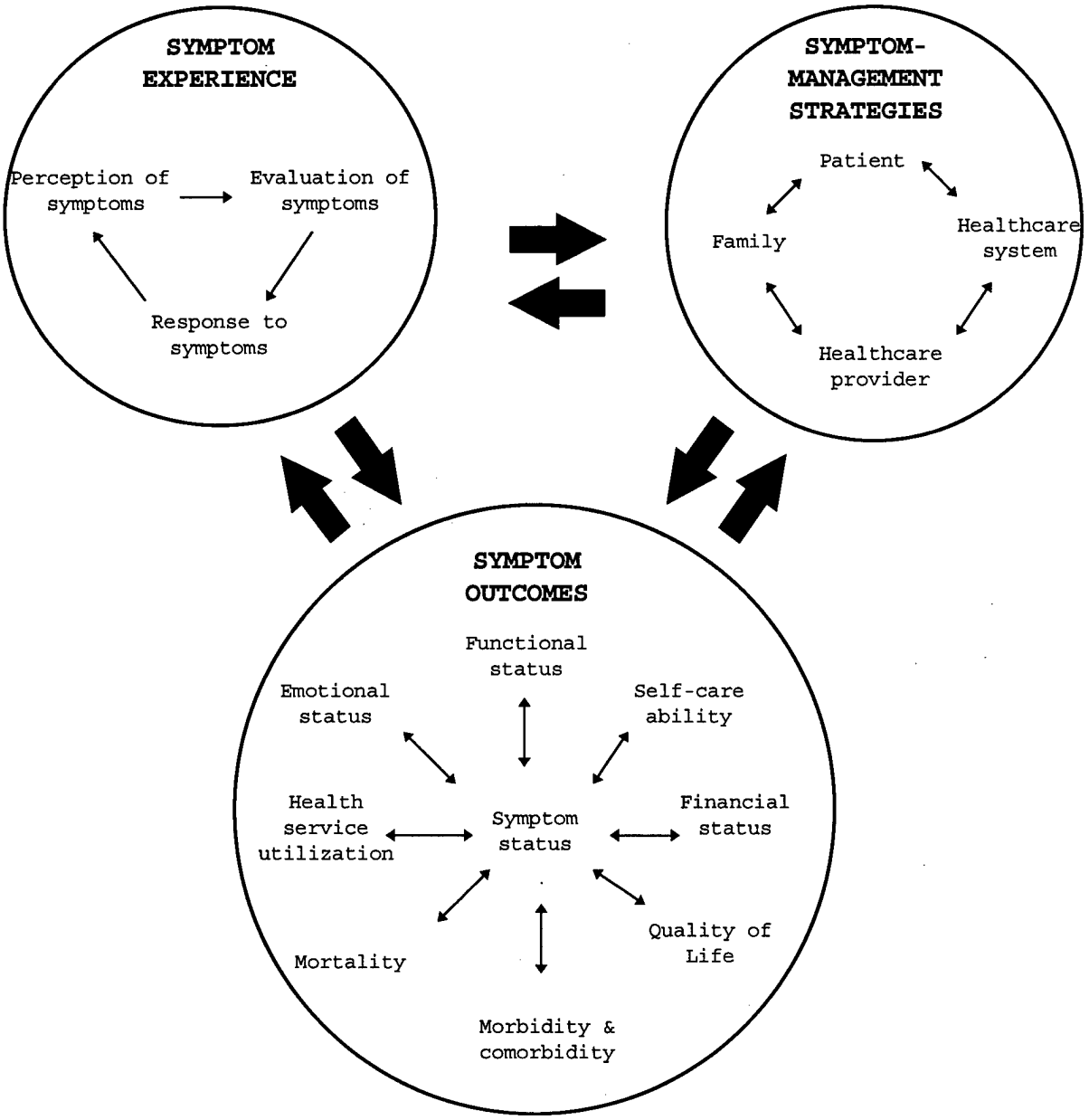

Figure 1.

Conceptual Model of Symptom Management

Source: Adapted from the Symptom Management Faculty Group, University of California, San Francisco School of Nursing Center for Symptom Management, 1994, p. 273

The symptom experience is a dynamic interaction of the patient's perception, the evaluation of the meaning, and response to a symptom. Perception of the symptoms occurs when the patient notices a difference in the way he or she feels or behaves. The evaluation of the symptoms refers to the judgment that is made such as the severity, cause, treatability and the effects. Responses include the feelings, thoughts, and behaviors that are secondary to the actual or potential problems. It is essential for the patient to understand this interaction for effective symptom management. Even when the asthma is effectively treated, the symptoms may often remain a concern. The patients must explore these experiences, learn about the disease, and participate in the care to develop appropriate strategies for control of the symptoms.

Symptom management strategies require a patient-family-clinician partnership to be successful. Management begins with the assessment of the symptoms experienced from the patient's perspective. The goal in management is to avoid or delay the negative outcome through educational, biomedical, professional, and self-care strategies. With asthma these strategies will include the avoidance of environmental triggers, proper use of medications and inhalers, and recognizing the variations and severity of the disease. The work of the provider must complement the work of the patient and family, encouraging and assisting efforts to manage the symptoms.

Outcomes in this model are identified as ten multidimensional indicators that include: symptom status, self-care ability, financial status, morbidity and comorbidity, mortality, quality of life, health service utilization, emotional status, and functional status.

As illustrated in Figure 1, the central indicator is symptom status with the other indicators related. An exacerbation of asthma with dyspnea, for example, has been found to have the greatest negative effect on the quality of life (SMFG, 1994). If a patient cannot afford the cost of a medication the treatment will need to be modified. If the prescribed treatment is too demanding the provider may have to select a less desirable strategy. Emotional and functional status must also be considered for the asthmatic if the outcome is the inability to perform the activities considered important for that person. Quality of life is often variable for persons who are experiencing symptoms. Therefore, as symptoms increase in severity and quantity, the quality of life is negatively affected. If symptoms are few and of short duration, the quality of life is less affected.

This framework was chosen for this study because it is designed to ensure a comprehensive approach to symptom management by incorporating the experience, the management strategies, and the outcomes in a systematic format (SMFG, 1994). This study will attempt to describe and compare quality of life in the areas of activity restrictions, emotions, symptoms, and environmental controls. The nurse practitioner can use this model and the results of the research in the areas of quality of life to gain a better understanding of the experience of the patient's asthma. In this way, interventions will be applied that are appropriate for the patient's experience and capability.

Definitions:

Symptom severity. The frequency of symptoms, exacerbations and nighttime symptoms, as expressed by Step 1 - 4 of the GINA guidelines (see Table 1).

Lung function. The percent of predicted peak expiratory flow (PEF) volume along with the percent of the variability of PEF. This is also expressed as Step 1 - 4 of the GINA guidelines (see Table 1).

Activity limitations. Activities in which an individual is limited because of asthma

Symptoms. Discomfort or distress due to chest tightness, wheezing, coughing, throat clearing, difficulty breathing, or awakening at night.

Emotional function. Fears, concerns, or frustrations related to symptoms and management

Exposure to environmental stimuli. Experience of asthma symptoms as a result of exposure to cigarette smoke, dust, weather, pollution, strong smells, or perfumes.

Total quality of life. The effect of the combined restrictions or limitations related to symptoms, activities, emotions, and environmental stimuli expressed as the mean score of the combined scores for activities, symptoms, emotional function, and exposure to environmental stimuli on the AQLQ (Juniper, 1996).

CHAPTER 4 - METHODOLOGY

This chapter describes the measures used to protect the human rights of the patients who completed the questionnaires. It also describes the research design, procedures and the sample. The instrument and measurement methods section includes details of the demographic data collected and a description of the Asthma Quality of Life Questionnaire (AQLQ).

Protection of Human Rights

Written permission for this study was first obtained from the medical center's Institutional Review Board and the Research Administration at Uniformed Services University of the Health Sciences.

Steps were taken to protect the rights of the patients who completed the questionnaires by eliminating any identifying data. Patients were instructed to omit questions that they considered potentially sensitive in nature if they were uncomfortable answering them. The clinics' staff who were not involved in the study distributed questionnaires. The completed questionnaires were then placed in a locked box until collected by the researcher on a bi-monthly basis. No personal contact occurred between the investigator and the participants. No unlicensed or experimental drugs were used. No painful procedures were employed.

Population and Sample

The data was gathered from a convenience sample of adults diagnosed with asthma who were managed in five adult outpatient clinics at a major military medical center on the East coast. This setting was chosen because of the cooperative nature of

other ongoing studies in the management of asthma. The five clinics that were originally slated for data collection included Flight Medicine, Family Practice, Allergy, Primary Care, and Pulmonary Medicine, however the Flight Medicine clinic had no respondents Forty-two patients with asthma completed the questionnaires from 30 September 1997 through 30 January 1998. Individuals must have a diagnosis of asthma in order to be included in the study. Questionnaires were excluded if the patients were younger than 16 and if their symptoms or activity limitations could be caused by another concurrent disease process.

Research Design and Procedures

This study used a descriptive correlational design. The purpose of this study was to investigate the relationship between levels of asthma severity and the measures of lung function and the quality of life in adults with asthma in the military health care system.

When a patient with asthma presented to each of these clinics, they were given a survey packet (see Appendices A-C) by the clinic staff. The cover page discussed the purpose of the study and included the consent form (see Appendix C). Completion of the survey implied consent for participation. If a patient agreed to participate the clinic staff were instructed to place the highest of three peak expiratory flow (PEF) measures in the upper right corner of the survey. The PEF reading was measured along with vital signs at the onset of the screening/check-in process. This measure was done with The Vitalograph PEF meter, catalog number 43.400A, standardized by The Asthma Working Group committee at this facility. This measure was recorded prior to the office visit to minimize bias.

While waiting for the provider's exam the patients completed the surveys. The participants then placed the completed surveys in a sealed envelope and deposited them in a special locked collection box at each of these clinics. The process took approximately ten minutes. The surveys were collected every other week by the researcher. The clinic staff had no other involvement in this study other than to identify those patients with asthma, ask them to participate in the study and record the highest PEF measure.

Obtaining accurate PEF readings by the clinic staff is part of the usual clinical competencies for their job, so no additional training was given. The study and the procedures were explained to the staff by the researcher at the beginning of the study. The officer in charge or non-commissioned officer in charge of each clinic provided instruction to the staff that were not present initially. Instructions were placed on the collections boxes as well. The researcher followed up with regular communication with the individuals in charge of the clinics to anticipate or problem solve any problems with data collection.

Measurement Methods

The survey consisted of two parts. The first part was the Asthma Data Sheet (see Appendix A). On this part questions related to age, gender, height, race, and frequency of nighttime symptoms. Average, high, and low PEF readings, number of school or work days missed in the past 12 months, and satisfaction with health care were also asked. The current PEF reading was used to measure the degree of lung function and was calculated as a percentage of predicted PEF measure for age, gender and height according to the

Peak Expiratory Flow rate nomogram illustrated in the 1991 publication by the NEAP *Executive Summary: Guidelines for the diagnosis and management of asthma* (1991).

The questions relating to average, high, and low PEF readings, as well as frequency of nighttime symptoms guided the classification of the asthma severity. The GINA guidelines step level of I - IV were used to represent the level of asthma severity which related to symptoms (Table 1). Prior to the study, a pulmonary medical specialist reviewed the Asthma Data Sheet to determine the appropriateness of the data information questions for determining the severity levels and lung function. Since the researcher could not be present for collection of the data needed for these measures, it was felt that the information on this form would serve that purpose.

After collecting 20 surveys in the first month of the research, much data was missing from the PEF readings both with the current values and the patient's average, high and low measures. This made it impossible to classify the patients accurately into the four steps as in the GINA guidelines. The question that related to nighttime symptoms was expanded from two choices for frequency of symptoms (two times per week or less / more than two times per week) to four choices. The choices offered were less than two times per month, more than two times per month but less than once per week, more than once per week, and frequent nighttime symptoms. In this way it was possible to classify the symptom severity without doing a chart review or interviewing the patient directly.

The Asthma Quality of Life Questionnaire (AQLQ) developed by Dr. E. Juniper and colleagues (1992) was used to measure the outcomes related to quality of life

(Appendix B). This tool has been shown to reflect impairments in quality of life that are important to adults with asthma. Estimates of reliability and validity were established in previous studies of airway responsiveness, occupational allergies, and clinical trials of inhaled steroids (Juniper, Guyatt, Ferrie, & Griffith, 1993; Malo et al, 1991; & Juniper, Johnston et al., 1995). These studies demonstrated reproducibility with an intraclass correlation coefficient = 0.92. Reproducibility within each domain was also very high with equally good intraclass correlation coefficients of 0.89 - 0.94. Longitudinal construct validity indicated strong relationships between change in quality of life and change in asthma control and medication requirements ($r > 0.30 - 0.67$). Weaker relationships were shown with PEF and airway hyperresponsiveness ($r > 0.26 - 0.42$) The observed cross-sectional correlations were strong between asthma control and quality of life ($r > 0.31 - 0.69$), and responsiveness to change ($p < 0.001$), even if the changes are small (Juniper et al., 1993, & Juniper, Guyatt, Willan, & Griffith, 1994). It is recommended for use with clinical trials to evaluate the effectiveness of treatments.

This tool consists of 32 questions or items that were identified by asthma patients and are important to quality of life. These items are in four domains: symptoms, emotions, exposure to environmental stimuli, and activity limitations. Patients rated the impairment they had experienced during the previous 14 days and rated each item on a 7 point scale. This scale is 1 = maximum impairment to 7 = no impairment. The wide range of options available in the rating scale allowed for greater detection of small changes.

Five of the eleven activity items were self-identified by the patient. At the clinic visit, each patient was asked to identify the five activities which he or she performs regularly, which are important, and in which there is some limitation due to asthma within the past two weeks. This allowed for evaluation of the most important activities as they related to each individual patient. These five activities were rated on the same scale as the rest of the questions. It was expected to have fewer than five activities identified in some cases where there may not be much restriction or if a respondent leads a sedentary lifestyle (Juniper, 1996).

Each item in the AQLQ was equally weighted. The questionnaire was directly analyzed from the scores recorded and data were expressed as the mean score for the answers in each of the four domains as well as for the overall quality of life. The domain for activity limitations consisted of items 1 to 5, 11, 19, 25, 28, 31, and 32. The symptoms domain included items 6, 8, 10, 12, 14, 16, 18, 20, 22, 24, 29, and 30. Emotional function was measured with items 7, 13, 15, 21, and 27. Items 9, 17, 23, and 26 related to the environmental exposure domain. The range of the scores for domains and the overall quality were from 1 to 7 using an interval scale. These scores were analyzed for significant differences and correlated with the scores of lung function and severity levels. The computerized statistical package, SPSS for Windows (version 7.55), was used for analysis. Frequency, percentage, mean, range, and standard deviation were calculated where appropriate for each variable of interval level data. For nominal level variable data descriptive analysis consisted of frequencies and percentages. Pearson's correlation coefficients were calculated between the asthma symptom severity, the lung

function, the overall score and each of the subscale scores for activity, symptoms, emotions, and environmental stimuli.

CHAPTER FIVE - ANALYSIS OF DATA

This chapter presents the findings obtained from 39 valid questionnaires returned by study participants. A narrative discussion of the demographic data begins this chapter along with symptom severity and lung function classifications of the participants. A further analysis is presented for the quality of life based on the respondents' answers to subsets of questions relating to activity restrictions, symptoms, emotions, and environmental restrictions. Finally, the correlation of the symptom severity and lung function classifications with the quality of life scores is described.

Forty-two surveys were completed in the time period for the data collection. Of these, two were children under age 16, and another survey indicated that restrictions were also due to heart problems. Since this study focused on adults with a primary diagnosis of asthma, these three questionnaires were eliminated from the data.

As discussed in Chapter 4, average, high and low PEF measures were missing on many respondents' surveys after collecting the data for one month The clinic staff had not consistently recorded the PEF measures on all surveys, as well. The nighttime symptoms question was not specific enough to classify the patients with the this amount of missing data into appropriate symptom severity categories. This necessitated a review of the survey procedures with the clinic staff and a change in the nighttime symptoms question. The data was analyzed in two sets, therefore, with the first set of data representing those twenty patients' responses prior to the question change. The second set of data consisted of the next 19 surveys.

Demographic data, use of the PEF meter, lost work or school days, and satisfaction with care for all 39 surveys are presented in Table 2.

Table 2.

Demographic Data on 39 Patients Seen in Outpatient Clinics with Asthma

	Count	
Characteristic	(n)	(%)
Gender		
Female	19	49
Male	17	43
Missing data	3	8
Age Range		
20 - 40	16	41
41 - 60	10	26
61 - 80	12	31
81 & older	1	2
Race		
Caucasian	25	64
African-American	9	23
Hispanic/Latin	1	2.6
Asian	1	2.6
Other	2	5
Missing data	1	2.6
Peak Flow Meter		
Use meter	16	41
Have no meter	10	26
Meter not used in 12 mo.	4	10
Missing data	9	23
Lost school or work days		
None	25	64
1-7 days	7	18
> 7 days	1	3
Retired	6	15
Satisfaction with care		
Satisfied	33	85
Can't decide	3	8
Dissatisfied	2	5
Missing data	1	2

Patients were instructed to select the five activities they felt were most restricted within the past two weeks. The five most restricted activities chosen on the Asthma Quality of Life Questionnaire (AQLQ) for the 39 respondents were: jogging or exercising or running, doing housework, going for a walk, walking upstairs or uphill, and playing sports. Many patients selected only a few activities. These data were missing for 25 of the activity questions. Table 3 lists these frequencies.

Table 3.

Frequencies of the Most Selected Activity Restrictions for Entire Sample

Activity	Frequency
Jogging or exercising or running	18
Doing your housework	16
Going for a walk	15
Walking upstairs or uphill	14
Playing sports	13
Playing with children or grandchildren	8
Other (includes a variety of activities not specified in the list of selections)	8
Hurrying	7
Carrying out your activities at work	7
Missing data	25

The first question for this study was to determine the overall QOL scores for individuals with asthma in the military health system. The overall QOL score for the 39 respondents was 4.4 on the Likert scale of 1 - 7, where 1 = the most impairment and 7 = no impairment. The standard deviation for this score was 1.35.

The second question sought to describe the relationships between severity of asthma and lung function and the quality of life in each of the four domains of activities, symptoms, emotions, and environment. The fact that nearly 60% of the surveys did not

include PEF readings necessitated a change one of the questions relating to nighttime symptoms to more clearly distinguish the severity level categories. The patient's age, gender and height provided the basis for the predicted PEF. This measure was then compared with the current or average PEF reading and combined with frequency of night time symptoms to determine the severity level. The lung function similarly was calculated from the predicted PEF and compared with current PEF reading and variability.

After collecting the surveys for one month, the first twenty questionnaires were returned without enough data to classify the symptom severity level beyond grouping them into two categories. These levels equated to Mild intermittent and Mild persistent as one category while Moderate persistent and Severe persistent together represented the second category. Sixty percent of the respondents in the first group were classified as having Mild intermittent or Mild persistent asthma. Thirty percent had moderate or severe persistent asthma. Ten percent could not be classified due to missing data. The mean scores for quality of life were lower in the more severe disease category, with a fairly small standard deviation. However, the standard deviation for the milder disease category was considerably larger despite the larger sample size. Table 4 illustrates the means, sample size, and standard deviation for each of the categories with the quality of life scores.

Table 4.

Quality of Life Scores[1] with Symptom Severity Levels for First Set of Data

Severity		Overall	Activities	Symptoms	Emotions	Environment
Moderate persistent or severe persistent n = 6	Mean	3.1	3.3	3.1	2.8	3.4
	SD[2]	0.55	0.47	0.73	0.64	0.89
Mild intermittent or mild persistent n = 12	Mean	4.7	4.5	4.7	4.5	5.0
	SD[2]	1.41	1.36	1.50	1.81	1.49

[1] Scores = Likert scale 1 - 7, 1 = maximum impairment and 7 = no impairment
[2] SD = standard deviation

Lung function was classified in a similar manner for this first set of 20 surveys. Thirty percent had > 80% predicted Peak Expiratory Flow (PEF) reading with < 20% variability. Twenty percent had >80% predicted PEF with 20-30% variability. Twenty percent had 60-80% predicted PEF with > 30% variability and 5% had < 60% predicted PEF with > 30% variability. Twenty-five percent had missing data for PEF readings. The quality of life scores again were predictably lower for those respondents who had the lowest PEF and the greatest variability. The standard deviation for these means ranged from 1.01 to 2.04 except in the level of the most impaired lung function where the sample was one. Table 5 illustrates these scores.

Table 5.

Quality of Life Scores[1] with Lung Function for First Set of Data

Lung Function		Overall	Activities	Symptoms	Emotions	Environment
PEF < 60% predicted, > 30% variable n = 1	Mean	2.2	2.9	2.3	2.0	1.8
	SD[2]					
PEF 60-80% predicted, > 30% variable n = 4	Mean	4.1	3.9	4.1	4.1	4.3
	SD[2]	1.86	1.83	1.93	1.75	2.01
PEF > 80% predicted, 20-30% variable n = 4	Mean	4.3	4.5	4.5	4.0	4.4
	SD[2]	1.43	1.02	1.44	2.05	1.30
PEF > 80% predicted, < 20% variable n = 6	Mean	5.0	4.7	5.1	5.0	5.3
	SD[2]	1.10	1.44	1.10	1.47	1.18

[1] Scores = Likert scale 1 - 7, 1 = maximum impairment and 7 = no impairment
[2] SD = standard deviation

The Pearson product-moment correlation coefficient was used to test for correlation between these variables. Although the variables for the quality of life scores are of a metric ordinal nature they have been treated as interval data. For purposes of comparison the correlations were described as excellent if $r > -0.8$, good if $-0.6 < r > -0.8$, moderate if $-0.4 < r > -0.6$, fair if $-0.2 < r > -0.4$, and poor if $r < -0.2$. The correlations were expressed as negative values because the higher scores for quality of life reflect little or no impairment and the low scores for severity and lung function reflect less symptom severity and better lung function The severity levels correlated at a

significant level ($p < 0.05$) to all quality of life categories except activities. The highest correlations were between severity level and overall and symptoms quality of life scores. There is moderate correlation for activities, but it is statistically insignificant. There were correlations between lung function and quality of life categories but these also were not statistically significant. There was moderate correlation between lung function and overall, environmental, symptoms, and emotions QOL scores. There was a fair correlation between the activities domain and lung function. Table 6 lists the values for these correlations and the statistical significance.

Table 6.

Correlations Between Means of Overall, Activities, Symptoms, Emotions, Environment Quality of Life, Symptom Severity Level, and Lung Function in the First Set of Data

	Symptom Severity		Lung function	
	r	p	r	p
Lung function	.565*	.035		
Overall	-.544*	.020	-.449	.094
Activities	-.464	.052	-.339	.216
Symptoms	-.540*	.021	-.447	.095
Emotions	-.500*	.035	-.400	.140
Environment	-.514*	.029	-.497	.059

* Correlation is significant at the 0.05 level (2-tailed).

After analysis of this first set of data the question asking frequency of nighttime symptoms on the asthma data sheet was changed to provide a better means to differentiate between the four severity levels. The data collection continued for three more months until an additional 19 questionnaires had been obtained. Sixteen percent were classified with mild intermittent asthma, 10% with mild persistent disease, 42% had moderate persistent asthma, and 32% had severe persistent asthma. Five percent had missing data.

Those with mild asthma had the highest quality of life scores and those with the most severe disease had the lowest QOL scores. However, the scores for the mild persistent and moderate persistent categories had mixed results. The standard deviations for these scores ranged from 0.83 to 3.5. Table 7 illustrates these scores, sample sizes, and standard deviations.

Table 7.

Quality of Life Scores[1] with Symptom Severity Levels for Second Set of Data

Severity		Overall	Activities	Symptoms	Emotions	Environment
Severe persistent n = 6	Mean	4.3	4.3	4.5	3.7	4.6
	SD[2]	1.48	1.46	1.06	2.05	1.54
Moderate persistent n = 8	Mean	4.4	4.7	3.9	4.2	4.7
	SD[2]	1.03	1.18	1.25	1.15	1.31
Mild persistent n = 2	Mean	4.3	4.8	4.4	4.1	4.0
	SD[2]	1.68	1.38	0.83	0.99	3.54
Mild intermittent n = 3	Mean	4.8	5.3	4.6	4.6	4.8
	SD[2]	1.80	1.86	2.05	1.80	1.56

[1] Scores = Likert scale 1 - 7, 1 = maximum impairment and 7 = no impairment
[2] SD = standard deviation

The lung function was calculated for these respondents as with the first set of data. Twenty-one percent had a PEF of > 80% predicted with < 20% variability. Eleven percent had a PEF of > 80% predicted with 20-30% variation. Forty-two percent had a PEF of 60-80% predicted value with > 30% variation. and none of the respondents in this

group had a PEF of < 60% with > 30% variation. There were missing data for 26% of the respondents for predicted PEF. The means of the QOL scores indicated that the individuals with the best lung function had the highest quality of life scores. Similarly, the individuals with the poorest lung function had the lowest QOL scores. The standard deviations for these scores ranged from 0.64 to 1.91, most grouped closer to 1.0. These scores are displayed in Table 8.

Table 8.

Quality of Life Scores[1] with Lung Function for Second Set of Data

Lung Function		Overall	Activities	Symptoms	Emotions	Environment
PEF 60-80% predicted, > 30% variable n = 8	Mean	3.7	4.0	3.6	3.4	3.9
	SD[2]	0.97	1.11	1.01	1.60	1.20
PEF > 80% predicted, 20-30% variable n = 2	Mean	4.6	5.0	4.1	3.9	5.3
	SD[2]	1.15	1.91	0.65	0.99	1.06
PEF > 80% predicted, < 20% variable n = 4	Mean	5.7	5.9	5.4	5.7	6.1
	SD[2]	0.75	0.71	0.97	0.76	0.75

[1] Scores = Likert scale 1 - 7, 1 = maximum impairment and 7 = no impairment
[2] SD = standard deviation

The correlations for this second set of data showed smaller, but no statistical significant correlation between the symptom severity levels and the quality of life scores. There was moderate correlation with the emotions, symptoms, activities, and overall QOL scores. There was poor correlation with environmental restrictions. In contrast, this second set of data correlated at significant levels between the lung function and QOL

scores in all of the subscales. There was good correlation with activities, symptoms, environment, and overall scores. There was moderate correlation between lung function and emotions. Table 9 lists these correlation coefficients and significance.

Table 9.

Correlations Between Means of Overall, Activities, Symptoms, Emotions, Environment Quality of Life, Symptom Severity Level, and Lung Function in the Second Set of Data

	Symptom Severity		Lung function	
	r	p	r	p
Lung function	.149	.627		
Overall	-.334	.176	-.721**	.004
Activities	-.294	.237	-.645*	.013
Symptoms	-.324	.190	-.656*	.011
Emotions	-.476	.054	-.582*	.037
Environment	-.171	.497	-.719**	.004

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed)

There were no statistically significant correlations between symptom severity and lung function and age, satisfaction, and use of PEF meters for both groups.

In summary, there was nearly equal representation of gender, an average age of 49 with a wide age range of respondents. Nearly one third have no PEF meter or have not used one in the last 12 months. Little school or work days were lost and most were satisfied with their health care. The mean score for overall quality of life was 4.4 which is between some limitation and moderate limitation. The relationships between the symptoms severity, lung function and the quality of life scores showed moderate correlations. There was statistical significance with the correlations between the

symptoms severity and QOL scores in the first set of data and between the lung function and QOL scores in the second set of data.

CHAPTER 6 - CONCLUSIONS

The purpose of this study was to examine the relationships between asthma symptom severity and lung function and the quality of life in adults with asthma treated in the military health care system. Data collection was accomplished through the completion of a questionnaire by study participants. The questionnaire included questions pertaining to demographic data, peak expiratory flow readings, symptoms, satisfaction , and the Asthma Quality of Life Questionnaire (AQLQ). The questionnaire was distributed to a convenience sample of patients with asthma in a military medical center in the Washington DC area. No attempt was made to control or manipulate the situation.

Discussion of Major Findings

Forty-two surveys were collected and three were invalid because two respondents were children, and one person had a co-existing heart disease which could have contributed to the limitations. This response rate was low over the four month data collection period. The researcher met with a designated staff member each time data was collected from the locked boxes. Discussions with the clinic staff revealed that there were not many asthma patients presenting to the outpatient clinics during this time period. It was felt that this may have been due to the mild winter weather. Other clinic staff mentioned that they forgot to suggest completion of the surveys to potential patients. Two of the clinics had made signs alerting patients to ask about the survey if they had a diagnosis of asthma.

Demographic data showed a near equal representation of males (43%) and females (49%) with no gender indicated on three (8%) of the surveys. The mean age of the respondents was 49, with the largest group (41%) between the ages of 20 to 40. One respondent was over 85. There were no significant correlations with severity, lung function, or quality of life scores for age or gender. The racial breakdown was examined to provide a baseline for future studies to determine if there is an increase in the rate of asthma among racial minorities. No conclusions could be drawn from this data.

The majority (64%) of the respondents reported no lost time from work or school. There was no place on the form to indicate the type of work, such as homemaker. The range for lost time was from 2 days to 17 days in the past year. Another 15% of the respondents indicated that they were retired. These results could be again attributed to the mild winter weather and the availability of health care providers with the necessary resources.

Eighty-five percent felt satisfied with the care they had received. Only two patients who had moderately persistent or severe persistent asthma indicated that they were dissatisfied. This compared with 20 patients who were satisfied with their care and classified into the same severity levels. The reasons for this level of satisfaction was probably due to the comprehensive care available at this medical center. The patients were not affected by financial or physical issues related to access to care. All of the individuals seeking care at this facility had a steady income in the form of active duty pay or retirement income. They also received medications and provider visits free of charge. In addition to regular access to clinics and medication, a pulmonary medicine specialty

clinic was available if the patient or the provider needed further consultation and management.

Of note is the information which related to the peak expiratory flow meter readings. Only 41% of the surveys had data recorded for measures of PEF readings. For those who answered this question, 36% indicated they did not have or use a peak flow meter. It is impossible to determine why nearly 23% didn't answer this question because of the self-administered format of the questionnaire. What is important is the fact that over one third of the respondents were not using a PEF meter to evaluate and control their symptoms. The NHLBI guidelines have been clear in the recommendations for use of this simple device to help patients and their providers manage asthma appropriately. This finding presents a clear implication for providers and patients alike to receive further education regarding the use of the PEF meter.

The respondents indicated that their level of impairment was between some limitation and moderate limitation for the overall quality of life. After one month of data collection and analyzing 20 valid questionnaires it was found that the severity levels could not be differentiated beyond two categories. Those categories were Mild intermittent and Mild persistent as the first category and Moderate persistent and Severe persistent for the second category. The means of the scores for the overall QOL was higher for the milder disease categories. The means for the subscales of activities, symptoms, emotions and environment restrictions for the mild disease were significantly higher than those scores for the more severe disease. The standard deviation was large

for the milder disease categories which could indicate a wide range of quality of life impairment even though there is less symptom severity.

Although the lung function scores for this first group of surveys indicated a similar pattern for the means of the QOL scores, the sample size was only 15 due to the missing data for PEF readings. The correlation was small but not significant for this part of the study. Again, the standard deviation was large for most of the categories indicating a wide range of perceived impairment for quality of life.

After changing one of the questions relating to frequency of nighttime symptoms, it became possible to classify the patients into the four severity categories. A total of 19 surveys were collected in the last three months of the study. This return rate was much less than expected, despite the cooperation of the clinic staff and frequent contacts to determine any problems or barriers to the data collection. None were identified so the data collection continued until the time limitations of the thesis completion necessitated a halt.

With the second set of data the means of the QOL scores were different than the first set. Those with mild disease had greater scores than those with severe disease as shown in the first set of data. However, in the two middle categories the data was inconsistent. The scores were greater in mild persistent for activity and symptoms only. The moderate persistent group had higher scores for overall, emotions and environment categories. The majority of the respondents were classified into the more severe categories (>60%). After examining this data closer a large standard deviation for these means was again noted to indicate that the range of impairment in QOL varied.

The lung function measures for this second set of data revealed a significant correlation between the QOL scores and the degree of lung function. The sample size was 14 because of the missing data for lung function, but the standard deviation was also smaller than the previous means discussed. These results indicated a closer correlation with the value of PEF reading with impaired QOL.

Conclusions

The data collected in this research cannot be considered to support the hypotheses. There was moderate correlations between the lung function and QOL in one group and moderate correlations between severity and QOL in the other group. The severity levels and degree of lung function did not necessarily correlate with the scores for overall quality of life, activity limitation, symptom presentation, emotional distress, or environmental restriction. The reasons could be attributed to the small sample size of the groups and missing data. However, the reason could more likely be that there is no significant correlation for the QOL with the severity and lung function in asthma as reflected by the relatively large standard deviations.

Quality of life may not necessarily be predicted on the basis of disease severity or impairment of lung function. In the National Asthma Survey of 1990/91 in Britain, asthma sufferers admitted to few symptoms but they did indicate moderate to severe restrictions of daily activities (Gruffydd-Jones, 1997)). In another study of PEF levels and use of the St. George's Respiratory Questionnaire (Jones, et al., 1992), patients with mild asthma and only a 90-95% reduction in predicted PEF had significant reduction in their quality of life.

These symptom scores and lung function parameters reflect the severity in one moment of time, and the symptoms can be deceiving. Patients may become accustomed to the symptoms as part of their everyday life. On the other hand, they may modify their activities and lives to avoid the symptom-inducing activities. Therefore, if an asthmatic avoids participating in a sporting event due to poor control of the symptoms, they might feel they had a symptom-free day. From another standpoint, a person may attach more importance to the restrictive problem, such as avoiding a pet, than the actual severity or lung function indicates. Previously active patients may report more restrictions than those less active patients if the changes needed in their lives had significant impact on leisure time and occupational activities.

Limitations of this Study

Methodological limitations of this study include the small sample size, the single setting, methods of measurement for asthma symptom severity, and limited control of data collection. There was no record of when the patient had last used a beta-agonist inhaler and the effect it may have had on the PEF readings. This study consisted of a convenience sample of adults at one military medical center. The generalizations can only be made to the adults in this study represented at this center. No attempt was made to separate the responses from the various clinics. The small sample size prevents generalization to the asthma population as a whole treated at this center. The missing data for PEF measures limited the classification of the asthma symptom severity and lung function.

Implications for Nursing and Nurse Practitioners

Quality of life is multifactoral and includes a variety of subjective and objective measures. There is likely to be variation in the same individual over a period of time. Therefore, the QOL measurement should be used with other markers of symptom control to measure the impact of asthma on an individual's lifestyle. The disease specific QOL questionnaires such as the AQLQ can represent the effect that asthma has on the everyday life of patients. These questionnaires can be used as effective tools within the Symptoms Management Model to provide a comprehensive approach to asthma control. The interrelatedness of the symptoms, activities, emotions and environmental restrictions affect each other. This information is not just specific to nursing but is applicable to all disciplines where the desired outcome is improvement in overall health status. Clinical measures may not have a significant relationship to QOL because attitudes vary greatly about the significance of individual symptoms. Family practice strategies should include environmental control, educational and medication therapy along with an understanding of the patient's perspective. Use of a QOL tool would help the provider and the patient to evaluate the benefits of a treatment protocol or plan when combined with the parameters of lung function and symptom reports.

Recommendations for Further Research

More research is needed in the area of quality of life for patients with a chronic illness such as asthma that requires intensive symptoms management. Replication of this study should include a review of the answers to minimize missing data or use of the interviewer-administered format. A larger sample size and a multicenter design would

increase the generalizabilty of the findings. A chart review could help to determine confounding variables such as length of disease, medications prescribed, other symptoms, exacerbations, and frequency of visits.

Other problems which require further investigation include the following questions: How does age or developmental stage affect the QOL? How does the length of illness affect the QOL, i.e.: do those with a longer duration of asthma have better QOL due to evolved adaptation strategies? Why aren't more persons with asthma using PEF meters? Do the number of outpatient visits correlate with disease severity and QOL measures? What types of interventions will improve the QOL of patients with asthma? How does self- management education affect QOL?

Summary

Within the Model of Symptom Management, the symptoms experience domain has variables which can influence the perception, evaluation, and response to a symptom. The variables that affect perception of a symptom include age, sex, ethnicity, environment, risk factors and health status. For the evaluation of a symptom such as shortness of breath or dyspnea, the factors that influence this experience are intensity, frequency, and the associated pattern of disability. Use of measures of lung function and symptom reports are only a part of the assessment of the asthma patient. Responses to a symptom include physiological, psychological, and behavioral components.

In the symptom outcomes dimension of this model, symptom status may affect one's functional or emotional state, self-care ability, healthcare utilization, financial status or quality of life, and may result in an increased morbidity or mortality. The

frequency, intensity and recurrence of asthma symptoms and dyspnea would have a negative effect on nearly all of these indicators. Quality of life measures reflect the impact of asthma on everyday life of the individual and applies to those with mild to severe disease.

In order for symptoms management strategies to be effective there must be a patient-family-clinician partnership. The goal of symptom management is to prevent or delay a negative outcome, with the use of biomedical, professional and self-care strategies. It is important to begin with the patient's perspective and identify the focus for intervention. Once interventions have been implemented, the outcomes need to be evaluated. The strategies should include medications, education, encouragement and assisting efforts to manage the symptoms when appropriate.

This study attempted to describe the quality of life in the military population at one major medical center and correlate the scores with symptom severity and lung function measure. There were moderate correlations between the symptom severity and lung function and the QOL. The wide range of responses to the QOL questions indicates variability in the perception of the QOL. Therefore, with an understanding from the patient's perspective, the nurse practitioner and other healthcare providers can better facilitate a comprehensive, individualized approach to care in the ever-changing military health care system.

REFERENCES

American Nurses Association. (1996). Scope and standards of advanced practice registered nursing. Washington, DC: American Nurses Publishing.

Blaiss, M. (1997). Outcomes analysis in asthma. JAMA, The Journal of the American Medical Association, 278(22), 1874-80.

Blixen, C., Tilley, B., Havstad, S., & Zoratti, E. (1997). Quality of life, medication use, and health care utilization of urban African Americans with asthma treated in emergency departments. Nursing Research, 46(6), 338-341.

Boulet, L., Belanger, M., & LaJoie, P. (1996). Characteristics of subjects with a high frequency of emergency visits for asthma. American Journal of Emergency Medicine, 14(7), 623-628.

Bousquet, J., Knani, J., Dhivert, H., Richard, A., Chicoye, A., Ware, J., & Michel, F. (1994). Quality of life in asthma: I. Internal consistency and validity of the SF-36 questionnaire. Journal of Respiratory Critical Care Medicine, 149, 371-375.

Brooten, D. & Naylor, M. (1995). Nurses' effect on changing patient outcomes. IMAGE: Journal of Nursing Scholarship, 27(2), 95-99.

Centers for Disease Control and Prevention. (1996). Asthma mortality and hospitalization among children and young adults - United States. Morbidity and Mortality Weekly Review, 45, 350-353.

Collins, P., Goodman, D., & McQueston, J. (1995). Special study on emergency and inpatient treatment of pediatric asthma in military medical facilities (MTFs), September 1993 through December 1993. Rockville: FMAS Corporation, Department of Defense Civilian External Peer Review Program; (Ad hoc 134.011).

Dales, R., Kerr, P., Schweitzer, I., Reesor, K., Gougeon, L., & Dickinson, G. (1992). Asthma management preceding an emergency department visit. Archives of Internal Medicine, 152, 2041-2044.

PharmacoEconomic Center (August 16, 1996). Management of asthma. PEC Update, 96-11, Ft Sam Houston, TX: Department of Defense PharmacoEconomic Center (1- A26).

Earwood, G. (1996). Managing adult asthma in the primary care setting. Journal of the American Academy of Nurse Practitioners, 8(1), 33-39.

Gibson, P., Talbot, P., Toneguzzi, R, & the Population Medicine Group. (1995). Self-management, autonomy, and quality of life in asthma. Chest, 107(4), 1003-1008.

Gruffydd-Jones, K. (1997). Quality of life measures in asthma - do they matter to the GP? British journal of General Practice, 1997(47), 392-394.

Guidry, G., Brown, D., Stogner, S., & George, R. (1992). Incorrect use of metered dose inhalers by medical personnel. Chest, 101(1), 31-33.

Hartert, T., Windom, H., Peebles, S., Freidhoff, L., & Togias, A. (1996). Inadequate outpatient medical therapy for patients with asthma admitted to two urban hospitals. American Journal of Medicine, 100, 386-394.

Interiano, B. & Guntupalli, K. (1993). Metered-dose inhalers: Do health care providers know what to teach? Archives of Internal Medicine, 153, 81-85.

Jones, P., Quirk, F., Baveystock, C., & Littlejohns, P. (1992). A self-complete measure of health status for chronic airflow limitation: The St. George's Respiratory Questionnaire. American Review of Respiratory Disease, 145, 1321-1327.

Juniper, E. (1996). Asthma quality of life questionnaire: Background and interviewing tips. Hamilton, Ontario, Canada: McMaster University.

Juniper, E., Guyatt, G., Epstein, R., Ferrie, P., Jaeschke, R., & Hiller, T. (1992). Evaluation of impairment of health related quality of life in asthma: Development of a questionnaire for use in clinical trials. Thorax, 47(2), 76-83.

Juniper, E., Guyatt, G., Ferrie, P., & Griffith, L. (1993). Measuring quality of life in asthma. American Review of Respiratory Disorders, 147, 832-838.

Juniper, E., Guyatt, G., Willan, A., & Griffith, L. (1994). Determining a minimal important change in a disease-specific quality of life questionnaire. Journal of Clinical Epidemiology, 47(1), 81-87.

Juniper, E., Johnston, P., Borkhoff, C., Guyatt, G., Boulet, L., & Haukioja, A. (1995). Quality of life in asthma clinical trials: Comparison of salmeterol and salbutamol. American Journal of Respiratory Critical Care Medicine, 151, 66-70.

Kropfelder, L. & Winkelstein, M. (1996). A case management approach to pediatric asthma. Pediatric Nursing, 22(4), 291-295.

Malo, L., Boulet, L., Dewitt, J., Cartier, A., L'Archeveque, J., Cote, J., Bedard, G., Boucher, S., Champagne, F., Tessier, G., Contandriapoulos, A., Juniper, E., & Guyatt, G. (1993). Quality of life of subjects with occupational asthma. Journal of Allergy and Clinical Immunology, 91, 1121-1127.

Marks, G., Dunn, S., & Woolcock, A. (1993). An evaluation of an asthma quality of life questionnaire as a measure of change in adults with asthma. Journal of Clinical Epidemiology, 46(10), 1103-1111.

National Asthma Education Program. (1991). Executive summary: Guidelines for the diagnosis and management of asthma. (NIH Publication No. 94-3042A). Bethesda, MD: National Institiutes of Health.

National Asthma Education and Prevention Program. (1997). Expert panel report II: Guidelines for the diagnosis and management of asthma. Retrieved April 21, 1997 from the World Wide Web: http://www.nhlbi.nih.gov/nhlbi/lung/asthma/prof/asthhc.htm

National Heart, Lung, and Blood Institute and World Health Organization. (1995). Global initiative for asthma: Global strategy for asthma management and prevention NHLBI/WHO workshop report. (NIH Publication No. 95-3659). Bethesda, MD: National Institutes of Health.

Noonan, M., Chervinsky, P., Busse, W., Weisberg, S., Pinnas, J., de Boisblanc, B., Boltansky, H., Pearlman, D., Repsher, L., & Kellerman, D. (1995). Fluticasone propionate reduces oral prednisone use while it improves asthma control and quality of life. American Journal of Respiratory Critical Care Medicine, 152, 1467-1473.

Orem, D. (1995). Nursing: Concepts of practice (5th ed.). St. Louis: Mosby.

Price, B. (1996). Illness careers: The chronic illness experience. Journal of Advanced Nursing, 24, 275-279.

Rowe, B. & Oxman, A. (1993). Performance of an asthma quality of life questionnaire in an outpatient setting. American Review of Respiratory Disease, 148, 675-681.

Rutten-VanMolken, M., Van Doorslaer, E., & Rutten, F. (1992). Economic appraisal of asthma and COPD care: A literature review 1980 - 1991. Social Science Medicine, 35(2), 161-175.

Steinwachs, D., Wu, A., Skinner, E., & Campbell, D. (1995). Managed Health Care Association outcomes management system project: Asthma patient outcomes study; Baseline survey summary report. (Unpublished Report)

Symptom Management Faculty Group, UCSF. (1994). IMAGE: Journal of Nursing Scholarship, 26(4), 272-276.

van der Molen, T., Postma, D., Schreuers, A., Boseveld, H., Sears, M., & Meyboom de Jong, B. (1997). Discriminative aspects of two generic and two asthma-specific instruments: Relation with symptoms, bronchodilator use and lung function in patients with mild asthma. Quality of Life Research, 6, 353-361.

van Schayck, C., Dompeling, E., Rutten, M., Folgering, H., van den Boom, G., & van Weel, C. (1995). The influence of an inhaled steroid on quality of life in patients with asthma or COPD. Chest, 107(5), 1199-1205.

Wilson, S., Scamagas, P., German, D., Hughes, G., Lulla, S., Coss, S., Chardon, L., Thomas, R., Starr-Schneidkraut, N., & Arsham, G. (1993). A controlled trial of two forms of self-management for adults with asthma . The American Journal of Medicine, 94, 564-576.

APPENDIX A

Asthma Data Sheet

ASTHMA DATA SHEET **PEF:**

Dear Patient with Asthma:

Before beginning the Asthma Quality of Life Questionnaire, we would like you answer a few additional questions about your yourself and your asthma. This information is important for the results of this study. The technicians will record your Peak Expiratory Flow (PEF) reading in the upper right corner.

AGE: _____ **GENDER:** (Circle one) Male / Female **HEIGHT:** _____

RACE: (Circle one)
Caucasian / African-American / Hispanic-Latin / Asian / American Indian
Other: _____

1. How many times do you experience asthma symptoms <u>at night</u>? (Circle one)
Less than two times per month
More than two times per month but less than once per week
More than once per week
Frequent night time symptoms

2. If you have your own Peak Expiratory Flow Meter (or Peak Flow Meter), what have the readings been in the past 12 months?
Average: _____
Highest: _____
Lowest: _____
(I don't have such a meter)
(I have a meter, but have not used it for 12 months)

3. How many days in the past 12 months have you missed work or school because of asthma?
_____**/ Retired**

4. How would you rate your satisfaction with the asthma care provided to you at Malcolm Grow Medical Center? (Circle one)

greatly satisfied	moderately satisfied	a little satisfied	can't decide	a little dissatisfied	moderately dissatisfied	greatly dissatisfied

5. With regard to your asthma care, what can we do to improve your satisfaction, function level, or quality of life?

_____

_____

Please continue on to the Quality of Life questionnaire. Thank you.

APPENDIX B

Asthma Quality of Life Questionnaire

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

SELF-ADMINISTERED

McMASTER UNIVERSITY
HAMILTON, ONTARIO
CANADA

For further information:

Elizabeth Juniper, MCSP, MSc
Associate Professor
Department of Clinical Epidemiology and Biostatistics
McMaster University Medical Centre, Room 2C11
1200 Main Street West
Hamilton, Ontario, Canada L8N 3Z5
Telephone: (905) 525-9140 x22153
Fax: (905) 577-0017
E-mail: juniper@fhs.mcmaster.ca

C:\WPWIN60\WPDOCS\QUESTION\ASTHMA\FORMS\NORTHAMR\ASSNA.96A

JANUARY 1996

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

SELF-ADMINISTERED

ACTIVITIES

We should like you to think of ways in which asthma limits your life. We are particularly interested in activities that you still do, but which are limited by your asthma. You may be limited because you do these activities less often, or less well, or because they are less enjoyable. These should be activities which you do frequently and which are important in your day-to-day life. These should also be activities that you intend to do regularly throughout the study.

Please think of all the activities which you have done during the last 2 weeks, in which you were limited as a result of your asthma.

Here is a list of activities in which some people with asthma are limited. We hope that this will help you to identify the 5 most important activities in which you have been limited by your asthma during the last 2 weeks.

1. BICYCLING	15. SHOVELLING SNOW
2. CLEANING SNOW OFF YOUR CAR	16. SINGING
3. DANCING	17. DOING REGULAR SOCIAL ACTIVITIES
4. DOING HOME MAINTENANCE	18. HAVING SEXUAL INTERCOURSE
5. DOING YOUR HOUSEWORK	19. SLEEPING
6. GARDENING	20. TALKING
7. HURRYING	21. RUNNING UPSTAIRS OR UPHILL
8. JOGGING OR EXERCISING OR RUNNING	22. VACUUMING
9. LAUGHING	23. VISITING FRIENDS OR RELATIVES
10. MOPPING OR SCRUBBING THE FLOOR	24. GOING FOR A WALK
11. MOWING THE LAWN	25. WALKING UPSTAIRS OR UPHILL
12. PLAYING WITH PETS	26. WOODWORK OR CARPENTRY
13. PLAYING WITH CHILDREN OR GRANDCHILDREN	27. CARRYING OUT YOUR ACTIVITIES AT WORK
14. PLAYING SPORTS	

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

SELF-ADMINISTERED

Please write your 5 most important activities on the lines below and then tell us how much you have been limited by your asthma in each activity during the last 2 weeks by checking the box with the appropriate rating.

HOW LIMITED HAVE YOU BEEN DURING THE LAST 2 WEEKS IN THESE ACTIVITIES?

	Totally Limited	Extremely Limited	Very Limited	Moderate Limitation	Some Limitation	A Little Limitation	Not at all Limited	Activity Not done
	1	2	3	4	5	6	7	9
1._____	☐	☐	☐	☐	☐	☐	☐	☐
2._____	☐	☐	☐	☐	☐	☐	☐	☐
3._____	☐	☐	☐	☐	☐	☐	☐	☐
4._____	☐	☐	☐	☐	☐	☐	☐	☐
5._____	☐	☐	☐	☐	☐	☐	☐	☐

HOW MUCH DISCOMFORT OR DISTRESS HAVE YOU FELT OVER THE LAST 2 WEEKS?

	A Very Great Deal	A Great Deal	A Good Deal	Moderate Amount	Some	Very Little	None
	1	2	3	4	5	6	7
6. How much discomfort or distress have you felt over the last 2 weeks as a result of CHEST TIGHTNESS?	☐	☐	☐	☐	☐	☐	☐

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

SELF-ADMINISTERED

IN GENERAL, HOW MUCH OF THE TIME DURING THE LAST 2 WEEKS DID YOU:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	Hardly Any of the Time	None of the Time
	1	2	3	4	5	6	7
7. Feel CONCERNED ABOUT HAVING ASTHMA?	☐	☐	☐	☐	☐	☐	☐
8. Feel SHORT OF BREATH as a result of your asthma?	☐	☐	☐	☐	☐	☐	☐
9. Experience asthma symptoms as a RESULT OF BEING EXPOSED TO CIGARETTE SMOKE?	☐	☐	☐	☐	☐	☐	☐
10. Experience a WHEEZE in your chest?	☐	☐	☐	☐	☐	☐	☐
11. Feel you had to AVOID A SITUATION OR ENVIRONMENT BECAUSE OF CIGARETTE SMOKE?	☐	☐	☐	☐	☐	☐	☐

HOW MUCH DISCOMFORT OR DISTRESS HAVE YOUR FELT OVER THE LAST 2 WEEKS?

	A Very Great Deal	A Great Deal	A Good Deal	Moderate Amount	Some	Very Little	None
	1	2	3	4	5	6	7
12. How much discomfort or distress have you felt over the last 2 weeks as a result of COUGHING?	☐	☐	☐	☐	☐	☐	☐

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

SELF-ADMINISTERED

IN GENERAL, HOW MUCH OF THE TIME DURING THE LAST 2 WEEKS DID YOU:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	Hardly Any of the Time	None of the Time
	1	2	3	4	5	6	7
13. Feel FRUSTRATED as a result of your asthma?	☐	☐	☐	☐	☐	☐	☐
14. Experience a feeling of CHEST HEAVINESS?	☐	☐	☐	☐	☐	☐	☐
15. Feel CONCERNED ABOUT THE NEED TO USE MEDICATION for your asthma?	☐	☐	☐	☐	☐	☐	☐
16. Feel the need to CLEAR YOUR THROAT?	☐	☐	☐	☐	☐	☐	☐
17. Experience asthma symptoms as a RESULT OF BEING EXPOSED TO DUST?	☐	☐	☐	☐	☐	☐	☐
18. Experience DIFFICULTY BREATHING OUT as a result of your asthma?	☐	☐	☐	☐	☐	☐	☐
19. Feel you had to AVOID A SITUATION OR ENVIRONMENT BECAUSE OF DUST?	☐	☐	☐	☐	☐	☐	☐
20. WAKE UP IN THE MORNING WITH ASTHMA SYMPTOMS?	☐	☐	☐	☐	☐	☐	☐
21. Feel AFRAID OF NOT HAVING YOUR ASTHMA MEDICATION AVAILABLE?	☐	☐	☐	☐	☐	☐	☐

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

SELF-ADMINISTERED

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	Hardly Any of the Time	None of the Time
	1	2	3	4	5	6	7
22. Feel bothered by HEAVY BREATHING?	☐	☐	☐	☐	☐	☐	☐
23. Experience asthma symptoms as a RESULT OF THE WEATHER OR AIR POLLUTION OUTSIDE?	☐	☐	☐	☐	☐	☐	☐
24. Were you WOKEN AT NIGHT by your asthma?	☐	☐	☐	☐	☐	☐	☐
25. AVOID OR LIMIT GOING OUTSIDE BECAUSE OF THE WEATHER OR AIR POLLUTION?	☐	☐	☐	☐	☐	☐	☐
26. Experience asthma symptoms as a RESULT OF BEING EXPOSED TO STRONG SMELLS OR PERFUME?	☐	☐	☐	☐	☐	☐	☐
27. Feel AFRAID OF GETTING OUT OF BREATH?	☐	☐	☐	☐	☐	☐	☐
28. Feel you had to AVOID A SITUATION OR ENVIRONMENT BECAUSE OF STRONG SMELLS OR PERFUME?	☐	☐	☐	☐	☐	☐	☐
29. Has your asthma INTERFERED WITH GETTING A GOOD NIGHT'S SLEEP?	☐	☐	☐	☐	☐	☐	☐
30. Have a feeling of FIGHTING FOR AIR?	☐	☐	☐	☐	☐	☐	☐

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

SELF-ADMINISTERED

HOW LIMITED HAVE YOU BEEN DURING THE LAST 2 WEEKS?

	Most Not Done		Several Not Done		Very Few Not Done		No Limitation
	1	2	3	4	5	6	7
31. Think of the OVERALL RANGE OF ACTIVITIES that you would have liked to have done during the last 2 weeks. How much has your range of activities been limited by your asthma?	☐	☐	☐	☐	☐	☐	☐

	Totally Limited	Extremely Limited	Very Limited	Moderate Limitation	Some Limitation	A Little Limitation	Not at all Limited
	1	2	3	4	5	6	7
32. Overall, among ALL THE ACTIVITIES that you have done during the last 2 weeks, how limited have you been by your asthma?	☐	☐	☐	☐	☐	☐	☐

APPENDIX C

Consent Form

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

Study Title: Quality of Life for Adults with Asthma in a Military Setting
Investigator: Captain Rhonda R. Adler, USAF, NC

Dear Patient with Asthma:

Captain Adler is a registered nurse currently in graduate school at the Uniformed Services University of the Health Sciences (USUHS). She is studying the relationship between the quality of life in adults with asthma and the severity of their disease with lung function.

Your participation in this study is voluntary; you are under no obligation to participate. You have the right to withdraw at any time without affecting your care and your relationship with the health care team. While this study may not help you personally, it may provide information to health care providers for future management of asthma and its effects.

This study involves no physical risk or discomfort to you. No unlicensed or experimental drugs will be used. Some of the questions may be potentially sensitive and you are free to omit these questions if you feel uncomfortable. There is no cost to you for your participation in this study, nor will you be paid for your participation.

If you agree to participate, please complete the attached survey. It will take approximately ten minutes. The clinic technicians will record your Peak Flow Reading (PEF) on the cover sheet. This cover sheet includes information about yourself that is important to the study. Do not put your name on the questionnaire. Please answer each question with one response. The questions deal only with asthma and no other health conditions you may have. It is important to answer these questions before your clinic visit. After you have completed the questionnaire, please place it into the envelope, seal it, and put the envelope into the collection box. Since your name does not appear on the questionnaire, your identity will not be revealed during the study or when reported or published. All of the surveys will be collected by Capt. Adler.

You are free to ask any questions about this study or about being a subject. You may call Capt. Adler at (301) 838-9139 evenings if you have further questions. Your completion of this questionnaire indicates your consent to participate in this study.

Thank you for your time and participation.

Sincerely,

Rhonda R. Adler

RHONDA R. ADLER, Capt, USAF, NC

APPENDIX D

Permission for use of AQLQ

Subj: Re: AQLQ
Date: 97-02-19 16:16:24 EST
From: juniper@fhs.csu.McMaster.CA (Elizabeth Juniper)
To: RnGAdler@aol.com

Dear Captain Adler,
We have a package that contains the Asthma Quality of Life Questionnaire in both interviewer and self-administered formats. an implementation manual and all the most recent published papers on validity. We'll pop a copy in the post. There is no fee for academics and clinicians (we have a user fee for commercial companies) and you are very welcome to use it in your studies.
Let me know if I can help further
Liz Juniper

Elizabeth Juniper, Associate Professor,
Dept. of Clinical Epidemiology & Biostatistics
McMaster University Faculty of Health Sciences.
1200 Main Street West, Hamilton.
Ontario. Canada. L8N 3Z5.
Phone: 1 905 525 9140 x 22153
Fax: 1 905 577 0017
WWW: http://www-fhs.mcmaster.ca/hrqol/qolintro.htm

On Tue, 18 Feb 1997 RnGAdler@aol.com wrote:

> Captain Rhonda R. Adler, USAF, NC
> 1024 Copperstone Court
> Rockville, MD 20852
> E-Mail: rngadler@aol.com
>
> 17 February 1997
>
> Elizabeth Juniper MCSP, MSc
> Assistant Professor,
> Department of Clinical Epidemiology and Biostatistics,
> McMaster University Medical Center, Room 2C11
> 1200 Main Street West
> Hamilton, Ontario L8N 3Z5
>
> Dear Professor Juniper,
>
> I am a graduate student currently in the Family Nurse Practitioner program at
> the Uniformed Services University of the Health Sciences (USUHS) in Bethesda,
> MD. I am working with Lt Col J. Mitchell and Commander J. McQuestan at
> Andrews Air Force Base to look at outcomes of the use of critical pathways
> for asthma care. I came across your Asthma Quality of Life Questionnaire in
> my literature search and felt it would lend itself well to my thesis study.
> I would like to know the procedure and the fee for the use of this tool.
> Also, I would like to know if you have any references since 1993 which have
> evaluated the validity and reliability any further. I have attached the
> draft of my research proposal abstract for your information. I would
> appreciate any suggestions or quidance you can offer. I look forward to
> hearing from you. Thank you.
>

APPENDIX E

Approval Letters

UNIFORMED SERVICES UNIVERSITY OF THE HEALTH SCIENCES
4301 JONES BRIDGE ROAD
BETHESDA, MARYLAND 20814-4799

September 15, 1997

MEMORANDUM FOR RHONDA R. ADLER, DEPARTMENT OF GRADUATE SCHOOL OF NURSING

SUBJECT: IRB Approval of Protocol **T06146-01** for Human Subject Use

Your research protocol entitled ***"Quality of Life for Adults with Asthma in a Military Setting,"*** was reviewed and approved for execution on 8/28/97 as an **exempt** human subject use study under the provisions of 32 CFR 219.101(b)(2). It was discussed and read into the minutes of the USUHS IRB meeting on 9/11/97.

The IRB understands that this is a descriptive correlational study to investigate the relationship between levels of asthma severity and measures of lung function and the quality of life in adults with asthma in the military health care system. The Asthma Quality of Life Questionnaire (AQLQ) will be used to determine subjects' perceived quality of life. Questions contained within this survey request nonsensitive information without identifiers.

Please notify this office of any amendments you wish to propose and of any untoward incidents which may occur in the conduct of this project. If you have any questions regarding human volunteers, please call me at 301-295-3303.

Michael J. McCreery, Ph.D.
LTC, MS, USA
Director, Research Programs and
Executive Secretary, IRB

cc: Director, Grants Administration

DEPARTMENT OF THE AIR FORCE
HEADQUARTERS 89TH AIRLIFT WING (AMC)

U.S. AIR FORCE
1947 - 1997

15 Aug 97

MEMORANDUM FOR CAPT RHONDA R. ADLER
1024 COPPERSTONE COURT
ROCKVILLE, MARYLAND 20852

FROM: 89 MDG/SGI
1050 W. PERIMETER RD.
ANDREWS AFB, MD 20762-6600

SUBJECT: Approval of Protocol "Quality of Life for Adults with Asthma in a Military Setting"

1. At the 13 Aug 97 meeting, the Institutional Review Board (IRB) approved the subject potocol. You may begin your study.

2. Ensure all required reports are forwarded to this office promptly.

William H. Aussiker

WILLIAM H. AUSSIKER, Col, USAF, DC
Director, Career Development Function