ASSESSMENT OF THE KNOWLEDGE OF ASTHMA AMONGST ADULT ASTHMATICS AND THEIR QUALITY OF LIFE

by

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DECLARATION

I declare that **ASSESSMENT OF THE KNOWLEDGE OF ASTHMA AMONGST ADULT ASTHMATICS AND THEIR QUALITY OF LIFE,** is my own work and that all the sources I have used or quoted, have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

Signature:……

(Mrs Z A WILLIAMS)

Date:……

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DEDICATION

This study is dedicated to my father and my family who through their encouragement and inspiration allowed me to finish this project, to GOD who gave me the courage and strength to persist and allow HIM to guide my life, to all the people who dedicate their professional skills and energy to improve the quality of life of asthma sufferers.

"HE WHO UPSETS A THING MUST KNOW HOW TO REARRANGE IT"

AFRICAN PROVERB.

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SUMMARY

Asthma is not a disease with a single etiology but a very complex syndrome. Irrespective of a better understanding of the pathophysiology of asthma and its related therapeutic regimens the disease still escalates in prevalence and severity. Characteristic features of chronicity and remission ensures a fertile ground for non-compliance by patients. This quantitative, descriptive study set out to determine the asthma knowledge, asthma control and quality of life of adult asthmatics who attended the respiratory outpatient clinic at Tygerberg Hospital. The purpose was to determine an association between asthma knowledge, asthma control and asthma quality of life.

A statistically significant association was found between asthma control and asthma quality of life, not with knowledge of asthma for either of the concepts. Important gaps in knowledge were identified namely an inability to recognise nocturnal coughing as a risk factor. The increased role of nurse practitioners in asthma care is highly recommended.

Key Terms: **asthma knowledge, asthma control, asthma quality of life, adult asthmatics**

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List of Abbreviations

ACQ	=	Asthma Control Questionnaire
AIRE	=	Asthma Insights and Reality in Europe
ANC	=	African National Congress
AQLQ	=	Asthma Quality of Life Questionnaire
ATS	=	American Thoracic Society
BHR	=	Bronchial Hyper-reactivity
CCAS-32	=	Chicago Community Asthma Survey-32
COPD	=	Chronic Obstructive Pulmonary Disease
DHS	=	Demographic and Health Survey
ECCS	=	European Community for Coal and Steel
ER	=	Emergency Room
FEV_1	=	Forced Expiratory Volume in one second
FVC	=	Forced Vital Capacity
GINA	=	Global Initiative for Asthma
HDM	=	House dust mite
HIV	=	Human Immuno-deficiency Virus
IgE	=	Immunoglobulin E
ISAAC	=	International Survey of Asthma and Allergy in Childhood
MRC	=	Medical Research Council
NAEP	=	National Asthma Education Program
NATC	=	National Asthma Training Centre
NFA	=	Near-Fatal Asthma

QOL	=	Quality of Life
SA	=	South Africa
SATS	=	South African Thoracic Society
SNAP	=	Stellenbosch Near-Fatal Asthma Project
TBH	=	Tygerberg Hospital
UK	=	United Kingdom
USA	=	United States of America
WHO	=	World Health Organisation

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CHAPTER 1

Orientation to the study

1.1 INTRODUCTION

Asthma is a chronic respiratory disease that can have varying effects on the quality of life of sufferers. The patho-physiology of asthma involves a circular progression of physical manifestations due to airflow obstruction as a result of inflammation of the airways. The types of inflammation differ between patients, even if the same mechanisms (such as allergy) are involved. Patients now respond differently to a variety of stimuli or, even, the same stimuli at different times. At the same time, the response to treatment can also vary greatly [Kemp 2002:1]. Those who are properly treated, well educated about all aspects of their illness and compliant are less affected. Those that are not may be severely impaired by chronic airflow limitation. It has been proven by research that the management and control of asthma greatly affects the quality of life of the person living with asthma, and that any level of symptom severity has an impact on quality of life even in people who only experience occasional symptoms [Leynaert, Neukirch, Laird, Bousquet and Neukirch 2000:1394].

Asthma is a disease of high prevalence in South Africa but, according to Zar, Stickells, Toerien, Wilson, Klein and Bateman [2002:2], the disease has assumed a low priority in this nation. This group retrospectively analysed the incidence of fatal and near-fatal asthma from 1980 to 1997 and reported 1506 asthma deaths during this period. Asthma medication is costly and can place a substantial financial burden on patients and their families. However, uncontrolled asthma puts patients at risk and increases asthma-related hospital admissions and emergency presentations. Understandably, the management and control of asthma greatly affects the quality of life of the person living with asthma. Patients that attend the

Tygerberg Hospital (in the Western Cape) for health care tend to stay in a state of uncontrolled disease with poor lung functions and increased requirements for reliever medication. This group's quantitative, descriptive study sought to discern the provenance of this uncontrolled disease and set out to determine the knowledge of asthma, control of asthma and quality of life of people suffering from asthma. The study was done in the respiratory out patients department of the Tygerberg Hospital in the Western Cape Province. Data was gathered with the aid of standardised questionnaires such as the asthma knowledge questionnaire the Chicago Community Asthma Survey (CCAS-32) [Grant, Turner-Roan, Daugherty, Li, Eckenfels, Baier, McDermott,Weiss 1999:189], as well as the control of asthma [Juniper, O'Byrne, Guyatt, Ferrie, King 1999:902] and the asthma quality of life [Marks, Dunn, Woolcock 1993:1103] questionnaires.

1.2 BACKGROUND TO THE PROBLEM

The Global Initiative for Asthma (GINA) guidelines and statistics released by the World Health Organisation (WHO) indicate that the prevalence of asthma is increasing worldwide [Ware1987:13]. It is estimated that about 5% of the adult population and 10 to 15% of children in the world are suffering from asthma. Children in developing countries appear to be particularly vulnerable. The International Survey of Asthma and Allergy in Childhood (ISAAC) report showed that the asthma prevalence was 9% in African school children between the ages 13 to 14 years. According to Bailey, the figure was 13% in Cape Town [Bailey 2001:12]. Morbidity and mortality associated with asthma is also substantial. Statistics published by the British Thoracic Society indicated that the asthma death rate remained at about 2000 per annum for over a decade [Tettersell 1993:103]. The prevalence of diagnosed asthma in England between 1995 and 1997 was 13% in adults between the ages 16-44 years [National Asthma Training Centre (NATC) 2001:3]. The number of asthma deaths in England and Wales in 2000 was 1 272 [Hoare and Bruce 2003:15]. The 1996

South African census estimated that 3 443 people died from asthma in South Africa in the early 1990's. Many patients suffering from asthma experience considerable morbidity as reflected by frequent episodes of worsening of asthma symptoms, limitation of their activities and impaired lung function. This probably demonstrates greater severity of underlying disease [Hong, Ng, Wong, Koh, Goh, and Ling 1994:639]. Smoking is also associated with an increase in morbidity [Hong et al 1994:641]. Another important reason for asthma morbidity is poor compliance with treatment regimens as it leads to improper symptom control and associated impairment of quality of life. Rising costs involved with poor compliance emanate from the increased number of emergency room visits, hospitalization, loss of productivity as well as absence from work or school [Manjra 1999:13].

Asthma ranges from mild episodes of exacerbations to a severe chronic condition requiring frequent medical care, hospitalisation and high doses of maintenance therapy [Little and Thompson 2000:12]. Because of the typical characteristics of the disease (chronicity, periods of remission, complexity of the treatment) particularly fertile ground exists for non-compliance by patients [Tettersell 1993:104]. Tettersell [1993:103] noted a 39% non-compliance rate in a group of moderate to severe asthmatics. However, the level of patient knowledge concerning the disease had no significant effect on compliance to drug therapy. Knowledge appeared to influence the ability of a patient to manage his/her asthma attack. This contradicts the general belief amongst health professionals that compliance is directly related to patient knowledge. Earlier studies done in Aberdeen, Scotland also reported that poor knowledge about asthma was very common in out-patient clinics [Ellis and Friend 1985:43]. Barritt and Davis [1993:229] demonstrated inadequate understanding of disease in 78% of adult asthmatics and 68% of parents of asthmatics children. At the Asthma for Africa conference [Cape Town 2001], it was highlighted that each patient with asthma brings to the condition a different personality, a different understanding of the illness and different past life experiences. Therefore, their needs will differ regarding management and control.

Although the understanding of asthma as a disease and the treatment thereof has grown over the past 20 years, there is still a body of evidence which suggests that asthma is not well controlled in many patients [Evans 1993:685]. Many subjects can identify specific triggers of their symptoms, but they seldom intervene to ensure abolition of symptoms because they have minimal expectations of success from their own initiated efforts. Insufficient knowledge and inappropriate ideas about asthma are considered major barriers to self-management of asthma [Markson,Vollmer,Fitterman, O'Connor, Naranayan, Berger and Buist. 2001:382]. A study done by Gibson, Henry, Vimpani, and Halliday [1995:1003] confirmed the assumption that although people with asthma strongly desire to get information about their illness, they do not want to be responsible for making the prime decisions during episodes of exacerbations.

This poses a problem for health professionals, as the latest guidelines recommend more autonomy in decision making for patients with the aid of written action plans. According to Jones, Quirck, and Baveystock [1994:79] treatment of airways disease should improve the health and well-being of patients. Recent advances in our understanding of asthma and its management should, therefore, improve patients' quality of life, but this aspect is often not observed in current clinical practice. Quality of life assessment is a reflection of a person's own subjective understanding of the impact chronic disease and its treatment has on his/her life. It was initially used as an outcome measure to assess management but now quality of life assessment aids in giving a holistic view of the patient compared to lung function testing alone. Caring for asthma patients should be directed towards increasing the quality of life of subjects [Hyland 1997:195], but should also allow them to voice the concerns that are important to them. Asthmatics should not be led to accept as normal a lower level of functioning [Markson et al 2001:383].

1.3. PROBLEM STATEMENT

Asthma sufferers who attend the Tygerberg Hospital respiratory clinic are categorised more frequently as moderate to severe asthmatics, according to assessment of spirometry on presentation to the clinic and measured against the local asthma guidelines. This demonstrates there could be a potential problem of under treatment or possible non-adherence to asthma management strategies. Such asthmatics have a poor understanding of their well-being and frequently underestimate the severity of their disease and the amount of treatment necessary to control it. Improper disease control hampers quality of life and is a risk factor for near-fatal attacks and asthma deaths.

The purpose of this study is to determine asthmatic patient's knowledge of asthma, asthma control and their quality of life, and to establish whether there is a relationship between asthma knowledge, asthma control, and quality of life. The motivation for the study was:

- The rate of emergency admissions for asthma at the Tygerberg Hospital
- Research Unit contact sessions with patients who showed no or minimal understanding of their disease
- Respiratory Outpatients Department contact sessions with patients who showed no or minimal understanding of their treatment regime

1.4 OBJECTIVES OF THE RESEARCH

A study was proposed of adult asthmatics attending the respiratory clinic of an academic facility. The following objectives stem from the research purpose, namely to:

- Establish the knowledge of adult asthma sufferers regarding their disease

- Assess the quality of life of adult asthmatics as measured by a validated disease-specific questionnaire
- Assess the control of asthma as measured by a validated disease-specific questionnaire
- Determine any relationship between knowledge regarding asthma, asthma control and quality of life.

The fourth objective will answer the following research questions, namely:

1. is lack of knowledge regarding asthma linked to impaired asthma quality of life?
2. is there an association between knowledge regarding asthma and asthma control?
3. is there an association between asthma control and quality of life of asthmatics?

1.5 SIGNIFICANCE OF THE RESEARCH

Asthma has a significant impact on the lives of people with the condition. Often they feel embarrassed and fearful and their perception of control is not reflected in the presentation of the severity of their symptoms. Asthmatics usually have an opinion of what the disease means to them. Their opinions are mostly derived from their own experiences and consequences of the illness. The patient's contextual framework affects the manner in which they react to new information about asthma and their decisions to either adhere to treatment or to ignore treatment suggestions. Asthma is perceived as problematic by asthma patients because of its variability. Sufferers are constantly on edge, because the disease process can be very unpredictable. At times, they are in remission and are able to control their situation, yet a slight environmental stimulus can easily change tranquillity into a situation of uncontrolled disease. The total control of asthma means freedom and improved quality of life

that leads to enhanced productivity. Whilst reaching this level of functioning and independence may be difficult, it should be generally achievable.

The limited contact time health professionals have available to spend with individual patients leads to a concentration on the signs and symptoms of the disease and the treatment of asthma with various medications. Although inhaled corticosteroids are the mainstay of treatment and are recommended by all the asthma guidelines, a large proportion of people do not adhere to treatment because they do not understand the rationale for its use [Kips and Pauwels 2000: 797]. Limited contact time denies health professionals the opportunity to go into detailed explanations to benefit the educational level of the patient and to ensure language barriers are overcome. The consequences of a chronic illness on the lives of asthma sufferers in terms of wellness in areas of life such as physical, spiritual, social, emotional and psychological wellbeing are seldom addressed.

The quality of life of the asthma population that make use of the Tygerberg Hospital as an academic health facility had not been studied previously. Information obtained from this study will aid health professionals to appropriately plan patient management protocols by adding to the body of knowledge and application and control that need to be addressed in this specific population. The focus in asthma management has recently shifted to patient-orientated measures of asthma control; the cornerstone of this endeavour is patient education and, in particular, to those aspects important to the individual patient. The study will also aid in the planning and organizing of health education strategies that will enhance patient skills to enable them to achieve asthma control in order to reduce/prevent emergency visits or hospital admissions. An Australian study showed that where patient skills were enhanced, improvement occurred in hospital attendance, symptoms and disturbance due to asthma [Donaldson 1995: 592]. Reduction in emergency admissions will lead to a concomitant decline in health care costs, health care expenditure and will also serve to reduce strain on family income. Fewer days off work or school are the result of proper

control. Issues of non-adherence could be addressed by appropriate self management strategies planned around the needs of the individual and encouraging achievable goal setting.

The role of the nurse in asthma management is important because nurses are usually the patient's first point of contact at regular follow-up visits. Some patients are also more comfortable in sharing their difficulties with nurses rather than other members of staff. The role of nurses in asthma clinics is currently more directed towards curative aspects of care. Due to staff shortages, their role as health promoters and asthma educators does not frequently materialise. Nurses could be a valuable asset to implement educational strategies that will lead to the promotion of change in asthma-related behaviour. Behavioural change, in turn, leads to the reduction of asthma symptoms and ultimately enhance quality of life [Forshee,Whalen,Hachel,Butt,Smeltzer,Martin,Lavin and Buchner. 1998: 83].

1.6 ASSUMPTIONS

An assumption is defined as:

"a proposition that is taken for granted without proof, that means, treated within the context of a discussion as if it were known. It therefore provides a basis for logical reasoning."

Burns and Grove [2001:59] define assumptions as:

"Statements that are taken for granted or are considered true even though they have not been scientifically tested. Assumptions influence the logic of the study, and their recognition leads to more rigorous study development."

People living with chronic disabling conditions such as asthma are, for a variety of reasons, constantly confronted with impaired quality of life. Quality of life is usually an outcome of the interaction amongst a range of variables including acceptance of the diagnosis. Stuifenberg,

Seraphine and Roberts [2000:122] investigated the issues surrounding the health promotion needs of individuals with a chronic disabling disease and outcomes associated with the performance of health-promoting behaviours to ensure optimal quality of life. Their proposed explanatory model is based on the premise: "perceived quality of life results from direct and indirect influences of contextual, attitudinal and behavioural factors" [Stuifenberg et al: 123]. The researchers assumed that: patients determine their quality of life subjectively; quality of life can change over time; and quality of life may be influenced by perceptions that the health/illness status is changing. The conceptual model proposes a process composed of contextual and antecedent factors that influence health-promoting behaviours and, thus, shape quality of life.

In this study, asthma will be the dominant contextual variable. A possible barrier to health-promoting behaviour might be the patient's knowledge of the disease, its treatment and management. This will adversely affect their ability to control their asthma and to have a better asthma quality of life. The following assumptions serve as departure points for this study:

- Adequate asthma knowledge may have a positive influence on self-efficacy and health-promoting behaviours and quality of life
- Lack of asthma knowledge may negatively influence acceptance and beliefs about the disease, and may lead to misconceptions
- Lack of asthma knowledge may be responsible for a poor quality of life
- Compliance is directly related to patient knowledge
- Sustained positive health-promoting behaviour will improve and have direct and positive effects on quality of life, mediating the effects of antecedent variables such as acceptance of disease and severity of illness
- Nurses are often not included when strategies are planned to ensure patients reach the goal of asthma control with associated improved asthma quality of life.

The population served by the Tygerberg Hospital has not been studied before in relation to the abovementioned aspects. Accordingly, information is necessary for future planning of patient management protocols as well as for developing patient educational strategies to ensure that essential behavioural changes are made by asthma sufferers.

1.7 DEFINITIONS OF KEY CONCEPTS

For the purpose of the study the following key concepts require clarification.

1.7.1 Asthma

The International Union against Tuberculosis and Lung disease define asthma as an:

"Inflammatory condition of the airways, involving many types of cells, especially mast cells, eusinophils and T- lymphocytes. In individuals predisposed, this inflammation causes recurrent episodes of wheeze, breathlessness, chest tightness and cough, particularly at night or early in the morning. These symptoms are usually associated with variable obstruction which is more or less reversible either spontaneously or under treatment. The inflammation also aggravates bronchial reactivity to a variety of stimuli" [Khaled and Enarson 1996:5]. For the purpose of this study, however, the statement of the American Thoracic Society (ATS) will be used as the definition to identify the study population.

The ATS statement reads:

"A history of asthma symptoms and current or historical proof of a response to bronchodilator and/or corticosteroid treatment."

1.7.2 Quality of life

Quality of Life will be defined as:

"An individual's satisfaction or happiness with life in those areas important to him/her." Being such a broad concept, quality of life is not limited just to health per se, but covers all dimensions of life. For the purpose of this study, the term "health-related" quality of life will be used. It reflects on the effects of disease on physical, social/role/ psychological/emotional and cognitive functioning. This supports the definition of health as described by the World Health Organization (WHO):

"Health is not merely the absence of disease but incorporates well-being or wellness in all areas of life [physical, mental, emotional, social, spiritual]" [Cochrane Review 2001].

1.7.3 Knowledge

Knowledge is seen as a major determinant of health enhancing behaviour, including compliance and is usually closely linked to a person's beliefs and attitudes as well as cultural background. For the purpose of this study it will be defined as:

"Comprehending facts, acquiring psychomotor skills and mastering a subject" [Burns and Grove.1997:11].

With regards to asthma, this study defined knowledge as the understanding of general disease-related concepts, perceptions and interpretation of symptoms, basic skills mastered to enhance self-management for example using a reliever inhaler.

1.7.4 Pack years

A pack year is defined as the number of packs (20 cigarettes) per day times the number of smoking years. Each 20 pack year lead to a 1.13 fold increased risk of chronic diseases [Tripath, Folson and Anderson 2002:1]. The current South African Chronic Obstructive

Pulmonary Disease guidelines state that 1 pack year equals 20 cigarettes per day for one year [O'Brien, Feldman, Batemen and Plitt 1997:49].

1.7.5 Spirometry

Spirometry is a medical screening test that measures various aspects of breathing and lung function. The measurement is performed by using a spirometer, a special device that registers the amount of air a subject inhales or exhales and the rate at which air is moved into or out of the lungs. Three measurements obtained through spirometry are particularly useful, namely:

Forced Vital Capacity (FVC), Forced Expiratory Volume at one second (FEV_1), and the ratio of the FEV_1 to the FVC [Webster's Dictionary].

1.7.6 Academic Hospital

An academic hospital is a facility where health professionals receive their clinical training and develop their clinical skills under the supervision of mentors. The hospital is usually affiliated to a tertiary institution such as a technicon or university

1.7.7 Out-patient Clinic

Is a follow-up service provided to patients with chronic diseases within the setting of an academic or regional hospital. This creates the opportunity for health professionals to discuss the management plan of difficult to treat patients with a consultant, who usually will be on site to facilitate all activities. For this particular study it refers to a respiratory clinic in an academic facility.

1.8 RESEARCH METHOD

A quantitative, descriptive survey was conducted. This method allowed easy data collection with the aid of questionnaires, and can also easily be repeated in follow-up studies to evaluate changes over time. By definition descriptive designs should picture events as they naturally unfold. The survey was chosen as the method to determine an association between the different variables [Burns and Grove 2001:256]. Results of descriptive studies provide information about disease frequency and can be an indicator of public health importance.

1.8.1 Research Setting

Adult asthma sufferers were studied in the Respiratory Outpatients' Clinic of the Tygerberg Hospital. Patients are referred to the clinic from surrounding day-hospitals and private practitioners in the catchment area when they need specialist attention. A minority of patients come from the surrounding rural areas and via the emergency unit of Tygerberg Hospital (TBH).

Approximately 500 asthmatics used the service in 2000. A sample of 20% [100] were selected for participation according to specific criteria (see addendum F). The case record files of all asthmatics that reported for follow-up visits at the clinic were assessed for suitability by the investigator. Follow up visits are usually scheduled on a monthly basis in poorly controlled patients and three monthly in stable asthmatics. All the suitable candidates were asked if they would be willing to volunteer for participation in the clinical study. Possible candidates were informed of their right to refuse participation.

1.8.2 Study Participants

The admission age for patients to an adult clinic at the Tygerberg Hospital is twelve years. To determine a true picture of the population served by the respiratory clinic, twelve year old participants were included. This group of patients form a more difficult subset to treat due to peer group pressure. Males and females who attend the respiratory out patient's clinic and who gave their informed consent, were studied. Newly diagnosed patients were not included as study participants because their diagnosis of asthma usually has not been confirmed by a respiratory physician. On first presentation to the respiratory clinic, all differential diagnoses still need to be excluded as well as the inclusion of newly diagnosed subjects would have introduced bias into the sample and increased the possibility of the inclusion of people who suffer from Chronic Obstructive Airways Disease (COPD) or just temporary bronchial hyper-reactivity due to respiratory tract infections.

1.8.2.1 Inclusion criteria

- Males and Females aged 12 to 70
- Suffering from asthma according to ATS guidelines (see definitions)
- Attending the Respiratory clinic for a routine follow up visit
- Non-smokers or ex-smokers with less than five (5) pack year history

1.8.2.2 Exclusion criteria

- Subjects who refuse consent.
- Subjects with a smoking history of more than five (5) pack years [because they are more likely to have Chronic Obstructive Airways Disease COPD].
- Subjects with other debilitating chronic illnesses, which affect their functional status and may bias their observations (eg. Ischaemic Heart Disease or Chronic Cardiac Failure).

1.9 MEASURING TOOLS

1.9.1 Spirometry

Spirometry was applied to assess Forced expiratory volume in 1 second [FEV_1], Forced vital capacity [FVC], FEV_1/FVC ratio readings on the day of the visit. The procedure was performed by a trained clinical technologist. Three repeatable attempts were used and participants completed the procedure in a sitting position.

1.9.2 Questionnaires (see addendum B)

1.9.2.1 Knowledge regarding asthma

Knowledge regarding asthma was assessed by means of a validated questionnaire (the Chicago Community Asthma Survey) [CCAS-32]. A series of statements about asthma, signs of asthma and health care for asthma were assessed on a true/false scale [Grant, Turner-Roan, Daugherty, Li, Eckenfels, Baier, McDermott, Weiss 1999:189].

1.9.2.2 Control of asthma

Control of asthma was measured by means of a validated questionnaire, developed by Elizabeth Juniper. Subjects included were nocturnal awakening, asthma symptoms, activity limitations, shortness of breath, wheezing and intake of short-acting beta stimulants [Juniper, O'Byrne, Guyatt, Ferrie, and King 1999:902].

1.9.2.3 Quality of life

Quality of life was measured by means of a validated disease-specific questionnaire developed by Woolcock and co-workers [Marks, Dunn and Woolcock 1993:1103]. Items such as breathlessness and physical restrictions, mood disturbance, social disruption and concerns about health were measured.

1.9.2.4 Data Analysis

Data Analysis was undertaken with the aid of a statistician. The package Statistica Version 7 was used. Data was entered onto a spreadsheet by the investigator. Frequency, mean and standard deviation were computed. Internal consistency of instruments was assessed by calculating Chronbach alpha. Details of statistical types are given in Chapter 3 as well as a discussion of the concepts reliability and validity.

1.10 ETHICAL CONSIDERATIONS

For the purpose of the study, informed consent was obtained from all the participants before any study related procedures were done. Patient initials and a study code for the purpose of data analysis were used to ensure confidentiality of information. Ethical approval was obtained from the relevant authorities, namely the Tygerberg Hospital Institutional Review Board and the Human Research Ethics Committee of the University of Stellenbosch (see addendums C and D). Patients were made aware that participation was voluntary and that they had the right to refuse.

1.11 SUMMARY

An introduction has been given to the many facets of asthma. Many asthmatics experience considerable morbidity and limitation of their activities. Asthma imposes limitations on all sufferers irrespective of the severity of their disease. Treatment often lasts for years and, in some cases, a lifetime. This raises important issues in patient management such as compliance, under-estimation of asthma attacks, appropriate management skills and the various costs.

The focus of this study was to assess the correlation knowledge and control of asthma had on the quality of life of asthmatics. Previous studies completed in the early 1990's concluded that there is a positive co-relation between self-management and quality of life. Self-management can only be successfully implemented if patients have sufficient knowledge to create behavioural change. If nurses can promote appropriate self-management skills to empower patients to the extent where they have the confidence to make decisions, not only will their quality of life improve, but it will also allow them to reduce health care related costs.

Chapter Two will reflect on the information currently available in the literature regarding the key concepts such as knowledge of asthma, asthma control, and asthma quality of life.

CHAPTER 2

Literature Review

2.1 INTRODUCTION

Chapter One introduced and outlined the background and significance of the problems faced by respiratory health professionals regarding the study area of asthma knowledge, asthma control and asthma quality of life. This chapter outlines the literature review undertaken to evaluate the research problem within the broader contextual framework and to demonstrate the need for undertaking the study in this specific asthma population.

The literature review is a critical step in the research process and allows researchers the opportunity to do research within a context of existing knowledge [Polit and Hungler 2001:79]. The problem is brought under sharper scrutiny and focus and unnecessary duplication is prevented. This study used both primary sources such as research publications and secondary sources such as reviews by prominent researchers in the field of respiratory disease. Medline, CINHAL, Cochrane search, Print indexes such as books, journals, publications of professional organizations, government documents as well as abstract journals were used. Established and new ideas about asthma as a disease were explored as well as the management of the disease. Problem areas such as disease severity, patient adherence and uncontrolled asthma were covered. The research also involved the key concepts of knowledge of asthma, control of asthma and asthma quality of life.

2.2 SCOPE OF THE PROBLEM

Asthma is a long-term incurable disease of the lungs. In the past, the mechanisms of the disease were poorly described and not completely understood. Since the early 1990's the application of cell and molecular biology techniques has completely changed the understanding of the patho-physiology of asthma and led to the implementation of new pharmacological strategies [Barnes 1996:3]. Despite this, there is well-documented evidence that the prevalence and morbidity of asthma actually increased in many countries, including South Africa. The subsequent development of both national and international guidelines to improve the care of asthma sufferers has not had the impact its designers had envisioned.

The severity of asthma is usually associated with the degree of disease activity present in airways. This process is also variable in nature and can differ considerably from day to day in the same patient and also between asthmatic individuals. Having asthma can be very alarming to the patient and his/her family. The quality of life of asthmatics and their family members is adversely affected when the disease is not well controlled. Causes of sub-optimal disease control are currently not understood, but studies of asthma deaths have implicated factors such as non-compliance with management strategies, failure to recognise the severity of an acute asthma attack as well as inappropriate actions during acute severe attacks. [Sibbald 1989:97; Wareham, Harrison, Jenkins, Nicholls, and Stableforth 1993:1117]. A study by Moosa [1997:42] suggested that judgemental errors and misconceptions about asthma should be a cause for concern, because of the potential for inadvertent non-compliance. These researchers have implicated inadequate knowledge and self-management skills as possible reasons for high rates of morbidity and mortality. Patients who lack knowledge will also lack the confidence to appropriately address disease-related problems. Wigal, Stout, Brandon, Winder, McConnaughy, Creer, and Kotses [1993:1144]

also suggested that knowledge may be a variable related to the success or failure of treatment strategies.

2.3 DEFINING ASTHMA

Several definitions of asthma have been proposed but to date there is no “gold standard” definition. The Global Strategy for Asthma Management and Prevention Report based their definition on the pathology and functional consequences of the disease.

Asthma is a chronic inflammatory disorder of the airways in which many cell types (mast cells, eosinophils, T lymphocytes) have a role in airway limitation that is at least partially reversible be it spontaneously or with treatment. [Bousquet, Jeffery, Busse et al 2000:1720]. Triggers that may provoke airway obstruction include exercise, common colds, cold air, cigarette smoke, and respiratory allergens such as house dust mite and pet hair and furs. Individual factors such as laughter and stress are sometimes implicated [Shreve 1999:3]. Asthma also has a strong seasonal cycle due to sudden changes in temperature or increased mould spores. According to Boushey and Stempel [2002:S479] asthma is a disease of high prevalence, morbidity and cost but studies have constantly shown asthma is both under-recognised and under-treated.

2.3.1 Etiology of Asthma

Asthma is a serious global health problem. The disease is broadly distributed by age, sex, ethnicity, and geographic location and remains the most common chronic disease in adults and children worldwide. The causes of asthma are unknown however heredity, allergens and environmental factors play a role. Asthma occurs in 5-12% of the population worldwide at any age but is most common in childhood and reduces at puberty. In some instances, the incidence increases as people get older. Asthma runs in families with atopy associated with

chromosomes 5 and 11 [Shreve1999:1]. Early onset usually indicates an allergic basis for the disease. Atopic asthma is the common cause for treatment resistant asthma in children. This type of the disease occurs in 30-50% of the general population. In the USA asthma prevalence increased to 63% in children and 45% in adults between 1980 – 1999 [Stafford, Jun, Finkelstein, Haver, and Cockburn 2003:729]. Currently one in six children suffers from asthma in Australia according to the National Asthma Campaign 2005.

2.3.2 Pathogenesis of Asthma

Views on the pathogenetic mechanisms of asthma have changed with the recognition that chronic inflammation underlines the syndrome. A genetic background sets the stage for a cytokine imbalance that promotes the formation of IgE. Previously, it was thought that abnormal contractility of the airway smooth muscle gave rise to variable airflow obstruction, responsible for the common symptoms of wheezing and shortness of breath. For many years, researchers also assumed mast cell mediators played the critical role in patho-physiology [Barnes 1996:4]. Recent research, however, established that asthma, even in its mildest form, involves the activation of many different inflammatory cells in the asthmatic airways. Inflammatory cells produce a variety of mediators, in particular mast cells, eosinophils, and T- lymphocytes, which act on target cells of the airways to produce the typical features of asthma [Barnes 1996:4]. The inflammatory process leads to airway hyper-reactivity, plasma excudation, mucus secretion and the activation of neural mechanisms. Airway obstruction occurs due to spasm of bronchial muscle, oedema of the airway, increased mucus production, cellular infiltration and subsequently injury to the epithelium. Classic symptomatic features are wheezing, increased shortness of breath, coughing, chest tightness. Tiredness can sometimes be the only affect some people complain of, especially in young healthy athletes. Chronic inflammation leads to structural changes such as an increase in airway smooth muscle and irreversible fibrosis. There is also increased evidence that transcription factors such as nuclear factor kappa B play a pivotal role in the expression

of inflammatory genes in asthma [Barnes 1996:3]. Epidemiological observation linked IgE antibodies to the severity of asthma.

When inhaled, allergens encounter the dendritic cells that line the airway. This stimulates dendritic cells to migrate to the draining lymph nodes and present the processed antigen to the T- and B- lymphocytes. Interactions between these cells elicit responses that are influenced by cytokines and co-stimulating molecules. Mast cells are stimulated to release histamine and leukotrienes, responsible for airway smooth muscle constriction. This response is called the early asthmatic phase and it may resolve within an hour. After four to six hours, however, a prolonged phase of airflow obstruction may follow, because of cytokines and chemokines generated by resident inflammatory cells [Busse and Lemansky 2001:353]. This is known as the late asthmatic phase and illustrates the danger in situations where an asthma sufferer is not observant and gets caught off guard, especially during the night or early morning. Decline in lung function occurs in all people but even more so with age in adults with asthma. Previous research on asthmatic non-smokers in Australia showed a decline of 50ml/year in FEV_1 compared to 35ml/year in controls. This was confirmed by the Copenhagen Heart Study with values 38ml/year and 22ml/year respectively [Beckett and Howarth 2003:166].

Where acute inflammation in the lung normally occurs in response to tissue injury and repair restores normal function, the same is not true for chronic inflammation. In asthma, the process of chronic inflammation may lead to altered structure, called remodelling of the airways. Remodelling entails thickening of the airway walls, with increases in submucosal tissue, the adventitia and smooth muscle. Although remodelling has been considered the result of inflammation, more recent research indicates that the process of remodelling may be independent of inflammation and part of the natural history of asthma. In part, this may contribute to the persistence of the inflammatory process [Busse and Lemanski 2001:359,

Beckett and Howarth 2003:166]. Whether there exists a mechanistic link between loss of airway function and structural remodelling of the airway early in life still remains to be demonstrated.

Nurses need to be very observant during both phases of the asthma exacerbation as some patients are unable to recognise the differences between the two phases and may insist on early discharge from the emergency unit which may be detrimental to the patient.

2.3.3 Disease Severity in Asthma

The degree of severity of asthma is determined by the amount of airflow limitation and the speed with which the situation is reversed. Severity is determined by the history of frequency and intensity of the symptom profile, bronchodilator needs, limitations to activities and lung function measurements. According to the WHO Global Strategy Management and Prevention of Asthma Report, degrees of severity range between intermittent asthma where symptoms disappear for certain periods of time, and persistent asthma where symptoms never go away for longer than a week [Khaled & Enarson 1996:12]. Persistent asthma is graded as mild persistent, moderate persistent, and severe persistent asthma. Because asthma is a variable disease, patients rarely remain in the same category over time [Mintz 2004:3]. In addition, patients are often categorized incorrectly because they underestimate their symptoms and lung function. Asthma results from the presence of airway inflammation and abnormal airway smooth muscle behaviour. Therefore, severity should be determined by factors that influence both aspects. The degree of inflammation present in the airways may be responsible for increased symptoms and airway hyper responsiveness [Woolcock, Dusser, and Fajac 1998:444]. A study by Bousquet et al [1998:40] showed a heterogeneous inflammatory process in intermittent asthma, the profile and magnitude of which present both similarities and differences compared with persistent asthma. Increased eosinophils are present in persistent asthma as well as epithelial damage. Increasing severity is also likely to

be associated with skin prick test sensitivity to house dust mite and alternaria and, in the absence of parasites, the total IgE level is likely to be a measure of severity [Woolcock et al 1998 :444]. Onset of asthma at an age younger than five years accompanied by a strong family history will also increase the likelihood of severe disease. Assessment of severity will always be difficult until a “gold standard” definition of asthma is formulated.

Determining severity is, however, necessary because all the guidelines for treatment are based on the severity grading of the patient. Health professionals should be aware, however, that lung function measurements do not always correspond with severity or frequency of asthma symptoms. Previous studies of the basement membrane of the airways showed that remodelling occurs in the mildest form of asthma and structural changes can be present very early, or, on diagnosis [Mintz 2004:3]. The severity of disease in adolescents is sometimes enhanced by factors such as non-adherence to treatment regimes. It is a health priority to educate people to understand why their disease can present in different degrees of severity and how to determine in which category they reside. This may be an opportunity to empower patients so that adherence to therapeutic strategies is achieved and to relay to them the importance of environmental control measures.

2.3.4 Diagnosing Asthma

The history of a patient is the key to making a diagnosis. Information should be gathered about past or present history of atopy or multiple episodes of breathlessness, wheezing, nocturnal awakening and coughing and chest tightness. A family history of hay fever, eczema, food allergies or food intolerance should also be determined. The history should also include information about trigger factors and active or passive smoking. Physical examination is seldom diagnostic of asthma because patients may have no chest symptoms during periods of remission. In young, active people information about symptoms during or

after exercise is particularly valuable, because they may only experience symptoms up to 1-2 hours post exercise.

Spirometry should be part of the assessment and should be done pre and post bronchodilator application to confirm reversibility after treatment. Peak flow readings in the morning before treatment, and at night before bedtime may help to determine diurnal variation. Peak flow readings at home and at work are very important during the assessment of occupational asthma. Broncho-provocation tests with the substances histamine and metacholine could be done to confirm bronchial hyper reactivity. A 20% drop in FEV_1 is interpreted as a positive test. In many cases the test is used to confirm or exclude occupational asthma. Exercise testing can be done in patients who suffer from intermittent symptoms to confirm the diagnosis. A chest X-ray is usually not required but should be done in cases where other pulmonary or cardio-vascular conditions should be excluded. The only blood test that probably can confirm the diagnosis of asthma is elevated levels of blood eosinophils.

Asthma can also be under-diagnosed in many instances because of the interpretation of the information that the patient give. In children in particular care should be taken because they may experience wheezing but the source may not necessarily be asthma. Wheezing may be present in the airways for months after a bout of pneumonia, for instance, because of bronchial hyper reactivity that does not resolve immediately. In the past, asthma was also not considered as a diagnosis in the elderly patient. This strengthens the debate for the implementation of national guidelines to ensure prompt identification of asthma sufferers and early commencement of treatment which may protect the airway epithelium from the damage of chronic inflammation which can be difficult to treat once it become fixed.

2.3.5 Management of Asthma

The major goal of any management plan should be to achieve:

- Complete symptom control
- Minimal or no exacerbations
- Restored respiratory function
- Normal activity levels
- Meet satisfaction of patient and family

All of the above will enable asthmatics to function physically as well as emotionally. In addition, relapses should be prevented by appropriately treating inflammation of the airways. Physicians aim to achieve the abovementioned goals with the minimal amount of asthma therapy to ensure minimal or no adverse effects from asthma drugs. However, asthma management should not only be about drug therapy. Every individual should be treated with a holistic approach because both social and psychological issues within a family environment may play a major role in any person's health [Kemp 2002:17].

Asthma patients have to commit to controlling their environment to avoid triggering factors such as pet fur, pollen and smoke. Passive smoking from family members in the home may be particularly challenging to control [Woolcock 1997:161]. Adjustment to lifestyle, diet and exercise regimen may also be necessary. Vaporizers and humidifiers should be avoided in bedrooms because of possible increase in the growth of house dust mite (HDM) and moulds. A vital part of management is rigorous education and training at every contact session. This should be built on a strong positive relationship between the patient and health professionals [Khaled and Enarson 1996:34]. Health education should be directed at enabling a patient to take the responsibility for self management within a community setting. Patients should be

knowledgeable about safe adjustment of treatment according to an individualized action plan.

Coordination of the different levels of care is inevitable because of strained health budgets. In this regard, the role of nurses is underestimated and under-utilized. Referrals should be made to asthma specialists for diagnostic purposes where technical expertise is needed, or, when occupational asthma is suspected. Management of complex cases should also be in the hands of asthma specialists. Whenever reinforcement is needed of compliance issues, inhaler techniques or for patient expectation purposes initial contact with an asthma consultant is most valuable. Once the patient is stable, referral should be back to the appropriate level of care within the health system. Regular follow-up and review visits need to be scheduled according to the patient's needs. Good communication about the reasons for referral, interventions done or planned as well as current health status, will ensure continuance of care for the patient. Patients are the central focus within the asthma care team. Both national and international guidelines advocate a stepwise approach in treating asthma. Asthma sufferers are grouped into different categories according to their symptom profile and lung function measurements as being mild, moderate, or severe sufferers. The working group of the South African Thoracic Society compiled guidelines applicable to adults and children in South Africa and recommended its use in all levels of health care [Lalloo, Bateman, Feldman, Bardin, Plitt, Irusen, O'Brien 2000;90(5):540-542]. It is of extreme importance that all parties concerned in the asthma care team show total commitment to adhere to short and long term treatment goals. Great care should be taken to set realistic, obtainable goals to prevent unrealistic expectations which can lead to disappointments and subsequent rejection of the management plan.

2.3.5.1 Pharmacotherapy in Asthma

Recent research in asthma has explored the possibility of total control based on clearance of clinical features and resolution of pathological changes in the airway ("pathological control") [Irusen 2003:36].

Understanding of the concept "control" may be completely different for asthmatics in comparison to the view of health professionals. The implementation of glucocorticosteroids as asthma therapy changed the world of asthma sufferers. Guidelines now recommend inhaled corticosteroids as the mainstay of therapy. Initiation should be started as early as possible to inhibit the inflammatory processes and to prevent possible remodelling caused by chronic inflammation. Inhaled steroids are used as preventer therapy but oral bursts of steroids are used during acute attacks.

B adrenergic receptor agonists are used as bronchodilators and is the reliever therapy recommended in case of emergency. Bronchodilators activate the receptor which increases cyclic Adenosine mono phosphate (AMP) which, in return, decreases intracellular calcium and leads to relaxation of airway smooth muscle.

Theophyllines are not used as often as in the past due to a narrow therapeutic range and unfavourable adverse effects. They inhibit phosphodiesterase and relaxes smooth muscle and acts as a respiratory stimulant. It can be valuable in patients who suffer from nocturnal coughing and increased phlegm production and is more frequently used as add on therapy in Chronic obstructive pulmonary disease (COPD). The latest research started using this compound as inhaler therapy which may present to patients yet another treatment option if it is proven to be effective.

Chromones act as mast cell stabilizers and, inhibit the release of mast cell mediators. This is usually used as add on therapy or in cases where atopy is a problem.

Leukotriene modifiers have been used as add on therapy in uncontrolled asthma sufferers since 1995. They are thought to reduce the influence of the inflammatory cascade caused by leukotrienes, preventing bronchial hyper reactivity and airway remodelling. It is very expensive treatment and therefore not available in the public health sector.

Combination therapy **(**also known as controller therapy), was started to achieve better asthma control with the combination of a long acting bronchodilator and an inhaled corticosteroid. Using only one medication device once or twice daily may improve patient compliance and adherence to the dosing regimen. More recent research showed an association between asthma and the gene ADAM 33. Future development will naturally target these proteins as treatment options [Beckett &Howarth 2003:170].

The treatment profile differs between patients because people present with different degrees of severity. All asthma sufferers should have at least a short-acting bronchodilator such as Ventolin for use during emergencies. Depending on the availability of resources, patients are treated with an inhaled corticosteroid (Beclomethasone, Budesonide) as maintenance therapy. As severity increases, the other substances will be added on under the guidance of a respiratory specialist (eg.Theophylline, Xolair). Oral glucocorticosteroids are used during exacerbations in the form of burst dosages that are quickly titrated (eg.40, 30, 20….), or, a course for 5 to 21 days depending on the severity of the asthma exacerbation.

The recent trend is to use combination therapy in an effort to simplify a treatment schedule and to try to overcome the problem of non-adherence to treatment. This, however, is a very

expensive option and may be out of reach for the people who rely on the public health system for their monthly medication supplies.

2.4 KNOWLEDGE AND ASTHMA

Asthma management has been revolutionized in recent years, especially with the introduction of both national and international guidelines. More emphasis is now being placed on patient self-management. However, these initiatives are not always successfully implemented and severe asthma attacks are not completely prevented. Gottlieb, Beiser, and O'Connor [1995:28] tried to determine which key factors acted as barriers to the optimal management of asthma. Major barriers implicated by the group were financial constraints, language problems and education. Educational barriers mirror:

- Impaired ability of patients to understand the advice given to them by health professionals.
- Inability to learn the necessary self-management skills.

Lacking ability in the abovementioned areas leads to frequent presentation at the emergency departments for asthma-related reasons, or subsequent hospital admissions.

The relationship between education, knowledge, illness behaviour and morbidity remains unclear. The traditional educational strategies were to teach patients about the patho-physiology of a disease, how the different drugs work, and how to avoid triggers of the disease. If one applies this to asthma, the majority of sufferers will confirm that they perceive the information as rather overwhelming, regardless of their educational level. Patients in general are poor at applying knowledge to action [Kolbe, Vamos, Frances, Elkind, andJeffery 1996:88].

The objectives of appropriate management of asthma are not only to internalize sufficient knowledge to be able to interpret any change in daily symptoms and lung function, but also to develop a positive approach, enabling the asthmatic to apply problem-solving skills necessary for truly effective self-regulation [Adams, Smith, and Ruffin 2001:130] and to embark on therapeutic measures. Kolbe, Vamos, Ferguson and Elkind [1998:18] confirmed the considerable gap that exists between knowledge of asthma and actual patient behaviour. Previous work by other researchers also confirmed that there is an association between the increased risk for asthma-related hospital admissions and lower decision-making autonomy preferences [Adams, Smith, Ruffin 2001:130]. Delays in starting the appropriate therapy during acute severe attacks are also a reason why adverse asthma outcomes are experienced. Lack of knowledge about the respective therapeutic modalities causes grave concern, because it is well-known that patients sometimes stop their treatment in error for this specific reason. Lack of knowledge creates fear, and fear influences the behaviour and attitudes of a specific patient. Health-care workers should be sensitive to this issue [Adams et al 2001:130]. One should supply patients with the appropriate information if one wants them to achieve good control of their asthma. Poor control is influenced by non-compliance, inability to recognize severity, and under-treatment [Bosley, Fosbury, Cochrane 1995:904]. Boulet [1998:587] also implicated lack of knowledge or understanding of asthma and its treatment as the reasons for non-adherence to therapeutic regimes or misuse of therapy. A review of interventions aimed at improving compliance through education had very negative results with less than half of the interventions having an effect. The poor results indicate that asthma knowledge may not be a strong predictor of compliance [Balkrishnan and Gunigati:2003: 19].

It is important to determine the level of patient knowledge of their asthma as well as assessing feelings and acceptance of the diagnosis. Only then can one truly reinforce appropriate, factual information to try to persuade patients to adjust their lifestyle. All asthma

sufferers should obtain the information and skills needed to equip themselves for the prevention and control of their disease. Insufficient knowledge, poor attitudes and improper beliefs are major stumbling blocks to the self-management of asthma [Markson et al 2001:382]. The cornerstone of a successful management regime is optimal patient education.

2.5 CONTROL OF ASTHMA

Despite asthma being highly prevalent in South Africa, the disease has assumed a low priority both locally as well as in other Sub-Saharan African countries [Zar, Stickels, Toerien, Wilson, Klein, and Bateman 2001:2]. There has been some limited improvement in the management of asthma, access to health care, and affordability of treatment. Asthma medication is costly and can place a great financial burden on sufferers and their families. All the current asthma guidelines advocate the importance of self-management in the overall treatment of asthma as poor self-management has been linked to poor outcomes of the disease. Control of the disease and self-efficacy are often seen as related concepts. Control is an indication of an individual's ability to handle disease. Self-efficacy on the other hand focuses mainly on the control and exacerbation of each symptom [Katz, Yelin, Smith and Blanc1997:581]. Being self-efficient means that the individual believe that he can perform a specific task, or adopt certain behaviours to empower himself. Katz et al [1997:581] also observed that, with greater perceived control, asthma sufferers had:

- Less severe asthma
- Greater asthma self-efficacy
- Lower perceived severity and danger of asthma
- Better functioning and better quality of life.

Vollmer, Markson, O'Connor, Sanochin, Fitterman, Berger and Buist [1999:1647] debated the current lack of distinction in the literature between underlying disease severity and the level of asthma control. These researchers advocated asthma control as an important vital sign similar to pulse rate, blood pressure and peak flow measurement. Their suggestion was that asthma control should be determined at every follow-up visit to demonstrate patient progress over time. The level of asthma control reflects current functioning and may (because of disease variability) change remarkably over relative short time frames. Control portrays current asthma status. Having control over symptoms and minimising the effects of disease on the patient are usually the main objectives of therapy. Emphasis on preventative disease management has also increased [Vollmer et al 1999:1647] in recent years. Patient adherence, medical management and disease severity collectively forms the sum total of level of control. In theory, a directly measurable phenomenon, but one should never forget to take into consideration the fact that control per se is a multi-dimensional concept [Vollmer et al 1999:1650] and lend itself to different interpretation of reality.

Uncontrolled asthma puts patients at risk, increases asthma-related health care utilization, and has further financial implications for families. Kips and Pauwels [2000:797] summarised the findings of the AIRE study (an international study conducted to access the reasons for lack of control in asthma patients) as follows:

- Despite experiencing symptoms, patients perceive their asthma as being well-controlled.

This means that there is under-reporting of symptoms to physicians. Similar findings were noted by a study done by Osman [2002:190].

- Follow-up of patients is insufficient.

This conclusion is based on the fact that 60% of all children and 45% of adults had never had their lung function tested.

- Patients expect asthma to cause a certain degree of disability.

Asthmatics, in general, accept a certain amount of symptoms and discomfort as normal for them. They then adjust their lifestyles accordingly to enable them to cope with their limitations on a daily basis. All current asthma guidelines, however, emphasise the fact that:

Asthma should not inhibit normal physical activities provided that the disease is properly treated.

- Absence of proper treatment

The Aire study reported that, although the majority of asthma sufferers used their short acting bronchodilator, only 25% of them used inhaled corticosteroids. A recent Canadian study also reported that

- The majority of patients still do not understand why they should be on inhaled corticosteroids;
- Major fears still exist concerning all the side-effects of steroids;
- The mere fact that inhaled corticosteroids are expensive actually contributes to poor patient compliance.

A change in both patient and health professional approach is desperately needed. Health professionals do not know if the patient is right or wrong in increasing or decreasing treatment at will. Education should be able to assist the patient to improve the overall degree of disease control [Kips and Pauwels 2000:797]. A large population study done in Oregon (USA) concluded that there is a highly significant association between asthma control and quality of life [Vollmer et al 1999:1647].

Findings were similar for both the younger and older than 50 years patients. Markson, Vollmer, Fitterman, O'Connor, Narayana, Berger, Buist [2001:379] surveyed 5181 patients to determine the association between patients' dissatisfaction with their treatment and their

reported levels of asthma control. When there were problems with control, dissatisfaction in general was higher. Patients reported the greatest percentage of dissatisfaction when their physicians did not include them in the treatment decision-making process [Markson et al 2001:382].

To supply patients with strategies they can follow, and which they believe will control their asthma, is of utmost importance. Better patient knowledge, improved communication between patient and caregivers are associated with a decrease in the utilisation of emergency rooms and admissions to hospital for asthma-related reasons and result in cost-saving and thus a better quality of life [Forshee, Whalen, Hachel, Butt, Smeltzer, Martin, Lavin, Buckner 1998:82-92].

2.6 UNCONTROLLED ASTHMA

Asthma is a variable disease with periods of exacerbations and remission. In some patients periods of remission never happen in spite of maximal medical treatment. These patients are prone to persistent symptoms such as nocturnal awakening due to asthma, need of bronchodilators more frequently, inability to do daily activities and exercise and are repeatedly on the brink of life-threatening attacks. This scenario is referred to as “BRITTLE ASTHMA” and patients have more presentations at emergency departments and hospitalization for asthma which can end in near-fatal attacks or admissions to intensive care units. Poor compliance is sometimes the only reason why control cannot be achieved and is probably the easier one to correct. Other differential diagnosis such as atopy, sleep apnoea, gastric oesophageal reflux or food intolerance may be complicating factors. Social problems can also cause a problem, especially in women who for specific environmental reasons are very emotional. In some instances the underlying severity of asthma may be the reason for apparent failure of treatment [Ayres 1997:127]. Asthma sufferers who continue to smoke

respond less well to asthma therapy and may be prone to uncontrolled asthma but this has not yet been proved conclusively [Calverley 1997:167]. A series of Australian studies found high rates of anxiety and panic disorder among people who suffered near-fatal episodes. Ayres and co-workers studied a UK population and found a high prevalence of psychiatric symptoms and psychiatric morbidity in patients with brittle asthma [Osman 2002:190]. Anxiety is not always higher in poorly controlled asthma because Barboni as quoted by Osman [2002:190] found no difference between asthmatics and a group of matched controls. Some researchers demonstrated that some anxiety can actually be useful in self-management because anxious subjects were more accurate in detecting changes in lung function. Denial of asthma symptoms and over-confidence about ability to control asthma may lead to a false sense of security and subsequent delay in taking action and non-compliance which may be the reason for uncontrolled disease [Osman 2002:191].

2.7 PATIENT ADHERENCE/COMPLIANCE

Patient adherence or compliance is a dynamic process and is affected by a multitude of issues relating to the patient, the physician, and the treatment of a chronic condition such as asthma. The effectiveness of therapy as a long term solution depends on how well the asthmatic adapts to his/her new life with asthma as well as a willingness to accept treatment recommendations. Compliance has to do with behavioural issues such as smoking, exercise, care seeking, alcohol consumption, diet and also socio-cultural issues such as attitudes and health beliefs, educational achievement, and household income. Biological factors such as ethnicity, gender and family structure influence compliance to a certain extent, because patients may reject information if it does not come from someone with a similar ethnic and cultural background as themselves. This can be particularly difficult in a multi-cultural society like South Africa.

"Poor compliance is a problem that can span across health conditions and has proven to be a particularly salient problem in the treatment of chronic conditions such as asthma. Non-compliance is considered the leading factor in poor asthma control"

[Balkrishnan& Guniganti 2003].

Non-adherence (non-compliance) manifests as:

- Primary = patient does not get prescription or does not attend follow-up
- Secondary = medication and treatment is not taken as prescribed
- Intentional = patient rejects the diagnosis and treatment of asthma
- Unintentional = patient would have taken therapy but has been prevented by

demographic, social, or clinical variables and influences such as dollars to pay scripts

It is very important for health professionals to be aware of the fact that adherence may shift over time because the circumstances and level of severity of the patient may change constantly. Health professionals expect patients to adhere to the complex interrelated behaviours required for compliance to:

- Medication, techniques for application, application devices
- Written management plan
- Follow-up appointments and regular reviews
- Trigger avoidance strategies
- Peak flow monitoring and symptom recording

The plea for adherence/compliance however competes with all the social issues, personal problems, and cultural lifestyle factors which constantly influence patients' choices and behaviour [Toelle, Peat, Dunn 1998: NAC Webpage]. Every patient is different with regards to:

- Beliefs about asthma and health
- Aspirations and goals
- Daily routine

- Capacity to adhere

Central to the problem of non-adherence is communication. Health professionals should equip themselves to be able to communicate with patients in their language of choice, taking into account patient aspects such as literacy skills, cultural background and age when they provide asthma education.

Asthma is a manageable condition but is also prone to patients being non-adherent to treatment regimens due to the following factors. Inhalation therapy is the mainstay of treatment and is very dependant on a patient's application technique. Secondly, preventer treatment should be continued even when the patient is well and asymptomatic. Patients have real and imagined beliefs about the adverse effects of asthma therapy. Patients calculate the cost of their asthma therapy against the benefits they will perceive for being compliant. There may be discrepancies between patient goals and those of the health professionals due to different beliefs about the diagnosis and treatment modalities. Patients may find it difficult to remember and understand concepts such as relievers, preventers, and controllers and may be overwhelmed by the amount and complexity of information they encounter [Toelle et al 1998]. Health professionals have to take into consideration behavioural and environmental factors which impact on adherence. Every individual should have a treatment plan that fits in as best as possible with that person's lifestyle and aspirations and that address feelings such as fear and loss of control. Acceptance, knowledge and self-awareness will aid self-management to be in control of asthma rather than being controlled by asthma.

2.8 QUALITY OF LIFE

In health care today, there is a growing appreciation for the importance of patient's feelings and how satisfied they are with their treatment [Higginson and Carr 2001: 1357]. Making use

of quality of life measures in the clinical setting, ensures that the focus is on the patient and not on the disease or its treatment alone. However, quality of life measures alone cannot capture all the important aspects of life, important to individuals. For asthmatics to have a good quality of life other aspects also need to be addressed. This includes information about a person's knowledge of the disease as well as aspects of asthma control. People with poor perceptions of asthma symptoms and asthma control seem to have an increased risk of an asthma attack [Hofland, Cloosterman, Folgering, Akkermans and Van Schayck 1999: 15]. The sequence of events exists not as continuum but rather as a circular spiral.

2.9 ASTHMA AND QUALITY OF LIFE

The need for outcome measures other than morbidity or mortality has been obvious for years. It is, however, very important to avoid simplistic approaches to quality of life [Greer 1987:629]. Clinicians and methodologists should have consensus on the definition of quality of life and the core component variables. Quality of life instruments provide physicians with valuable information yet these tools are not intended to replace clinical judgment. Quality of life instruments assist with the structuring and transmission of clinical information, which actually enhance their credibility [Greer 1987:630].

Asthma is a disease that imposes a huge burden on the well-being of patients and society as a whole. Quality of life explores general well-being from the different domains of physical status, psychological impact, and social interactions [Malo, Boulet, De Witte, Cartier, L'Archeveque, Cote, Bedard, Boucher, Champagne, Tessier, Juniper and Guyatt 1993:1121]. Quality of life reflects the perceptions and adaptations to the functional consequences of a chronic disease like asthma. Clinical and functional variables arguably are only an impairment that is secondary to chronic conditions [Malo et al 1993:1126]. It is well known that asthma is a chronic condition in which social life is altered. The importance

of these restrictions on social life can be illustrated by the impairment suffered by subjects with severe disease or uncontrolled symptoms [Bousquet et al 1994:371]. It is equally well known that people usually only consult their physician once their quality of life is affected by their disease [Van den Boom, Rutten-van Molken, Tirimanava, Van Schayck, Folgering, Van Weel 1998:67]. Asthma treatment is directed towards the improvement of a patient's health and well-being. Measurements of airways functioning (spirometry) do not always reflect the amount of disease activity present in the airways. Spirometry correlates poorly with health and patients care is complicated by the fact physicians use different criteria to estimate health.

Quality of life questionnaires provide a method of quantifying the effect of disease on a patient's life. These instruments have the potential to identify a threshold response to treatment that may be considered worthwhile and allow for comparisons between therapeutic strategies with regard to the health gain each strategy provides [Jones, Quirck, and Baveystock 1994:79]. A basic principle of quality of life measurement is that it should be assessed from the view of the patient. Research evidence suggests that the patient's view of health may change as the disease progresses and they adjust their perception of what "normal" entails. A strength of quality of life instruments is their ability to give a valid global assessment of the overall effect of the disease on the patient's health and the fact that they have considerable potential to quantify the magnitude of health gains from therapeutic strategies [Jones et al 1994:82]. To date, functional outcomes such as quality of life have not achieved widespread acceptance or use in asthma research. Objections are that these outcome measures do not satisfy accepted criteria for measurement instruments such as sensitivity, reliability, validity, responsiveness and acceptability. There is an emerging need for measurement instruments that will capture changes that are important to patients, particularly changes in the quality of life [Rowe and Oxman 1993:675]. A person's quality of life is an important factor to be considered in making decisions regarding effectiveness of

treatment. The quality of life of this study group has never been determined and, to organize their future care, it was necessary to include this aspect to the research instrument.

Quality of life measures provide an opportunity to consider treatment impacts in various domains: physical, emotional and social [Rowe and Oxman 1993:678]. This, in turn, allows researchers to advance their understanding of underlying biological and social processes. Quality of life instruments may also be able to detect small, but important differences that would otherwise remain undetected by less responsive instruments.

2.9.1 Quality of Life Concerns

Rowe and Oxman [1993:679] described the following reservations regarding quality of life instruments:

- Do the instruments measure what they purport to measure?
- Do the instruments measure the attributes accurately [test-retest] using other observers and settings?
- Do the instruments have the ability to detect changes in patient status as a result of treatment, or over time?
- Can the instruments determine clinically important differences in a specific research setting?
- Can the instruments measure some component of airway inflammation?

Quality of life instruments are acceptable to asthmatic patients. Their properties allow researchers to detect small but important changes in function, previously difficult to determine. Using them as tools allows researchers the opportunity to obtain more clinically relevant information [Rowe and Oxman 1993:680].

2.9.2 The purpose of Measuring Quality of Life

Quality of life measures are important when clinical decisions are made. Patients should be engaged in the process of making treatment choices. Measuring quality of life at a population level helps policymakers to appreciate population trends when allocating funds. Quality of life outcomes provide a broader perspective showing the benefits and satisfaction patients derive from their treatment. This includes monitoring of change over time and assesses relative impact of alternative treatments. Quality of life changes can help to monitor the impact of a change in health-care services on populations under investigation. Quality of life information is also frequently used by the pharmaceutical industry and regulatory authorities to decide which drugs or treatment devices should be developed and marketed, and to assess the relative benefits of various treatment options [Scott and Garrood 2000:666].

2.9.3 Current Application of Quality of Life

According to Scott and Garrood [2000:683] quality of life assessments are currently utilised as:

- Outcomes research methodology to try to define overall outcome in a way comparable to and better than traditional clinical measures.
- Decision-making in the individual patient
- Defining the needs of special groups
- Policy-making showing the impact of management strategies on the population in general
- Prediction of costs or individual resource components
- Development of new drugs or for clinical trial purposes.

Quality of life assessments as a measure of the effect of disease on a patient's health and well-being are considered important tools in clinical studies on asthma [Moudgil, Marshall, Honeybourne 2000:178]. The purpose was also to obtain baseline data in this population for reference in future because the quality of life has never before been studied in this group.

2.9.4 Recent Research Regarding Quality of Life

Work done by Osman, Calder, Robertson, Friend, Legge, and Douglas [2000:501] showed that current respiratory symptoms were associated with impaired quality of life in patients with mild to moderate asthma. Any level of symptom severity had some effect on quality of life, even in people with occasional symptoms. Although men and women had the same level of symptom severity, women reported a poorer quality of life in comparison to their male counterparts. A study by Leynaert, Neukirch, Liard, Bousquet, and Neukirch [2000:1394] reported that quality of life impairment increased with asthma severity. They also concurred that asthma had less impact on quality of life in men. Demographic and socio-economic factors have also been shown to be important determinants of health-related quality of life in asthma sufferers. Lifestyle choices such as smoking are also associated with quality of life. Asthmatics are more likely to have problems with physical activities such as sports and face limitations in their lives every day. Even ordinary activities such as handling a vacuum cleaner can be laborious. Researchers, however should be very careful when they interpret the differences in quality of life scores because statistical significant differences may not be of any clinical value from the patient's viewpoint. Asthma-specific quality of life measures quantify the effects of asthma on the patient's daily life and well-being and the extent to which treatment reduces these effects [Leynaert et al 2000:1391].

Research suggests that there are also perceptual differences in quality of life among persons of different socio-economic and cultural backgrounds. Epidemiological data from the USA states that minority populations bear a disproportionate share of the disease burden of

asthma, with higher prevalence rates, less resources to maintenance care, and more visits to hospitals and emergency rooms. This adversely affects their health-related quality of life [Leidy, Chan, Couglin1998:1082]. In 1992 Weiss et all suggested that social, cultural, and physical environments of the minority and socially deprived groups influenced their symptom recognition exposure to irritants, therapy compliance and care-seeking behaviour, each of which may contribute to the greater disease burden experienced by these populations. Adults with asthma who are economically disadvantaged experience poorer health-related quality of life [Leidy et al 1998:1089].

2.9.5 Assessing Quality of Life Outcomes

As early as 1948, the World Health Organisation (WHO) accepted a new definition of health and, ever since, quality of life of patients has been studied as part of research and health care practice [Testa and Simonson 1996:835]. However, clinical research only started using quality of life assessments in 1973. Based on the WHO definition of health, health-related quality of life addresses social, physical, and psychological domains. Information obtained in this fashion usually reflects different people's beliefs, understanding, and expectations and is subjective in nature. Researchers, however, tried to quantify the information by addressing each domain with a different set of questions. Questions are compiled from responses evaluated as those most important to patients and experts of a particular field of research.

2.9.6 Measuring Quality of Life

Quality of life assessments measure changes in the physical, functional, mental and social health in order to evaluate the human and financial costs and benefits of new programs and interventions [Testa and Simonson 1996:835]. Health-related quality of life moves beyond direct manifestations of illness to study personal morbidity. Quality of life research essentially seeks two kinds of information namely functional status of an individual and the person's appraisal of health as it affects his/her quality of life [Muldoon, Barger, Flory,

Manuck 1998:542]. To a certain extent quality of life is independent of health status, because it reflects on the way a patient perceives and reacts to his health status and also to other non-medical aspects of their lives [Muldoon et al 1998:543]. It really is part of a whole life experience.

2.9.7 Quality of Life Problems in Health Care Practice

In the quest to assess the effectiveness of management strategies for appropriate asthma care, it is important to make sure that these tools measure those aspects of concern to the patient [Marks et al 1993:1103]. The perception that a patient's view is as valid as the clinician when one measures outcomes has a great deal of merit [Leplege and Hunt 1997:47]. Researchers have acknowledged that changes in a patient's quality of life, constitutes the key determinants of the demand for care, adherence to therapeutic regimens, and satisfaction with health care. This led them to use quality of life as a parameter when evaluating health care. Despite the consensus decisions to make use of outcome measures that include the patient's view, there is some doubt as to whether the perceptions can be taken into account if there is no consensus about the conceptual basis for quality of life. Quality of life is derived from a variety of indicators when existing tools are used, but there is confusion between fields of health status and quality of life [Leplege and Hunt 1997:47]. This aspect constitutes a problem for QOL measurements, because comparisons cannot be made if decisions are not shared. The types of questionnaires currently available place enormous emphasis on functional aspects [tasks, occupation, social roles] and sometimes ignore the relevance of such roles to the individual. Patient's views are then still masked by professional opinions. This is a contradiction of the most positive gain from quality of life assessment which is to give the patient a voice even if it is not perfect [Leplege and Hunt1997:50].

2.10 CONCLUSION

This chapter reviewed the literature pertaining to the key concepts of asthma knowledge, asthma control and asthma quality of life. Attention was also given to problems associated with asthma such as adherence, disease severity and uncontrolled disease which influences asthma control as well as quality of life. Chapter Three will introduce the research design and methodology.

CHAPTER 3

Research Methodology and Design

3.1 INTRODUCTION

Chapter Two addressed the literature review on the disease asthma and the many variables that form a part of the intricacies such as asthma knowledge, asthma control, asthma quality of life, and debate about current developments in asthma research. Of special importance is the growing appreciation for the importance of patient's feelings. Accordingly, the focus is on the patient and not on the disease or treatment alone. The research methodology including the design, setting, population, method of sampling, instruments, pilot study, reliability, validity, method of data analysis, and the ethical considerations are described next. Little is currently known about the quality of life of adult asthmatics in South Africa and, therefore, the aim is to describe quality of life, asthma control and asthma knowledge in an adult population attending the respiratory clinic of an academic facility in the Western Cape Province. In addition, the relationship between asthma knowledge, asthma control and asthma quality of life was determined.

3.2 RESEARCH METHODOLOGY

For the purpose of the study, the quantitative approach was used. This approach allowed the researcher to determine facts by means of an objective systematic process. Numerical data were used to obtain the information needed to describe the variables under scrutiny, which is quality of life, asthma knowledge and asthma control. The information will also be used to determine the relationship between the named variables.

Quantitative research is based on rigor, objectivity and control in order to find the objective truth. When a study is conducted about human beings, their behaviour is seen as objective, purposeful and measurable. However, it is essential that an appropriate tool is developed to measure all variables [Burns and Grove1997:28]. Quantitative research also depends on explicit statistics and facts to explain findings. Structured techniques were used to explain the relationship between variables. Quantitative research makes use of deductive reasoning skills. Therefore a body of existing knowledge is needed on which to base deductions [Wilkinson 1991 : 1113]. A well designed deductive study can be replicated by other researchers. Concrete numerical information is needed to support external findings of research projects and treatment protocols. Objective data can provide the reasons for change required in the delivery of nursing care [Wilkinson 1991 : 1113].

3.3 RESEARCH DESIGN

A descriptive design was used to assess asthma knowledge, asthma control and asthma quality of life in a population of adult asthmatics. The design provided an explanation of quality of life in a real life situation [Burns & Grove 1997:4]. An accurate portrayal was gleaned of the characteristics of asthma sufferers, who comprised the study-group. Information gained will provide a knowledge base from which potential new hypothesis could be formulated for further research. In non-experimental research where no interventions are planned, but where the information is needed as a basis for planning future interventions, the survey is usually the method of choice.

For this study the survey was the selected method because the design was descriptive in nature, and the data could be gathered through self-report instead of face to face interview, saving time, money and other human resources.

3.4 RESEARCH SETTING

This specific study used data from a survey in an academic hospital environment. Responses were a self-report from study participants. The Tygerberg Hospital is an academic facility situated in the northern suburbs of Cape Town. The respiratory out patient clinic functions as a referral clinic from the emergency department of the hospital as well as other rural hospitals in the catchment area. General Practitioners also have access to the clinic via referrals. The Day Hospitals situated in the northern suburbs refer difficult to treat patients. All patients who need assessment for disability grants are also evaluated as required by the department of social services. All children treated in the pediatric asthma unit are referred to the adult clinic for follow-up visits once they turn twelve years of age.

3.5 POPULATION and SAMPLE

The sampling process forms an important part of quantitative research. A portion of the study population is selected and their data will then effectively represent the entire population. Researchers generalize the results of the group to a much broader group of people. Central to this issue is the ability of the researcher to identify a representative sample by skillfully minimizing or control standard errors [Polit and Hungler 2001:279]. The population of this study consisted of asthma sufferers between ages 12 to 70 who attended the respiratory clinic for a follow-up visit. No newly diagnosed asthmatics were included. The age distribution gives a true reflection of the patients treated in the respiratory clinic. Once children reach the age of twelve they are referred to the adult clinic for continuation of their asthma management. This period of change may sometimes contribute to non-adherence to treatment because of fear and uncertainty within this new environment. A strict exclusion criteria on smoking was used to ensure no COPD sufferers were included in the sample. For the purpose of this study, convenience sampling was used.

3.5.1 Convenience Sampling

This method entails using the most conveniently available subset of people; also called an accidental sample. Convenience sampling is most commonly used in nursing studies, but is often described as a limited approach because it provides little opportunity to control for biases [Polit and Hungler 2001: 281].The available patient group may be atypical of the population where it concerns the measurement of critical variables in the study groups. However Polit and Hungler [2001:282] comment that where fairly homogenous phenomena within a sample group are investigated the risks of biases are minimal. Researchers, however, need to take the necessary precautions to prevent subtle and unrecognized biases and also take the necessary steps to improve the representativeness of a sample [Burns and Grove 1997: 374]. The convenience sampling method was used because patients were easily accessible and it is an inexpensive and quick procedure. To ensure homogeneity of the group, a checklist was used to identify suitable candidates [Burns & Grove 1997:375]. This method obviously has its intrinsic limitations despite the convenience of its accessibility.

3.5.2 Study population

Asthmatics between the ages of 12 to 70, were recruited from the adult respiratory clinic of the Tygerberg Hospital. Although the upper age limit is quite high, it allowed the inclusion of people with late onset asthma. Possible COPD sufferers were excluded by the strict application of a pack-year value of less than 5 pack years. A total of 100 participants were targeted for enrollment after they qualified according to the inclusion and exclusion criteria (see Chapter One) and gave their informed consent to willingly participate. The sample size was determined by calculating a 20% portion of people who present at the respiratory clinic for their assessments. Screening for suitable candidates was done by the investigator before the regular clinic procedures started over a three month period. To prevent sampling biases and ensure a representative sample, a screening checklist (see Addendum F) was

completed by the investigator on all the subjects identified as potentially suitable. Screening criteria was based on the South African Thoracic Society guidelines and also the American Thoracic Society guidelines [National Institutes of Health. Expert Panel Report 2.1997: 97-4051]. Only one investigator was used to prevent differences in method and to ensure similar explanations were given to all subjects. The disease severity of participants was graded as mild, moderate, or severe based on their FEV_1 values in the respiratory clinic. Mild referred to values above 80% predicted, Moderate to values between 60 to 80% and Severe to values less than 60% predicted.

3.6. PILOT STUDY

To ensure validity of questionnaires, remove complications and difficulties in design, pilot studies are conducted according to the specific needs of the study as a small pre-test. A subsection of the target population was assessed to determine the adequacy of the data collection plan as well as the suitability of the questions to obtain the relevant information required to answer all the questions in the research project. Ten volunteers who adhered to both the inclusion and exclusion criteria were asked to complete the measurement tool. This was to ensure that a 10% portion of the sample actually pre-tested the questionnaire. The resultant information clarified whether respondents understood the questions as well as the prompts supplied to direct them through the process. Volunteers were also questioned following completion of the questionnaire about their impressions of the project and whether the questionnaire contained any areas too difficult or sensitive to answer, or contained offensive information [Polit &Hungler 2001: 320]. No reports of negative experiences were received about the way in which questions were constructed. Based on the findings unclear statements were revised as required. The only area that needed attention was question 2 on the asthma knowledge section where the meaning of the word “vaporizer” was unclear to the participants. The pilot run also determined that fifteen minutes was a reasonable time to

complete the questionnaire. Data from the pilot study questionnaires was also scrutinized with the assistance of the statistician to examine the reliability and validity of the measurement instruments.

All pilot activities were done in the same setting as for the ultimate research population.

3.7 DATA COLLECTION PROCESS

On arrival at the clinic while patients waited in the waiting room, the investigator approached them to inform them about the study and enquired about their willingness to participate. Eligible patients who had been informed verbally and in writing about the purpose, and who had given written informed consent (see Addendum A) were asked to self-complete the questionnaires. Eligibility was assessed by the investigator according to a checklist of the inclusion and exclusion criteria. Patients were advised on how to complete the instruments according to the provided instructions. Any clarifications were made in similar fashion to all participants. Patients received the instrument in their language of choice which was either Afrikaans or English. A quiet environment was provided and there was no contact between respondents during the completion period. Afterwards, the instrument was scrutinized to determine if the patient answered all the different subsets of the questionnaire. Patients were taken to the lung function rooms for assessment of spirometry on the day of evaluation. For FEV_1 the highest value from three repeatable attempts was chosen. Predicted values were calculated according to the ECCS formula [Quanjer, Tammeling, Cotes, Pederson, Peslin, Yernault 1993:5]. All measurements were done in a sitting position and all participants rested ten minutes before the test commenced.

3.8 RESEARCH INSTRUMENT

Quality of life is a multi-dimensional concept and, therefore, information may be interpreted from different perspectives. Researchers tend to re-use already validated questionnaires as measurement tools, either to be completed by the patient as a self-report, or a face to face interview by the researcher. Assessments are usually based on the measurement principal where numbers are assigned to specific responses based on pre-defined criteria. All data are then quantified with the aid of specific set rules. Scales on questionnaires reflect discrete responses such as good, fair, poor, or Likert scale statements of agreement or disagreement for the purpose of rating patient responses [Scott and Garrood 2000 : 664]. Questionnaires specifically designed for this purpose can evaluate health directly. These instruments quantify the effect of disease on a person's daily life and well-being in a formal and standardized way [Jones 1995: 885]. When assessments are made to determine the appropriateness of a questionnaire for use, it is of critical importance that the researcher understands the concepts' sensitivity and specificity. In the study of asthmatic subjects it is even more difficult because of the absence of a "gold standard" definition for asthma. In the past, researchers tested the validity of asthma questionnaires by one of two methods, namely:

(i) Questionnaire responses versus clinical investigations such as meta-choline challenge tests;

(ii) Questionnaire responses compared to the clinical diagnosis of asthma.

The most important aspect of validating a health questionnaire is to test the existence of a relationship between total item scores and severity of the disease [Toren et al 1993:1310]. When researchers used bronchial hyper-reactivity (BHR) as the "gold standard", they were confronted with the reality that not all the people with increased BHR reported coincident experience an increase in their respiratory symptoms. A problem such as this one may lead

to an underestimation of how sensitive the instrument is. According to the literature, none of the currently used instruments are superior to the others. Researchers have to test the responsiveness of a questionnaire and not just assume its efficacy. Studies by Rutten van Molken [1999:995] confirmed that disease specific quality of life questionnaires do correlate with other measures of asthma control. Researchers have little reason to expect that patients will have good quality of life scores and yet, at the same time, have deteriorating asthma. Health-related quality of life questionnaires offer the potential to distinguish between clinically and statistically significant changes with treatment. Instruments may even allow further validation of measures of airways functioning.

The investigator was responsible for the supply of materials needed to complete the questions. Maintenance of confidentiality of information was ensured throughout the study by making use only of a study number and patient's initials.

3.9 DATA GATHERING TOOL

For the purpose of the study, three instruments were fused and used for data gathering purposes namely the; Asthma Quality of Life questionnaire measuring the impact of asthma on quality of life; the Asthma Control questionnaire developed by Elizabeth Juniper to assess control of asthma by the patient; and the Asthma Knowledge tested by means of the Chicago Community Asthma Survey (CCAS-32) developed in Chicago and tested in both a community as well as a hospital setting. The quality of life section has twenty Likert scale responses; the asthma control section consists of seven questions and the asthma knowledge section of thirty two questions. Demographic information was obtained to describe the social variables affecting the population under scrutiny. This was based on a survey questionnaire specifically developed by Steyn and co-workers at the South African Medical Research Council (MRC). Information included age, gender, population group,

family income, education and smoking status. Pack years were calculated according to standard unit practice. A pack year equals the amount of cigarettes smoked per day divided by 20 (one packet) and multiplied with the amount of smoking years.

3.9.1 Asthma Quality of Life Questionnaire

The Asthma Quality of Life Questionnaire (AQLQ), for the purpose of the study, was the disease specific instrument based on the original version of Marks and Woolcock [1993:1111]. The AQLQ is a validated instrument that measures the impact of asthma on the quality of life of adult asthmatics. Assessments are made on four subscales, namely breathlessness, mood disturbance, social disruption, and concerns for health**.** Both qualitative and quantitative methods were used to optimize the construct validity. The responsiveness of the AQLQ was tested against lung-functions, bronchial hyper reactivity and symptoms. All the data supported the continued use of the instrument as a measure of change and outcome of asthma in adults. AQLQ was also tested in both the community and hospital settings, making it a very suitable choice.

3.9.2 Asthma Control Questionnaire

The Asthma Control Questionnaire (ACQ) was developed and validated to measure asthma control in adult asthmatics, by Juniper, O'Byrne, Guyatt, Ferrie, King [1999: 902]. Patients complete the questionnaire in the clinic setting by recalling their experiences of the week prior to the visit. Specific aspects addressed are symptoms, rescue therapy intake, and activity limitations**.** Assessments include measure of FEV_1% predicted values**.** The instrument has seven questions starting with aspects of nocturnal symptoms. Questions are scored on a seven point scale where zero means good control and six poor control. The mean of the seven responses is the overall score [Juniper et al 1999: 1130]. Reliability of the ACQ was assessed from data derived from a stable group of asthmatics. Responsiveness was tested in a group of unstable asthmatics to check whether the instrument could detect

within patient changes. The reliability was estimated as within subject standard deviation. ACQ was found to have good discriminative and evaluative measurement properties [Juniper et al 1999: 1131]. The ACQ is a copyrighted instrument and permission had to be granted to use this instrument. Vollmer et al found that asthma control was an important "vital sign" suitable for both population based management and management of individual asthmatics [1999: 1647]. In this study, asthma control was determined in conjunction with asthma quality of life.

3.9.3 Asthma Knowledge Questionnaire

The American Lung Association of Chicago developed a tool for their Chicago Community Asthma Survey [CCAS-32], to determine people's opinions about asthma. CCAS-32 was assessed to be a useful tool to determine the community's knowledge, attitudes and beliefs about asthma and to determine how the responses differ between different segments of a population [Grant, Turner-Roan, Daugherty, Li, Eckenfels, Baier, McDermott, Weiss 1999: 189S]. The first ten statements about asthma were answered as true or false. Statements eleven to twenty one needed a yes or no response, while statements twenty two to thirty two required a five point Likert scale response which started with never true, rarely true, sometimes true, often true, and always true. The first twenty one questions tested factual knowledge about asthma, while the Likert responses determined people's attitudes and perceptions. This specific questionnaire was an appropriate one to use in the current study population because it resembled the Chicago community in terms of social aspects. One of the recommendations by the Chicago researchers after completion of the instrument was to test it in diverse populations, which was done with this study. To complete this section of the overall questionnaire took about five minutes of the patient's time.

3.10 RELIABILITY

The reliability of research instruments refer to the degree of consistency with which it measures the characteristics and attributes it is supposed to be measuring [Polit and Hungler 2001:411]. The less variation an instrument produces in multiple measurements of an attribute, the higher the reliability of that specific measuring tool. Reliable instruments enhance the power of a study to detect those significant differences or relationships actually occurring in the population under scrutiny [Burns and Grove 1997:396]. Reliability testing examines the degree of random error in the measurement technique and should be completed before any other statistical analyses are performed and recorded in a published report. Specific characteristics equated in terms of reliability are stability, consistency, dependability, comparability, and accuracy [Burns and Grove : 397 ; Polit and Hungler 2001 : 411].

Stability is derived from the procedures that evaluate test-re-test procedures and is also affected by more than one administrator of the instrument. On this study, only one administrator was used.

Homogeneity testing (internal consistency), examines the extent to which all items of the instrument consistently measure construct. This is a most widely used method.

Equivalence also refers to the comparison of two versions when sampling is done by more than one researcher, (called interrater reliability) [Burns and Grove 1997 : 397]. The data was gathered by one person only, therefore explanations to subjects about queries they had were consistent. There was no need to ensure the proper level of agreement as would be the case with more than one data gatherer. Misclassification of participants was also prevented because the same person screened all subjects and a checklist was used to assess suitability [Pak and Adams 1994: 68].

3.11 VALIDITY

The concept validity reflects the degree to which a measurement or study reading comes to the correct conclusion. It is a statement of authenticity because it tells whether the tool measure what it is supposed to measure. In effect this means consistent implementation of measurements. Before engaging into a study, the researcher should measure beforehand the validity of all the instruments. When validity is assessed the researcher actually establishes the parameters' specificity, sensitivity, and the predictive value of a positive or a negative response [Pak and Adams 1994: 67]. All the instruments identified for use in this study as measurement tools had already previously been scrutinized in other studies and their validity as appropriate tools ascertained. Furthermore, the appropriateness of all three of the questionnaires were tested during the pilot study and confirmed as suitable for use in this specific population group. It is very important to remember that no test can be valid without being reliable. The kinds of validity information gathered, depends on the aims of a measurement.

Types of validity tests most frequently used include: content validity, a subjective judgment useful for cognitive assessments. Construct validity starts with a theory and compares observations with responses. To analyse them, different correlation techniques as statistical choices, such as Chronbach alpha or Spearman's rank order correlations are needed. Both of these techniques were used in this study. The Spearman's test is a non-parametric test of association that determines how well ranks agree. Spearman's testing is suitable for variables that are not normally distributed. Criterion-related validity determines how well actual scores relate to predictive scores, for example, the researcher can draw conclusions from the lung-function assessments.

3.11.1 External Validity

Only one researcher was used and that prevented instrumentation influence on the data collector where more experience with the instrument influences the way in which data was collected. External validity was ensured in this study because exclusion criteria were used to provide the homogeneity of the sample. External validity is concerned with the degree in which the study findings can be generalized beyond the population used in the study [Burns & Grove 1997:232]. The study participants in an academic setting by nature make them a very specific type of the population which may not easily be compared to a dissimilar population.

3.11.2 Internal Validity

Internal validity has to do with subject selection and applies to other diseases that could influence the responses of the participants. It determines the extent to which the effects detected by the study are a true reflection of reality [Burns & Grove 1997:228]. All studies should address this concern to prevent false positive or false negative responses. In this study, patients were excluded as subjects if they suffered from concurrent diseases such as cardiac conditions or anaemia that could influence their responses to quality of life questions as well as responses to questions about breathlessness. Instrumentation influence was prevented by the fact that answers were self-reported by the respondents. The environment was controlled to prevent contact between subjects to ensure minimal threat to the validity of the data.

3.12 STATISTICAL ANALYSIS

Descriptive analysis is usually undertaken to obtain a clearer picture of the population under scrutiny. This particular study was completed to quantify the problem of asthma in an adult

population. Descriptive statistics give researchers the opportunity to organize their data in ways that will give meaning and facilitate insight into a phenomenon from a variety of angles in order to understand more clearly what is being seen by way of oversight. The statistical package Statistica version 7 was used for data analysis by the statistician. Only one population group was under scrutiny and, therefore, the findings were explained by means of summary statistics such as:

3.12.1 Frequency Distributions

Frequency distribution is the strategy of choice to organize the data and, also to check for any errors in programming and coding of information. The results will influence all further decisions on how to further analyze the data. Histograms were used to graphically display summaries of the data. This allowed the researcher to relate the findings to the research question and objectives: for example, age in years, men versus women, or, population totals.

3.12.2 Measures of Central Tendency

Numeric presentation of normal distribution to assess patterns in the data and to decide about the most suitable way to describe the data was achieved by making use of mean, variation, and standard deviation. The mean percentage of desirable responses was calculated from the quality of life questionnaire, as well as the asthma control questionnaire. Social demographic differences were summarized and comparisons were drawn between men and women. The participant's age was associated with desirable responses on the questions but responses were also assessed in conjunction with the educational level of the respondents. Correlations were drawn to compare asthma quality of life and asthma severity of disease. Tests of significance were performed by utilising the x^2 or non-parametric analysis of variance.

Although the measurement tools had never been used in a South-African population, their discriminative validity were confirmed for the settings they were tested in. The appropriateness of the different tools was tested for future implementation in a South African context.

3.13 ETHICAL CONSIDERATIONS

Clinical trials should not exploit subjects who agree to voluntarily participate. This is based on the principle of justice and individual autonomy [Shapiro H & Meslin E 2001:139]. The patient's welfare should always be of primary concern and researchers should provide people with sufficient information to allow them to make informed decisions. People should also not be coerced to participate by promises of reimbursement as, not only would this be a removal of freedom of the individual, but it could result in the confounding of results. All clinical research projects need to be presented for ethics approval before study-related events can start. The Internal Review Boards of both the Tygerberg Hospital and the University of Stellenbosch gave their permission for the study to be conducted (see Addendums C and D).

3.13.1 Informed Consent

Participants were given time to read the informed consent document and to ask questions before they committed themselves. All participants younger than eighteen years had a parent/guardian with them who jointly gave consent for participation. Justification for conducting the trial was adequately articulated and the researcher made sure that the research questions were of clinical importance and supplied answers that could be of use to future patients. Patients were informed that there would be no direct benefit or disadvantage to them if they participated or refused. Their health care would not be affected by either course of action.

3.13.2 Ethical Approval

The protocol was presented for review to an ethics committee who had the responsibility to protect humans by giving their approval to the implementation of the protocol. The institutional review board of the University of Stellenbosch as well as the Tygerberg Hospital respectively granted ethical approval for this study to be completed [see addendums C and D]. The Human Research Ethics Committee reviewed the protocol as well as the screening checklist, informed consent document, and the respective questionnaires. Patients were allowed to give/refuse consent for their information to be used for publication and at research meetings as presentations. This was included on the document used for study purposes. Ethics committees should ensure that participants are drawn from a broad enough cross-section of the population to allow the researcher to apply findings to the general population. The safety of subjects should also be ensured and procedures must be in line with cultural acceptability, local customs, conditions, and ethical requirements for the country [Shapiro and Meslin 2001: 139].

3.13.3 Confidentiality

Researchers must ensure that there is adherence to confidentiality principles. No personal information obtained during the study will be revealed in reports or publications that may emerge from this study. All study-related health information was kept strictly confidential and was not accessible to unauthorized parties. All patients consented to their data being used in a publication (see informed consent document). Individual results of participants will not be available. However, general information about the study may be available on request.

3.13.4 Anonymity

No individual who participated in this study will be identifiable in published data that may develop from the study findings. The researcher used only the participant's initials and a study number to identify different volunteers for data capturing purposes.

3.14 SUMMARY

The research methodology and research design that was implemented to obtain the information needed to describe the asthma knowledge, quality of life, and asthma control of a population of asthmatics who attend the respiratory clinic of an academic facility has been discussed. Disease specific instruments previously tested for reliability and validity were utilized as measurement tools. How applicable these instruments were for use in a South-African population was tested in a pilot study by the researcher on a subset of people representative of the target population. Chapter four will report on the process of data analysis and the statistical assessments done to describe the findings and to draw the relevant comparisons between the specific data sets.

CHAPTER 4

DATA ANALYSIS AND FINDINGS

4.1 INTRODUCTION

This chapter presents a summary of the data analysis and findings of the study conducted to assess the asthma knowledge, asthma control and asthma quality of life in a population of adult asthmatics. The relationship between knowledge of asthma, asthma control and asthma quality of life was also determined.

Data collection was done using a self-administered questionnaire completed by patients. The aim was to complete 100 questionnaires or to do the survey over a three months period, and the study was subsequently completed after three months. Of the ninety one (91) questionnaires handed out to potential participants, eighty nine (89) were acceptable for data analysis. One person did not return the questionnaire and one recruit was omitted from the analysis, being a person suffering from COPD and not asthma. The questionnaire had four sections, namely a section to confirm that the person suffered from asthma, a section to gather information about the person's knowledge of asthma, a section to gather information about the person's asthma quality of life, and a section to gather information about the person's asthma control.

4.2 SELECTION OF SUBJECTS

4.2.1 Screening Process

A screening checklist was used to ensure that patients identified as possible participants really suffered from asthma (see Addendum F). The participants supplied the information to the researcher verbally; the researcher ticked the checklist and then confirmed the

responses against the information available on the clinic records. Criteria on the checklist were based on the South African Thoracic Society (SATS), (and American Thoracic Society (ATS) guidelines, used by respiratory physicians to assist them in confirming the diagnosis of asthma. Question one and its subsections addressed asthma symptoms such as recurrent episodes of coughing, wheezing, chest tightness and breathlessness. Participants also indicated whether symptoms worsened at night or worsened and occurred in the presence of exercise, viral infections, animals with fur, house dust and pollen. Information was also obtained to confirm a positive skin prick test to common allergens and a family history of asthma, hay fever and or eczema. The figure (4.1) illustrates a summary of the screening data.

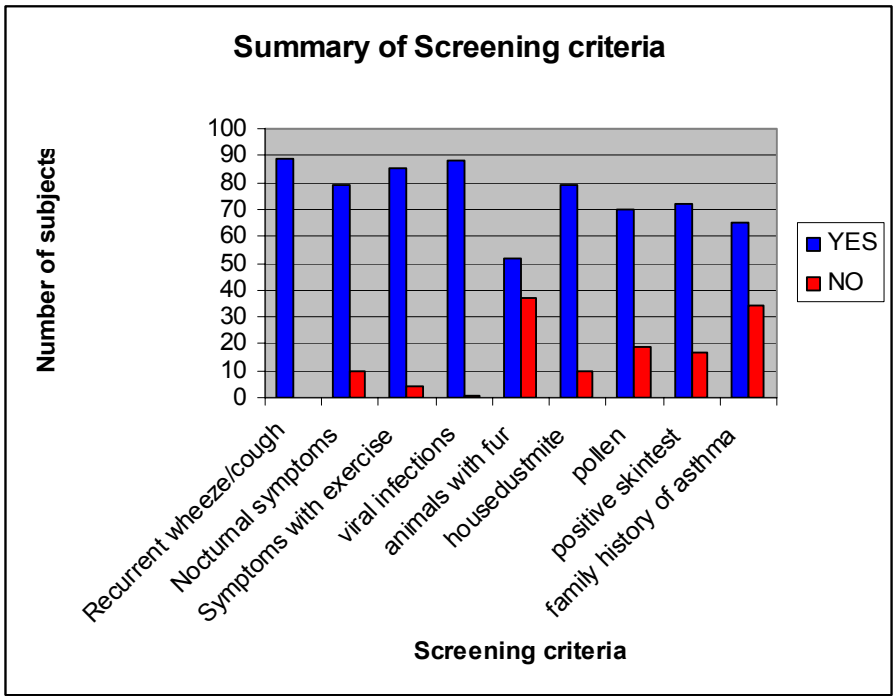

Figure 4.1 Summary of screening data

Question two documented the absolute value and percentage predicted value of FEV_1 on admission to the clinic as determined from the clinic record. This information was used to categorize participants into mild, moderate and severe asthma groups where mild was indicated by readings of 80% and above, moderate by 60 to 80% and severe by values less

than 60% of predicted lung function values. This information is displayed on the pie graph in figure 4.2

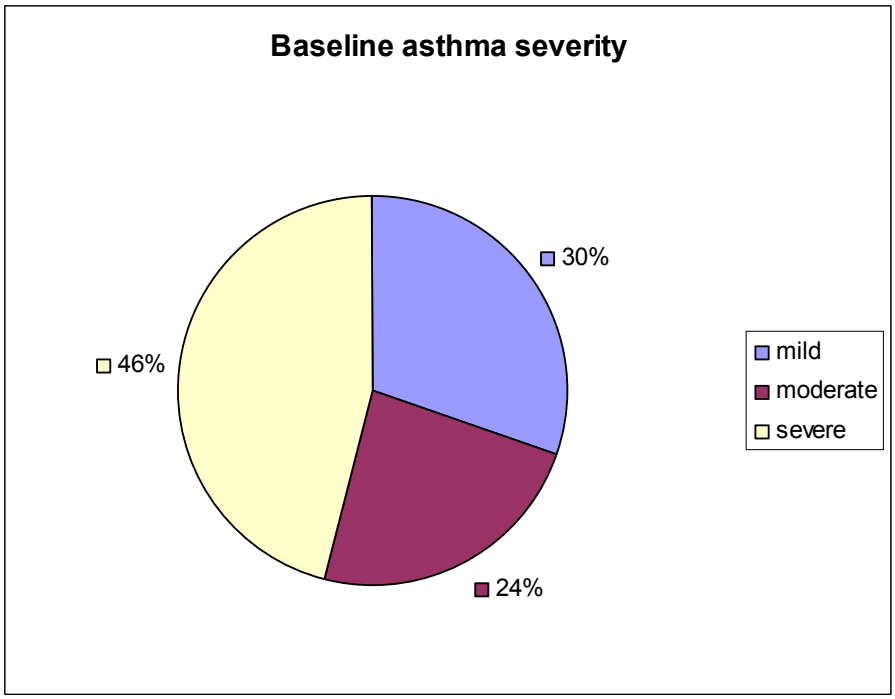

Figure 4.2 Baseline categorization of Asthma Severity

Asthma severity on presentation to the clinic was mild in 30% of respondents, moderate in 24% and severe in 46% of respondents as measured by FEV_1values and determined by ECCS standards. All patients who are treated for asthma need to be categorized according to severity of disease in order to adhere to national asthma guidelines when asthma management is planned for each individual. Questions three to six determined reversibility of lung functions after treatment with bronchodilators and or a course of corticosteroids. The presence of reversibility in the airways usually confirms the diagnosis of asthma because COPD is seen as a disease of irreversible damage to the airways due to smoking and other causes such as occupational exposure to asbestos.

4.2.2 Demographic profile of Study population

The demographic profile is used as a basis for the research. The study population consisted of all asthmatics between the ages twelve to seventy who attended the respiratory clinic for a scheduled follow-up visit. Patients are referred to the Tygerberg Hospital from the practices of General Practitioners in the surrounding urban and rural areas as well as day hospitals from the Northern suburbs of Cape Town. The hospital is used by all the different ethnic groups of the country but favours the Coloured population because of the location of the hospital. All patients who present at the emergency department of the Tygerberg Hospital with acute exacerbations are also referred to the respiratory clinic within a month of presentation for assessment and management until their disease is evaluated as being stable. They are then usually referred back to the Day Hospital system or a General Practitioner if preferred.

4.3 DATA COLLECTION TOOL

4.3.1 Questionnaire about Knowledge of Asthma

The first objective of the study was to establish the knowledge of asthma sufferers in the identified study population. To obtain this information a questionnaire, based on the Chicago Community Asthma Survey (CCAS -32) was used to assess participant's knowledge and perceptions about asthma in questions one to ten. Questions eleven to fifteen listed things that may or may not be a sign of asthma. Triggers of asthma were handled in questions sixteen to twenty one and statements twenty two to thirty two addressed management strategies and opinions about asthma care. Answers were indicated as a true or false statement. A total score was calculated out of thirty two with a high score indicating good asthma knowledge and a low score poor asthma knowledge. As this sample represents the knowledge of asthma sufferers, the researcher assumed that the knowledge score could be

on the higher end of the scale because some knowledge could have been gained from a patient's own experiences. However, the education level of respondents had to be determined and taken into consideration as well, in order to ascertain the susceptibility to assimilate educational information.

4.3.2 Questionnaire about Asthma Quality of Life

The second objective was to determine the asthma quality of life of the study population.

The Asthma Quality of life Questionnaire (AQLQ), first compiled by Woolcock and co-workers Marks and Dunn [1993:1103- 1111], is a validated disease-specific measurement tool and was used to learn about the ways in which asthma affects the lives of people suffering from the disease. A series of statements describes the way in which the disease or its treatment affects asthmatics. It was expected that the respondent would tick the response to each statement which applied to his/her situation best for the four weeks prior to the clinic visit. Responses were indicated on a scale from one to five ranging from "not at all, mildly, moderately, severely to very severely." Statements included symptoms, restrictions of activities, feelings about the disease, impact on social life, and concerns about the future. Subset scores were added and divided by 20 to obtain a mean AQLQ score per individual case. A high asthma quality of life score indicated poor quality of life and a low asthma quality of life score indicated good quality of life.

4.3.3 Questionnaire about Asthma Control

The third objective was to assess the control of asthma as perceived by the study population. For this purpose, a section of the questionnaire described how participants felt during the week prior to the clinic visit. The questionnaire, a validated disease- specific instrument was compiled by Juniper, O'Byrne, Guyatt, Ferrie, and King [1999:902-907]. It consisted of 6 questions addressing nocturnal symptoms, early morning symptoms, limitation to activities, shortness of breath, wheezing, and bronchodilator use. Question seven

indicated persentage predicted FEV_1 value on the day of the clinic visit. The values were calculated by the researcher and completed on the questionnaire. Lung function testing was conducted by a registered clinical technologist. European Community for Coal and Steel (ECCS) data was used to determine predicted values [Quanjer, Tammeling, Cotes, Pederson, Peslin and Yernault 1993:5].

Internal consistency of the questionnaires was confirmed by high values of Chronbach alpha (0,95) confirming their suitability for use in the study. A pilot study was also administered to ascertain that the measurement tool was appropriate for implementation in this particular study group (3.3.3). Pilot studies are frequently used to uncover important variables that the researcher would not have thought of initially. In this instance, none were found.

4.4 DATA ANALYSIS AND FINDINGS

4.4.1 Study Population

The volunteers for this study were obtained from an adult respiratory clinic at an academic facility. Asthmatics between the ages twelve and seventy were recruited. Recruitment duration was the three month period between October and December 2002. In total 91 subjects were recruited, but only 89 respondents were eligible for data analysis. The following table 4.1 illustrates the demographic profile of the respondents

Table 4.1 Study population demographics profile

SUBJECTS (N)	N=89	%
GENDER:		
Male	16	19%
Female	73	81%
MEAN AGE (yrs)	39.8	
ETHNICITY		
Coloureds	78	88%
Caucasian	6	7%
African	5	6%
SMOKING		
Non-smokers	64	72%
Ex-smokers	25	28%
*current smokers excluded		
EDUCATION		
Primary	23	26%
Secondary	58	65%
Tertiary	8	9%

The sample consisted of 89 eligible subjects, Females 73 (81%) and Males 16 (19%). Their mean age was 39.8 years. When participants were categorized into age groups, 4 subjects represented the 12 to 20 age group, 27 the 21 to 35 age group, 43 the 36 to 50 age group and 15 the 50 to 70 age group The fact that the sample favoured females was completely coincidental and the researcher attributed this to the strict exclusion criteria on smoking. The greater portion of the sample consisted of Coloured people reflecting the location of the hospital. Non-smokers were represented by 72% of participants and 28% of participants were ex-smokers. Ex-smokers were included only if they had a less than 5 pack year history. The majority of participants indicated that they had an income of less than R12 000 per year with 37 (42%) receiving a social grant as their only method of income and 14 (16%) indicated they had no means of income. However all participants indicated they had exposure to schooling with 23 (26 %) at primary, 58(65 %) at secondary and 8(9 %) at tertiary level. The researcher did not consider using education as one of the exclusion criteria because it would not have been an accurate representation of the people that use the respiratory clinic as a health facility. Table 4.2 illustrates the distribution of FEV_1 values as calculated for males and females.

Table 4.2 Distribution of FEV_1 Values

VARIABLES	N=89	MALES	FEMALES
MILD = >80%	28 (30%)	6 (38%)	22 (30%)
MODERATE= 60-80%	21 (24%)	4 (25%)	17 (23%)
SEVERE=<60%	40 (46%)	6 (38%)	34 (47%)

Asthma severity at the clinic was mild in 30%, moderate in 24% and severe in 46% of respondents as determined by FEV_1 values measured on the day of first review at the respiratory clinic. This finding of 46% of participants in the severe asthma group may be an indication of uncontrolled disease that needs specialist involvement or a sign of the degree of patient non-adherence with existing asthma management strategies.

4.4.2 Findings on Asthma Knowledge

An adapted version of the CCAS-32, a questionnaire formulated by Grant, Turner-Roan, Daugherty, Li, Eckenfels, Baier, McDermott and Weiss [1999:178], in a Chicago community and tested for suitability, was used to assess the asthma knowledge of adult asthmatics attending the respiratory clinic of an academic facility. The participants reflected their responses by indicating statements to be either “true” or “false” or “yes” or “no” where appropriate. Table 4.3 illustrates patient responses to the asthma knowledge questionnaire.

Table 4.3 Patient responses to Asthma Knowledge Questionnaire

QUESTIONS	PATIENT RESPONSES			
	TRUE	FALSE	% TOTAL TRUE	% TOTAL FALSE
1. Asthma cannot be cured	50	39	56	44
2. A vaporizer is good treatment for asthma	79	10	89	11
3. People with asthma cannot exercise or play	45	44	51	49
4. When a person with asthma is doing well they do not need to go to their doctor	29	60	33	67
5. Asthma is a common reason for many school absences	58	30	65	34
6. Asthma tend to run in families	81	8	91	9
7. Asthma is mainly an emotional illness	56	31	63	35
8. When asthma attacks stop, you don't have asthma anymore	9	80	10	90
9. If you have asthma, you would know where to go for treatment	87	2	98	2
10. You can't have asthma as an adult without having it as a child	16	73	18	82
	YES	NO	% TOTAL YES	% TOTAL NO
11. Is shortness of breath a sign of asthma	80	9	90	10
12. Is tightness in the chest a sign of asthma	82	7	92	8
13. Are severe headaches a sign of asthma	18	71	20	80
14. Is a cough at night a sign of asthma	49	40	56	44
15. Is wheezing after exercise a sign of asthma	82	7	92	8
16. Are pets with fur a trigger of asthma	78	11	88	12
17. Are mosquito bites a trigger of asthma	14	75	16	84
18. Is dampness a trigger of asthma	74	15	83	17
19. Are cockroaches a trigger of asthma	17	71	22	78
20. Is poor diet a trigger of asthma	22	67	25	75
21. Is pollen a trigger of asthma	78	11	88	12
	TRUE	FALSE	% TOTAL TRUE	% TOTAL FALSE
22. Hospitalization for asthma are preventable	69	19	79	21
23. Asthma symptoms can be prevented by the right medications	84	5	94	6
24. People with asthma who get relief from over the counter drugs still need to see their doctor	80	9	90	10
25. Asthma is a serious health problem in South Africa	81	8	91	9
26. Asthma care is expensive	74	15	83	17
27. When a person has an attack they should see a doctor immediately	82	7	92	8
28. The emergency room is the best place to get treated for an asthma attack	80	9	90	10
29. People can get addicted to their asthma medicines	56	33	63	37
30. Children with asthma have overprotective mothers	71	18	80	20
31. People without medical aid do not get asthma care	10	79	11	89
32. Stress makes asthma worse	85	4	96	4

The first 10 questions consisted of knowledge statements about asthma, such as: "Asthma cannot be cured**".** The response to this specific question indicated that 50 (56%) people agreed that asthma cannot be cured, but 39 (44%) participants disagreed. This perception has the potential to negatively influence their receptiveness to asthma education and instructions about management strategies. If a patient believes the disease can be cured, it will make no sense to them if a health professional were to try to convince them to take therapy on an ongoing basis, and even when they are asymptomatic. Another question which showed a huge difference of opinion was: **"**people with asthma cannot exercise**"**

where 45 (51%) participants indicated it to be a true statement against 44 (49%) who indicated it to be a false statement. This highlighted an important misconception that can be corrected by proper asthma control and asthma education. Athletes who suffer from asthma can compete at the highest level, for example the Australian swimmer Susie O'Neill.

A very worrying factor was that 40 (44%) of the sample subjects did not identify nocturnal coughing as a sign of asthma. Nocturnal asthma symptoms have been recognised as an important severity marker [Colice, Van den Burgt, Song, Stampone and Thompson 1999:1965]. If people don't know the risk factors of the disease they will not respond appropriately when confronted with that risk. Studies of asthma mortality suggested that people often die because of a delay in seeking help, or under-estimating their own asthma severity [NATC 1997:187]. The SNAP study [De Klerk, Van Schalkwyk, Williams and Bardin 2001:872], a case control study which assessed the risk factors for Near-fatal Asthma for the first time in a South-African population, found that 29% of acute severe asthma admissions at the emergency department of the same hospital were in the Near-Fatal Asthma [NFA] group. This supports the finding that patients in this population group do not have control of their asthma. Under-treatment or non-adherence to treatment may be variables to investigate to determine the cause if it is not lack of asthma knowledge.

Statements assessing trigger factors showed that 23 (25,2%) participants indicated poor diet to be a trigger and 71 (78%) participants responded that cockroaches are not a stimulus of asthma. This is probably not a fact that is as well known by the general public. However, in previous years, the press covered the baby deaths in hospitals because of transmission of infection by cockroaches as well as the increase in asthma related illness for US inner-city children [Folkers 1997:1]. Droppings and body parts of cockroaches form part of the dust in cockroach infested dwellings and exposure over time may induce an allergic response from patients. This lack of knowledge may also result from an inability to access new information

about asthma. Another disturbing response was that 21% of respondents still indicated: “Hospitalization for asthma can be prevented **“** as a false statement. As many as 56 (63%) respondents still indicated people can become addicted to their asthma medication versus 33 (37%) who believed it to be a false statement. The SNAP study which assessed risk factors for NFA, reported that people in the NFA group used significantly less short-acting bronchodilators in the days prior to their emergency room admissions [De Klerk et al 2000]. This may be explained by our finding that people do not want to become addicted to asthma medication and, therefore, use less during attacks. These responses indicated areas of education that needs serious attention. This also suggests that beliefs and attitudes of people cannot be ignored when asthma education interventions are planned. The overall summary of this section of the questionnaire showed that adult asthmatics in this particular study group had good knowledge about asthma with a mean of 23 and a standard deviation of 2,4.

When the asthma knowledge total score was compared between the different racial groups, the data showed that Caucasian participants had a better knowledge of asthma compared to coloureds and blacks ($p<0,01$). However, given the small number of Caucasian participants in the study a definitive conclusion cannot be formed. The data was also categorized according to participant age group and the results showed no relationship between knowledge and age. The difference in asthma knowledge was also calculated with gender as a category. The data showed that females as a group had, on average, a higher total knowledge score in comparison to their male counterparts. This was, however, not statistically significant with p 0.11 (see figure 4.3). This finding may be because of the differences in participant totals between males and females in this particular sample. The same pattern was shown for the individual sections of the knowledge questionnaire as well.

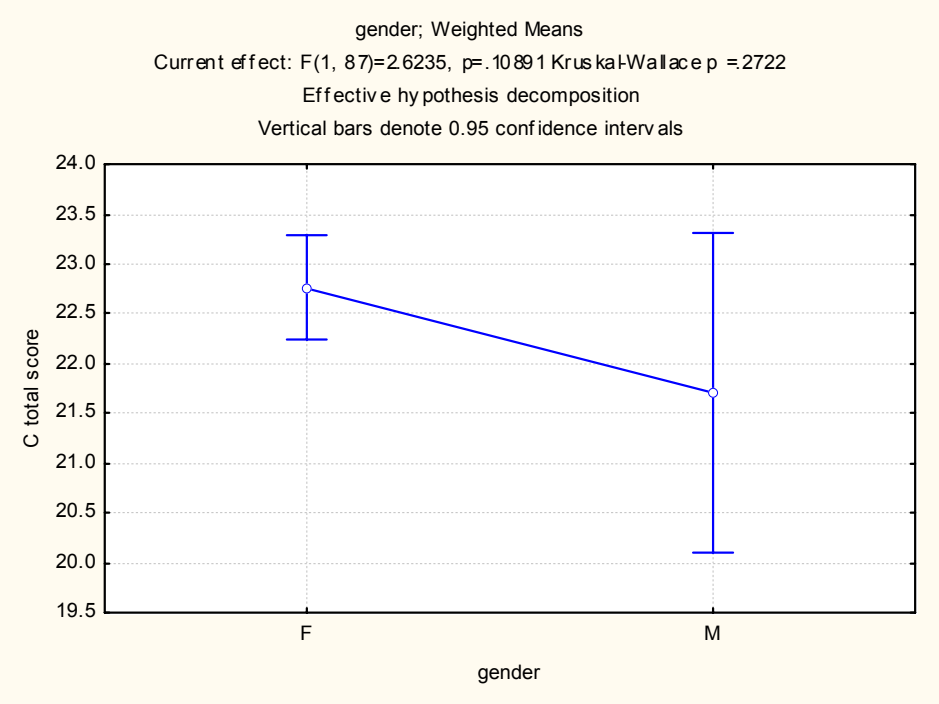

Figure 4.3 Knowledge differences between males and females

When the education data was analysed, the data showed that the higher the level of education, the better the asthma knowledge of the respondent with a Spearman correlation of r= 0,32 (p< 0.01). The results did not differ from earlier research from the UK and USA. Comparison of total knowledge scores between ex-smokers and non-smokers showed no statistical significant difference between the two groups (p0.53). To allow for proper calculation the mean value was used in areas where participants had no response on the questionnaire.

4.4.3 Findings on Asthma Quality of Life

Asthma quality of life was measured by means of a disease-specific questionnaire, developed by Marks, Dunn & Woolcock [1993: 1103]. The instrument consists of twenty Likert scale responses. Information gathered reflected participants reports on items such as breathlessness and physical restrictions, mood disturbance, social disruption and concerns for health. Scores from the subset scales were calculated by simple addition. A low score

(20) reflected good quality of life and a high score (100) reflected poor quality of life. Comparison of quality of life data to race and gender as parameters showed no significant differences between the groups. As expected, non-smokers reported better quality of life compared to ex-smokers but this was again not shown to be statistically significant. No statistically significant correlation could be detected between quality of life when correlated with age ($r=0.01$, $p= 0.92$). A negative correlation was found between quality of life and education with $r= -0.40$ ($p< 0.01$), showing that the higher the level of education, the better the asthma quality of life was reported by participants. A negative correlation was also found between quality of life and income with $r= -0.29$ ($p= 0.01$) thus demonstrating that the subjects with lower incomes had reported a poorer quality of life. In reality, asthmatics may have to make the decision between purchasing asthma medication or to put food on the table for their families. Non-adherence to treatment is generally perceived as the preferred option because of the cost involved in purchasing maintenance inhaled cortico-steroids, or long-acting bronchodilators such as salmeterol which are not supplied in the government system. However, this may have a very negative influence on asthma quality of life over time. This also demonstrates why education and health promotion should be directed at areas that will improve wellness behaviour by patients. Improvement of wellness behaviour is one of the strategic goals of the national health plan for South Africa. [Department of Health 1997. Government Gazette,382:26-46]. Table 4.4 summarises the asthma quality of life data. The questions where total responses do not reflect the population total of 89, one or two subjects did not complete that particular question.

Table 4.4 Summary of Asthma Quality of life data

ASTHMA QUALITY OF LIFE QUESTIONNAIRE DATA SUMMARY						
QUESTION	1 (not at all)	2 (mildly)	3 (moderately)	4 (severely)	5 (very sev)	N = 89
Troubled by shortness of breath	4 (4%)	17 **(19%)**	35 **(39%)**	21 (24%)	12 (13%)	89
Troubled by wheezing attacks	16 (18%)	17 (19%)	23 (26%)	24 (27%)	8 (9%)	88
Troubled by tightness in the chest	7 (8%)	16 (18%)	30 (34%)	23 (26%)	13 (15%)	89
Restricted doing light activities	22 (25%)	24 (27%)	24 (27%)	14 (16%)	5 (6%)	89
Restricted doing heavy activities	11 (12%)	18 (20%)	27 (30%)	23 (26%)	8 (9%)	87
Felt tired/general lack of energy	9 (10%)	9 (10%)	39 (44%)	24 (27%)	8 (9%)	89
Unable to sleep at night	22 (25%)	16 (18%)	30 (34%)	13 (15%)	8 (9%)	89
Felt sad or depressed	25 (28%)	13 (15%)	28 (31%)	14 (16%)	9 (10%)	89
Felt frustrated	22 (25%)	14 (16%)	19 (21%)	24 (27%)	10 (11%)	89
Felt anxious/ stressed	19 (21%)	13 (15%)	25 (28%)	26 (29%)	6 (8%)	89
Asthma prevents achievements wanted	30 (34%)	11 (12%)	12 (13%)	18 (20%)	18 (20%)	89
Asthma interfered with social life	30 (34%)	9 (10%)	20 (22%)	17 (19%)	13 (15%)	89
Limited to go to places that's bad for A	26 (29%)	6 (8%)	19 (21%)	25 (28%)	13 (15%)	89
Limit to go places/ afraid of an attack	31 (35%)	6 (8%)	15 (17%)	19 (21%)	18 (20%)	89
Restricted to engage in sport	24 (27%)	12 (13%)	17 (19%)	22 (25%)	14 (16%)	89
Felt generally restricted	28 (31%)	7 (8%)	25 (28%)	20 (22%)	9 (10%)	89
Asthma is controlling life	31 (35%)	7 (8%)	18 (20%)	17 (19%)	16 (18%)	89
Worry about present/future health	16 (18%)	9 (10%)	15 (17%)	26 (29%)	23 (26%)	89
Worry asthma will shorten life	22 (25%)	12 (13%)	10 (11%)	22 (25%)	23 (26%)	89
Felt dependent on asthma sprays	5 (6%)	15 (17%)	10 (11%)	28 (31%)	31 (35%)	89

The different components of the AQLQ such as breathlessness, mood disturbance, social disruption and concerns for health were compared to the asthma knowledge total score but no statistical significant correlation could be demonstrated with r=-0.17 and p=0.10. No statistical significant correlation could be illustrated between mood disturbance and asthma knowledge total score with a Spearman r=-0,12 and p=0,25. No correlation could be demonstrated between social disruption and asthma knowledge total score with a Spearman r=-0,02 and p=0,82. No statistically significant correlation could also be found between concerns for health as an aspect of quality of life when compared to the asthma knowledge total score r=-0,03 and p=0,74. When the different components were assessed as single

entities, 21(24%) of respondents indicated that they suffered from severe shortness of breath and 12(13%) reported very severe episodes of shortness of breath. Respondents reported that 30(34%) experienced moderate chest tightness, 23(26%) experienced severe and 13(15%) experienced very severe chest tightness during the four weeks prior to the clinic visit. The assessment of mood disturbance was calculated on feedback from aspects such as depression, frustration, anxiety as well as feelings of inability to reach goals. Only 9 (10%) of respondents felt very severely depressed and 14 (16%) indicated feelings of severe depression**.** However 24(27%) felt severe frustration and 10(11%) felt very severely frustrated by their situation. Social disruption, evaluated on feedback about ability to visit places for recreation purposes showed that 34% did not have any difficulty but 15% of respondents were very severely affected. Concerns for health were addressed by the statements about fear that asthma will shorten life and fear about future health and the results showed that 45 respondents were in the severe (22) to very severe (23) range of the questionnaire. Dependence on asthma sprays was also evaluated and the responses showed that 10(11%) had moderate dependence, 28(31%) had severe dependence and 31(35%) very severely depend on asthma sprays. Consumption of such high dosages of short-acting bronchodilators indicates either very severe or uncontrolled asthma. It is also not clear whether medication was used as needed or on a regular schedule as a preventative measure because that question was not addressed by this study. Although there was no significant association between the total asthma quality of life score and the individual variables that assessed quality of life the individual components showed some forms of impaired quality of life for a subsection of the study population.

4.4.4 Findings on Asthma Control

In this section the findings on asthma control is discussed. The Asthma Control Questionnaire (ACQ) assessed asthma control for the week prior to the clinic visit. The six questions addressed nocturnal awakening due to asthma symptoms, severity of asthma

symptoms on awakening in the morning, hampering of activities due to asthma, shortness of breath due to asthma, wheezing of the chest and the average number of bronchodilator puffs taken. Question seven assessed FEV_1 as percentage predicted for the day of the visit and was expressed as six different options between <50% to >95% of predicted FEV_1 value where <50% scored 6 and >95% scored 0. Good control was illustrated by a mean value of less or equal to 2. Satisfactory control was demonstrated by a mean score of between 3 and 4. Poor control was illustrated by a mean value of more or equal to 4. Table 4.5 illustrates asthma control values categorized according to age. Although no statistically significant association could be confirmed, it is of interest to note that the age group 12 to 20 had either poor control or good control although the numbers were small. This is usually the period where asthma education needs to be vigilant. The biggest group that showed satisfactory control were the age group 36 to 50. This group reflects the active workforce and with proper control they will have less days off work. It is very important to try to shift them to become part of group with good control.

Table 4.5 Asthma control versus age

Age group	N (89)	Poor Control	Satisfactory control	Good control
		m≥4	m 3-4	m ≤ 2
12 – 20	4	1	0	3
21 – 35	27	3	11	13
36 – 50	43	5	27	11
51 – 70	15	3	5	7
Total	89	12	43	34
%		14%	48%	38%

The sample showed poor asthma control in the week prior to the clinic visit in 14% of the participants. Satisfactory control was documented by 48% of the participants and 38% of the participants had good asthma control the week prior to their clinic visit. The patients with just satisfactory control are the subjects who may benefit the most from major educational exposure and skills improvement efforts. Patients with poor asthma control are the subjects

who need to stay in an academic setting for follow-up visits and who will need one-on-one contact to ensure that they understand the intricacies of their disease and have the information to reduce their fear and anxiety. On the asthma control scale, 0 indicated good control and 6 poor control. Asthma symptom rankings for example varied as follows: 0 indicated no symptoms, 1 indicated very mild symptoms, 2 indicated mild symptoms, 3 indicated moderate symptoms, 4 indicated quite severe symptoms, 5 severe symptoms and 6 very severe symptoms. Each question, however, had its own ranking explanation.

Table 4.6 summarises the asthma control data.

Table 4.6 Summary of Asthma Control

			ASTHMA CONTROL SUMMARY					
QUESTION	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**N=89**
	No Sx	**Very mild Sx**	**Mild Sx**	**Moderate Sx**	**Quite Severe sx**	**Severe sx**	**Very severe Sx**	
1.Nocturnal	16	9	20	15	11	7	10	88
awakening	18%	10%	22%	17%	12%	8%	11%	
2. Morning	10	13	13	21	17	8	7	89
symptoms	11%	15%	15%	24%	19%	9%	7%	
3. Impaired	22	9	4	23	17	6	8	89
activities	25%	10%	4%	26%	19%	7%	9%	
4.Shortness of	6	8	15	16	23	12	9	89
breath	7%	9%	17%	18%	26%	13%	10%	
5.Wheezing chest	14	8	20	19	11	10	7	89
	16%	9%	22%	21%	12%	11%	9%	
6 Puffs needed	4	17	19	29	10	5	5	89
	4%	19%	21%	33%	11%	6%	6%	
7. FEV_1	7	9	10	14	12	10	27	89
	9%	10%	11%	16%	13%	11%	30%	

One of the initial concerns was that participants would underestimate their symptoms and asthma control if they were to be compared with the FEV_1 % of the day. This concern was reflected in the data obtained from 4 subjects (5%) who had a good control score ≤ 2 but FEV_1 values of 55% and lower. Overall 27(30%) of respondents had a pulmonary function of less than 50% predicted value, 10(11%) had a pulmonary function in the range 50 -59, and 12(13%) had a pulmonary function within the range 60-69. Laboratory studies have suggested that some patients with asthma are simply unaware of just how poor their lung

function is, reporting their breathing as “good” or “normal” when they have peak flow recordings less than half of their respective predicted values [NATC 1997: 188]. This indicated that some patients have no previous reference of what normal should be to make that comparison. A negative correlation was found between education and asthma control with r= -0,34 (p<0,01), showing the higher the level of education the better asthma control was displayed. A similar pattern was found for asthma control versus income with r=-0,26 (p= 0,01), demonstrating people with less income had a poorer asthma control score.

4.5 COMPARISON OF THE DATA SETS

In order to answer the research questions, non parametric testing was applied to determine associations between the different variables. The questions were as follows:

- is lack of knowledge regarding asthma linked to impaired asthma quality of life?
- is there an association between knowledge regarding asthma and asthma control?
- is there an association between asthma control and asthma quality of life?

To determine associations among variables, Spearman rank order correlations were used to examine any significant bivariate associations. Scatterplots demonstrate the trends and relationships of 2 numerical-variable data sets. A line of best fit is used to indicate the direction of the association. Table 4.7 illustrates that no correlation could be found between asthma knowledge and asthma quality of life. However, an association was noted between breathlessness and asthma knowledge (p=0,05), as well as mood and asthma knowledge (p=0,07).

Table 4.7 Asthma knowledge versus asthma quality of life

Variables	Spearman R	p-level
Total knowledge & Breathlessness	**-0.20**	**0.05 ***
Total knowledge & Mood disturbance	**-0.19**	**0.07***
Total knowledge & Social disruption	**-0.08**	**0.45**
Total knowledge & Health Concerns	**-0.09**	**0.40**

The total scores of the variables asthma knowledge and asthma control were also compared to determine an association but no correlation could be illustrated between the named variables with r=-0,02 (p=0.8). This could imply that factors other than knowledge influence asthma control. Although spirometry (lung functions) was one of the variables used to determine the asthma control score, it was also important to compare it as an entity against the average asthma control score. Asthmatics more often than not report a major difference between other aspects of asthma control such as symptoms and bronchodilator usage in comparison to actual lung function data when tested in the laboratory. The following scatterplot (figure 4.4) demonstrates the correlation between the asthma control score average and spirometry data obtained on the day of the visit to the respiratory clinic. A significant negative correlation was found between asthma control scores (high scores denote poor control) and spirometry with r=-0.45($p<0.01$). This implies that good control of asthma is linked to superior lung function as reflected by FEV_1 measurements.

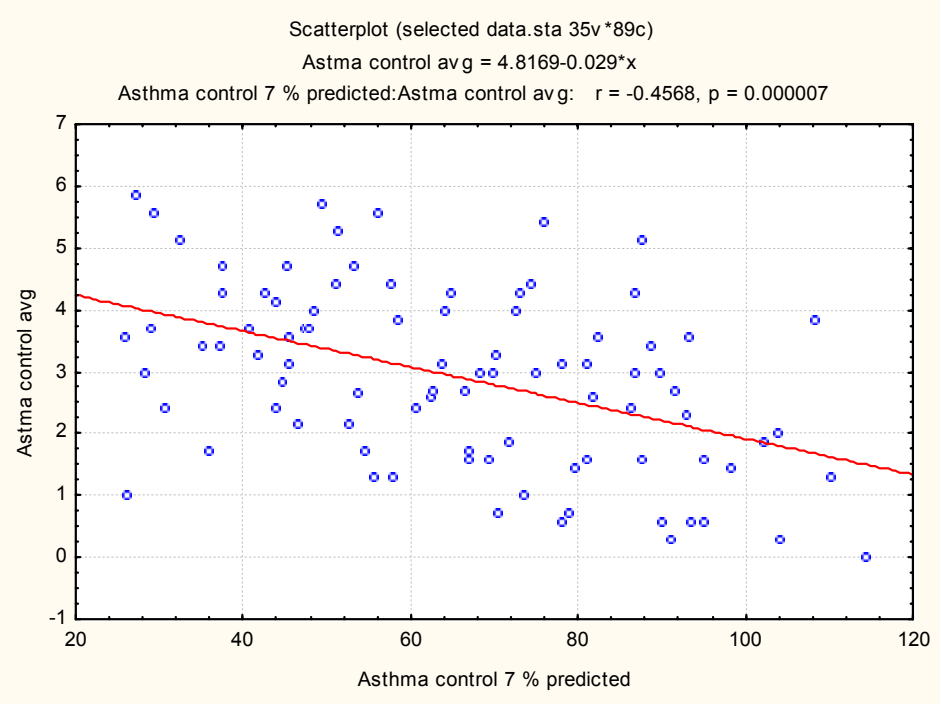

Figure 4.4 Correlation between asthma control and spirometry

When the asthma control data was compared to asthma quality of life data, a completely different picture was found compared to the asthma total knowledge score. Table 4.8 demonstrates the correlation between asthma control and asthma quality of life.

Table 4.8 Asthma control versus asthma quality of life

Variables	Spearman R	p-level
Breathlessness & Asthma Control avg	**0.84**	**<0.01***
Mood disturbance & Asthma Control avg	**0.77**	**<0.01***
Social disruption & Asthma Control avg	**0.78**	**<0.01***
Health Concerns & Asthma Control avg	**0.81**	**<0.01***

A highly significant positive correlation was found between asthma control and asthma quality of life as shown in figure 4.5

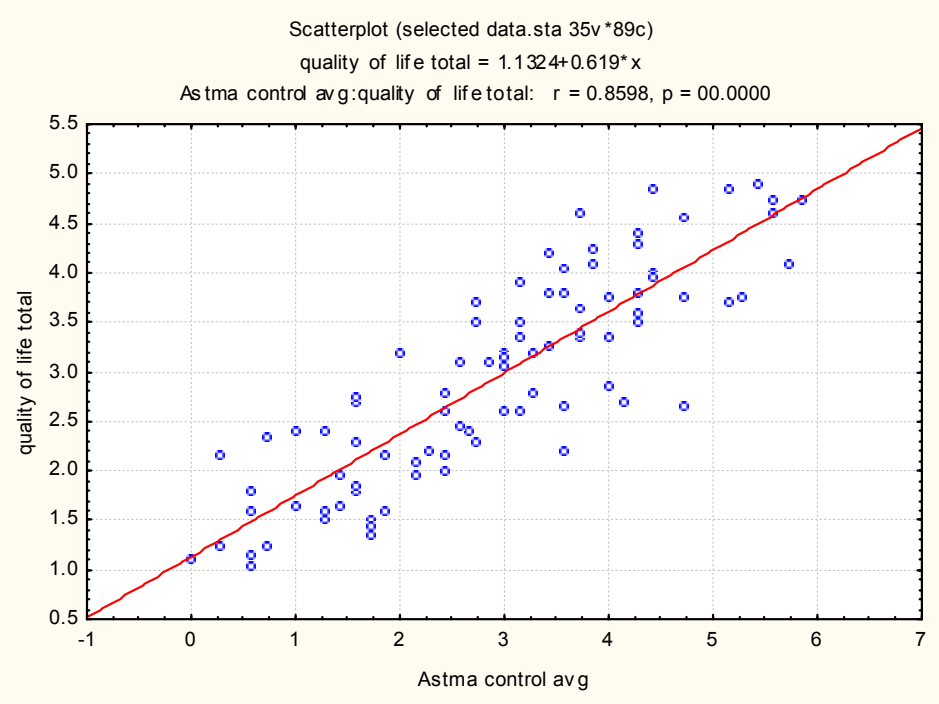

Figure 4.5 Association between asthma control and asthma quality of life

Similar results were found when a comparison was made with the individual components of quality of life such as breathlessness, social disruption, mood disturbance and concerns for health, and asthma control data (see Table 4.8). It is of interest to know whether there are aspects of asthma control that do not necessarily require cognitive knowledge, but which affects behaviour and, therefore, improves or hampers aspects of control and quality of life. A recent study by Shingo, Zhang, and Reiss [2001:223] suggested that the fluctuating mood of asthma patients may influence their perception of asthma symptoms. Dickinson, Hutton and Atkin [1998:226] postulated that patients who perceive themselves as well controlled asthmatics, do so because they use their bronchodilators regularly despite instructions that may indicate the opposite. This situation develops over time because patients get used to a certain degree of disability and accept it as normal. Frequent use of asthma sprays is part of this acceptance.

4.6 DISCUSSION

Clark and Partridge [1997:1661] contend that: “Knowledge without application is of marginal value to those with asthma, who suffer as individuals from the disease, and to society which increasingly bears the growing financial burden.” This sample of subjects demonstrated good knowledge about signs and symptoms and asthma triggers. However, the fact that nocturnal coughing was not identified as a symptom of asthma by 40 participants is worrying because nocturnal asthma is a marker of severity of symptoms and unstable asthma and has been linked to life-threatening exacerbations. The following gaps in patients’ knowledge were identified by the study:

Items 1, 3, 14, 19, 22, 28, 29 these are all noteworthy findings.

- 71 (78%) people did not recognise cockroaches as a trigger factor
- 39 (44%) people believed that asthma can be cured
- 45 (51%) people believed that you cannot exercise if you have asthma
- 56 (63%) people believed that you can get addicted to your asthma medication
- 80 (90%) people believed that the emergency room (ER**)** is the best place to get treatment for an asthma attack

The organization of the South African health system is probably responsible for the last statement because initially no services were available within communities and the emphasis was on curative care. Some patients may also not be comfortable taking the initiative for their care during exacerbations because they may not trust their own ability to assess severity of symptoms effectively. Patients may not be in possession of a management plan or confident of their skills to handle crisis situations. All the guidelines recommend self management by patients and, because of their role in the health system as patient advocates and educators, nurses are in the perfect position to act as change agents. Asthma education programmes increase patient information but often fail to improve morbidity.

Studies in asthma, diabetes, and hypertension showed that improved patient knowledge on its own does not improve morbidity nor mortality [NATC 1997: 185]. Enabling patients to identify problems by providing the necessary skills, and solve them with the assistance of the health care team may revolutionize the world of asthma, especially if patients have raised confidence levels.

This study confirmed that knowledge of asthma is not a pre-requisite for asthma control or asthma quality of life. This finding corresponds with the literature. Meyer, Sternfels, Fagan, Copeland and Ford [2001: 538] studied asthma knowledge amongst emergency department users in Harlem and found that knowledge that require active education varied widely, compared to aspects that can be acquired through personal experience. Knowledge, however, remains an important marker to reduce asthma morbidity and mortality [Meyer et al 2001: 538]. Wade, Holden, Lynn and Ewart [2000:345] also found that in caregivers of children with asthma their knowledge of asthma was unrelated to measures of asthma symptoms. A good correlation was found between asthma control and asthma quality of life. The study population still consisted of 14% cases with poor control and 48% cases with satisfactory control. Strengthening aspects other than knowledge to enhance asthma control might be beneficial for proper asthma management. For health care providers, the aim should be to empower people suffering from asthma to be responsible and confident enough to control their own disease. Emphasis away from only knowledge is important and should involve patients in a self-management plan [NATC 1997:186]. Self-management will also increase patients' knowledge and awareness about asthma and its treatment because people will learn what to do when they are well and when they are symptomatic [NATC 1997: 187]. The credibility of such programmes will also increase if health professionals give attention to patients' beliefs or their goals to satisfy their specific needs [NATC 1997: 186].

Asthma control is not an art. Asthma control should be a habit.

4.7 CONCLUSION

This chapter presented the data analysis and the results obtained from the study. Chapter five will conclude the study by discussing how the findings link to the study objectives and current good clinical practice. Recommendations will be made for further research and possible proposals to improve current practice, health education strategies and campaigns.

CHAPTER 5

Conclusions, Limitations, and Recommendations

5.1 INTRODUCTION

The purpose of the study reported in this dissertation was to determine the interrelationship between the knowledge of asthma amongst adult asthmatics, their asthma control and their asthma quality of life. A quantitative, descriptive design was used and data was gathered by means of a questionnaire survey. Participants (89 in total) were recruited from the respiratory outpatients clinic of the Tygerberg Hospital in the Western Cape Povince. Data analysis was done by a statistician and the Statistica version 7 package was utilized for that purpose. This final chapter will present the conclusions drawn from the research as well as discuss the limitations of the study. Recommendations and proposals are made for future research and management of asthma. Suggestions to address the problem are offered in order to link current findings with future developments and strategic planning. The objectives of this research project were to:

1. Establish the asthma knowledge of adult asthmatics
2. Assess the quality of life of adult asthmatics as measured by a validated disease-specific questionnaire
3. Assess the control of asthma as measured by a validated disease-specific questionnaire
4. Determine the relationship between asthma knowledge, asthma control, and asthma quality of life. The research questions were:
    - Is lack of knowledge regarding asthma linked to impaired quality of life?
    - Is there an association between knowledge regarding asthma and asthma? control

- Is there an association between asthma control and asthma quality of life?

Asthma imposes limitations on all sufferers irrespective of the severity of their disease. This raises important issues in patient management, such as adherence to therapeutic strategies, underestimation of asthma attacks, appropriate management skills and health care costs. In recent years, there have been many improvements in asthma treatment and the availability of asthma services. Services have also been taken into the primary care arena and, in general, asthma has become socially more acceptable. Smith and Partridge [2000: 106], contrasted this against the reality that asthmatics have to experience every day, such as a difficult to control severe condition or for some always dangerous and life threatening, while the rest have very little or sometimes no restrictions on their life. These two researchers concluded that for 42% of the asthma population the disease presents with continuing and significant challenges which often prevent them from leading the kind of life others take for granted.

5.2 THE DEBATE ACCORDING TO THE LITERATURE

Irrespective of a better understanding of the pathophysiology of asthma and its related therapeutic regimes, the disease still escalates in prevalence and severity. According to the literature, a positive relation exists between self-management and quality of life. However self-management can only be implemented successfully if patients have enough knowledge to create behavioural change. To comprehend the gaps in asthma management, an assessment has to be made of the impact of asthma on the individuals suffering from the disease. Knowledge about asthma and asthma therapy affects asthma control and, ultimately, the quality of life of an asthma sufferer. If health professionals can promote appropriate self-care methods the outcome may be a relief on the healthcare system, with

less hospitalization for asthma, emergency department visits and presentation at outpatients departments.

Health care policy makers are faced with the challenge to preserve the quality of life and functional capacity of people who suffer from chronic illnesses such as asthma in order to keep them in school and at work. All of this needs to happen within the economic constraints of a health budget and restrictions within the health care system [Jayasuriya, Roach and Thomas 2001:1123]. It is, therefore, appropriate to search for a solution that will enable people with chronic diseases to adopt the self-management approach. This is possible within the organisation and principles of primary care. However, programmes need to be developed according to the actual needs of the patients because their participation will ensure the best outcome for all parties involved [Jayasuriya et al 2001:1123]. These researchers advocate the acquisition of knowledge and skills that is supported by a self-management culture that integrates with existing practice. Jones et al [1994:79] added to this the all important role of asthma nurses equipped with the necessary tools to empower their patients by enhancing existing knowledge and assistance in the development of those skills that will ensure appropriate asthma control, and a better asthma quality of life.

Nurses are not always as aware of the importance of asthma education and continuous monitoring as strategies of prevention. According to Partridge, Barnes, Price, and Barnes [2001:1122], the belief that education alone is the key to success is not supported by evidence. They debate the fact that asthma sufferers do not like the uncertainty associated with the disease. Therefore, all sufferers should know what to do in the event of deteriorating asthma control.

Over the past few years, there has been an increase in asthma guidelines. Health professionals should pay equal attention to the dissemination and implementation of asthma

guidelines to deliver effective asthma care [Partridge, Fabbri and Chung 2000:235]. Partridge and his co-workers endorsed the work and recommendations of the Italian researchers Massa and Corbetta [2000:235] who suggested that there should be a collaboration between primary care and secondary health care to facilitate feedback on actual asthma care on a practical level as well as the level of the patient [Partridge et al 2000:236]. The level of asthma knowledge, degree of asthma control, and asthma quality of life had to be assessed in this particular population because the baseline knowledge was needed to further intensify and build a holistically appropriate health education programme. The important gaps in knowledge identified by the study, such as that you can be addicted to asthma medication, explains why people are under-treated and have poor asthma control. The fact that the dangerous symptom of nocturnal asthma is not well known by this study population may explain why people do not always trust themselves in a self-management scenario and work by Markson et al showed that insufficient knowledge and inappropriate beliefs are major barriers to self-management of asthma [2001:382].

5.3 CONCLUSIONS

Asthma is not a disease with a single etiology but a very complex syndrome. New diagnostic methods such as broncho-alveolar lavage and bronchoscopy have made it clear that the process of inflammation is present even in people suffering from mild disease. Therefore, there can be no instant solution for a cure because of the interrelationship between genetic factors, atopy, bronchial hyper reactivity and environmental factors. Certain public health issues such as culturally competent care and individual variations in the management of asthma further complicates the picture. Research reports quoted by Partridge [2000:175] showed that asthma outcomes may differ between asthma sufferers, even if the same information was given to different cultural groups. This tends to be a problem in South Africa, too, with the multi-cultural population and messages from people of a different ethnic group

may not be accepted. Information delivered during education sessions may be interpreted by the audience in a completely different way to what the educator actually intended. We, therefore, must ask whether we can rely on subjective data such as quality of life to plan health care. According to the findings of the study, 46% of participants presented with severe asthma. This could be an indication of a group with a very severe form of asthma, being referred to an academic facility. However, this may also be an indicator of uncontrolled disease in a group of people on active treatment because all the participants who volunteered for participation were not newly diagnosed asthma sufferers. Patient factors such as non-adherence to treatment regimens may also be a factor. The report may also reflect that, although asthma guidelines have been implemented, its full impact is not being seen yet.

5.3.1 Is lack of knowledge linked to impaired asthma quality of life

The study population displayed good asthma knowledge with the average total score of 23 which was 22% better than the mean score, but this occurred within a setting of uncontrolled asthma 14%(n=89) of the participants, and satisfactory control in 48% of participants in the study (see table 4.5). There is the possibility that knowledge alone is not utilized in daily activities to optimize quality of life. From the data it is clear that gaps still exist in knowledge and behaviour. The study was necessary to determine the reasons for the problem of uncontrolled asthma in this population and to try to identify perceptions that influence behaviour and compliance.

According to Markson et al [2001:382], insufficient knowledge and inappropriate beliefs of asthma are major barriers to the self-management of asthma. This study identified the belief amongst participants that asthma medication can be addictive. This is a major setback if people have to initiate their own treatment during episodes of worsening of their disease. In the population studied no association was found between race, age, gender, knowledge of

asthma, and asthma quality of life (see 4.3.3). Asthma interventions should, therefore, target attitudes, perceptions, and practical skills that influence day to day practices rather than factual knowledge to be successful in reducing morbidity [Wade, Holden, Lynn and Ewart 2000:345]. By improving problem-solving capabilities through self-management strategies, functional status may improve and enhance asthma quality of life. Good quality of life leads to positive expectations regarding the outcome of the disease and will, therefore, reduce fear and anxiety. All of these aspects will improve asthma morbidity and give patients the confidence to self-regulate their disease. A negative association was found between education, income, and asthma quality of life showing that the higher a person's income or education exposure, the better was their asthma quality of life.

5.3.2 Is there an association between asthma knowledge and asthma control

It is important to improve factual knowledge to better understand asthma as a disease, yet there is no clear evidence that more factual information leads to a decrease in asthma morbidity. Research has moved beyond knowledge as focus for intervention and increasingly targeted practical problem solving skills to try and combat uncontrolled disease. The Social Action Theory [Ewart 1991:931], an approach to health behaviour change, emphasizes that you can alter knowledge about an illness but long term change is often not obtained if you fail to include practical problem solving skills and positive personal expectations regarding one's ability to use these skills effectively. Wade et al [2000:345] found that knowledge of asthma was unrelated to measure of asthma symptoms, suggesting that knowledge is less important than problem solving skills and expectations regarding their success. In this population, the researcher could not demonstrate an association between knowledge and asthma control (see table 4.5). Whether full asthma control can be achieved is a fertile field for research. Control has a different meaning for different patients. The economical implications of uncontrolled asthma in a third world country are unaffordable and should be of concern to all health professionals.

5.3.3 Is there an association between asthma control and asthma quality of life

Uncontrolled asthma puts patients at risk and increases asthma-related hospital admissions and emergency presentations. Earlier research has shown that any level of symptom severity had an impact on quality of life even in people with occasional symptoms [Leynaert et al 2000:1394]. In this study, a significant positive correlation was found between asthma control and asthma quality of life (see figure 4.5). When asthma control was compared to the individual components assessed as markers of quality of life, such as breathlessness, social disruption, mood disturbance, and concerns for health, similar results were found (see table 4.8). If a patient had poor asthma control their concerns for their health increased and poor quality of life resulted. This strengthens beliefs that everything should be done to ensure proper asthma control. The attitudes and perceptions of patients with long-standing asthma change constantly over time. This leads to continual change in a patient's need for appropriate asthma care. Attitudes and problem-solving skills play an important role in the determination of health outcomes. If health professionals improve practical problem-solving skills of patients, there may be a reduction in symptoms and this may lead to improved asthma control which will enhance a patient's quality of life (functional capabilities).

5.4 LIMITATIONS OF THE STUDY

Non-adherence to medication regimens, poor inhaler technique and resistance to adhere to regular follow-up schedules are very important reasons for poor asthma control in any asthma clinic. The information about asthma knowledge could have changed if medication and inhaler technique was included as variables on the asthma knowledge section of the questionnaire. However, those aspects were not included because of the existing program to improve the inhaler technique of patients who attend the respiratory clinic. These particular factors are important in the relationship between asthma knowledge, asthma control and

asthma quality of life and may explain why some people with severe asthma may experience a poor quality of life even when they have good asthma control according to their own subjective assessment. Including information about health economics such as hospital admissions, emergency presentations and length of stay in hospital could have been added to determine asthma costs due to poor asthma control. Information about health economics is important when an asthma care program is planned. Examining patient's satisfaction with their asthma treatment could have been used as an indicator of hidden attitudes that could influence asthma control data. Generalisability of the data may be a limitation because this group of participants were recruited in an academic facility and their information may not be completely applicable to people who present in the primary care sector. Asthmatics who attend the respiratory services of an academic facility may be, by virtue of their disease, a manifestation in a more severe category.

5.5 RECOMMENDATIONS

Based on the literature review and findings of this study the following recommendations are suggested.

General

- Empowerment of the South African population in general and asthmatics in particular via a national asthma awareness programme could be instrumental in supplying knowledge that will create a change in behaviour and attitudes. Public awareness is the biggest asset for change and, therefore, the national media should be involved. Information should reach people in urban as well as the most remote rural areas. Patient information leaflets about asthma should be freely available to all the general public. Information should be easy to understand and available in the language of choice of the different communities.

- It is recommended that the promotion of the National Asthma Education Programme (NAEP) be endorsed with the help of the asthma patients, their families, and the communities within which asthmatics have to live their lives. The asthma education programme that is driven by the Medical Research Council (MRC) of South Africa (SA) should not be implemented in isolation but include the important other role players responsible to ensure the best scenario for asthma sufferers and their families.

- Government involvement should be applied where it is needed and that is not only in crisis areas such as Tuberculosis and HIV. More often than not, the attention given to chronic diseases is miniscule regardless of documented high prevalence. It is important that the approach to asthma care be separated from that of COPD (chronic obstructive pulmonary disease) because the needs of asthma sufferers are different from people with chronic bronchitis or emphysema. If asthmatics are well they can be productive citizens and responsible for their own income and not reliant on government grants. Funding should be made available to support the asthma campaigns launched by NAEP to enhance public awareness and to fund patient information leaflets.

- Surveys of chronic diseases should be conducted in a manner to ensure that the information is not skewed towards the people not affected by the disease. This can easily happen in big national surveys of chronic diseases where sampling cohorts don't reflect the true picture because the target population is not reached.

Smoking is one of the problems that keep patients in the dangerous frame of unstable disease. Anti-smoking campaigns are important and have already been implemented in

South Africa which is a positive. Every health facility should roll out their own smoking cessation program as part of their ongoing service to the public.

Education of Health Professionals

- Health professionals at all levels should be empowered by all the new knowledge available about asthma management. This include exposure to implementation of asthma guidelines, peer group education about the latest developments in research and, strategies to enable them to change their own attitudes and perceptions. Appropriate knowledge that will enhance patient care may create a positive behavioural change. This aspect has partially been addressed by the South African Thoracic Society who established their education role by forming the National Asthma Education Program (NAEP). Most of the major pharmaceutical companies in South Africa contribute to the training of doctors.

- In the past the role of nurses in asthma care has been limited and has been generally curative in nature. The curriculum for training of nurses covers asthma as part of the general medicine topics but only the most basic concepts are covered. If nurses do not have respiratory nursing as a field of interest even they will not know how to use different medication application devices. This leaves a major gap in their ability to teach appropriate asthma education to asthmatics, as well as to the general public. Like other health professionals, nurses will need specialist training to function as asthma clinicians and educators. Asthma is one of the chronic conditions which can be managed successfully in the community (NACT 1997:221).

- It is, therefore, appropriate to increase the role of nurses in asthma care to allow them the opportunity to implement holistic care for asthma sufferers. It is, however,

the responsibility of the nurse to update his/her skills and knowledge with current trends in asthma treatment and management strategies. The nurse is usually the patient's first contact within the health care system and it is important that the message the patient receives is based on national guidelines to ensure uniformity of information from all health professionals.

Nursing Practice

Patient participation in health care planning is very important and advocated by most asthma guidelines and the WHO. Not many patients in the public sector are currently in possession of an asthma action plan. To build confidence, health professionals should try to work with asthma sufferers to set goals that are important to the patient and within his/her ability to achieve. The importance of less hospitalisation and emergency visits as cost saving strategies should be advocated to patients as best practice. Adherence to treatment plans should be encouraged to establish proper asthma control. This will allow patients to stay functional and independent in the workplace and school. Self-management will enhance patient independence.

Nurses should be able to train their patients in the practical skills that will enhance self-regulation such as:

- How to use a peak flow meter and how to interpret the information to know when asthma is well controlled or beginning to get unstable.
- How to identify the symptoms and warning signs that asthma is not well controlled.
- How to identify the danger signs of a near-fatal-asthma attack, and the appropriate approach to prevent frequent presentations at emergency units and hospital admissions.
- How to implement an asthma management plan and one that is patient specific.

- How to administer their asthma medication so that the best up-take is achieved per individual actuation. This should be evaluated and corrected if necessary at every contact session with the patient.
- How to use the different administration devices or to determine which device is most appropriate for a specific patient. This should be tested at every contact session with the patient.
- Evaluation of trigger factors and appropriate methods to ensure environmental control
- Implementation of peer-education especially in a group of adolescents who by nature will not adhere to advocated management strategies if it is not perceived as cool or in.
- Enhancing self-esteem and motivation by forming asthma support groups to allow asthmatics the opportunity to take ownership of the disease and to ensure cost effectiveness when management strategies are planned.
- To enhance patient participation in the planning of their care and to allow patients to set their own goals to improve their quality of life.
- To implement an asthma register for the specific health facility and to develop an alert system that will identify frequent flyers who may need a different approach to their management plan.

For successful implementation of the abovementioned strategies, nurses should build a positive relationship with the patient to develop their trust. A relationship of trust will enhance the effectiveness of asthma care because patients' beliefs and perceptions can be explored more easily. A study by Forshee, Whalen, Hackel, Butt, Smeltzer, Martin, Lavin , and Buchner [1998:82], assessed asthma outcomes after high risk adult and paediatric asthma sufferers were exposed to a six months program of one-on-one nurse-to-patient education. The results showed a significant increase in asthma knowledge and significant decreases in the utilization of emergency care and hospital admission rates. A significant reduction was

also shown in work or school days missed. A 40% increase was noted in the appropriate preventative care visits. This data showed that a one-on-one nurse education program proved to be an effective and rapid way in which to improve asthma outcomes.

The role of the nurse in asthma care should also be to ensure effective communication between the different components of care and to function as an advocate for the patient. Referral between primary and secondary health as well as general practice should be uncomplicated. If an approach is followed consistently, it may turn out to be the essence of success. Nurses should be instrumental in building and being the cohesion factor of the asthma collaboration team. A liaison role will allow the nurse to uniquely function across boundaries to create and ensure improved care for asthmatics [NACT 1997:226].

Another avenue where nurses have not been involved in is participation when the national asthma guidelines are formulated. Participation may have a positive influence on nurses and encourage them to implement the guidelines to the advantage of the patient and to improve asthma outcomes. The nurse who specializes in asthma care should make sure that knowledge about the different aspects of asthma care is disseminated to the other members of her team. This will ensure co-operation and teamwork.

Research

- It is very important that the study be repeated in the primary health care setting because the population may be slightly different from the academic setting and it will allow health professionals the opportunity to improve the asthma care based on the information of their own setting. It would be valuable to do a follow-up assessment of asthma control and asthma quality of life in the existing study group to determine whether subjects have improved or deteriorated over time.
- A comparison of asthma knowledge, asthma control and asthma quality of life between a first world country and a third world country could also be studied

because, theoretically, the same problems should not be present in a first world country because of better health systems and availability of resources.

5.6 SUMMARY

An assessment of the asthma knowledge, asthma control, and asthma quality of life in an adult population was conducted in the Western Cape Province to determine whether there is an association between asthma knowledge, asthma control and asthma quality of life. Asthma patients in this study group had access to high level asthma care in an academic facility, but still presented with symptoms of poor control and impaired quality of life. The reasons for poor asthma control in the population of asthma sufferers that attended the respiratory out patient's clinic of the Tygerberg Hospital needed identification to plan a change in approach that will get the patient involved. Patients will benefit from the information gathered in this project because the knowledge will be used to improve their ability to employ self-management strategies and to fully participate in the planning of their care. The approach to patient education will need to be adapted to include aspects of self-regulation and problem-solving. Patients need to be responsible and accountable for their own health. It is the responsibility of health professionals to empower people to ensure that they will have minimal anxiety and fear to implement self-care. Health professionals should be active in planning their own asthma training to stay in touch with the ever changing scientific scenario. The challenge is there for the taking by an innovative, enthusiastic team of asthma carers and their enlightened, empowered asthma patients.

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ADDENDUM A

INFORMED CONSENT DOCUMENT

APPENDIX B

CONSENT DOCUMENT

Study:

A survey to evaluate the quality of life of adult asthmatics at Tygerberg Academic Complex.

Asthma is a chronic respiratory disease which can have varying effects on the quality of life of asthma sufferers. Some are hardly affected, especially those who are properly treated and well educated about all aspects of their illness, but others may be severely impaired by asthma.

The aim of this study is therefore to determine what the quality of life of adult asthmatics are, attending the respiratory clinic at Tygerberg Hospital.

We would like to know if you are willing to participate in this study. Your participation will involve the following aspects:

1. Consent to participation
2. Completion of an asthma quality of life questionnaire (with a research nurse).
3. Investigations and treatment will not be changed and remains as is the standard practice during your follow-up visits at the respiratory clinic.

Your participation in the study is completely voluntary and can help to improve the care of people with asthma. Your treatment won't be affected if you choose not to participate. The results will be treated confidentially, your data will only be identified by a number and the results can be published in a scientific magazine.

Ethical approval was obtained from the research committee of the University of Stellenbosch.

If you need more information you can contact the following persons:

Sr Zelda Williams	Tel:	(W)	938 9464
Dr EM van Schalkwyk	Tel:	(W)	938 5524

Thank you for your help and co-operation.

I ..... read all the information and understand the study. All my questions have been answered to my satisfaction. I understand that I will receive no reimbursement for my participation. I agree voluntarily to participate in this study.

....

SIGNATURE OF PATIENT **DATE**

....

SIGNATURE OF RESEARCHER **DATE**

ADDENDUM B

SURVEY QUESTIONNAIRE

APPENDIX C

Questionnaire about your knowledge of Asthma

We are interested in your opinion about asthma.
Mark (✓) the appropriate statement which you think is true or false.

Here's the first statement:

1. Asthma cannot be cured.

   Do you believe this statement to be true or false? TRUE ☐ FALSE ☐

2. A vaporizer is a good treatment for asthma. TRUE ☐ FALSE ☐

3. People with asthma cannot exercise or play hard. TRUE ☐ FALSE ☐

4. When a person with asthma is doing well they do not need to go to their doctor TRUE ☐ FALSE ☐

5. Asthma is a common reason for many school absences. TRUE ☐ FALSE ☐

6. Asthma tends to run in families TRUE ☐ FALSE ☐

7. Asthma is mainly an emotional illness TRUE ☐ FALSE ☐

8. When asthma attacks stop, you don't have asthma anymore TRUE ☐ FALSE ☐

9. If you have asthma, you would know where to go for treatment TRUE ☐ FALSE ☐

10. You can't have asthma as an adult without having it as a child TRUE ☐ FALSE ☐

A list of things that may or may not be a sign of asthma.
Indicate with a (✓) Yes if it is a sign of asthma and No if it is not a sign of asthma.

11. Is shortness of breath a sign of asthma? YES ☐ NO ☐

12. Is tightness in the chest a sign of asthma? YES ☐ NO ☐

13. Are severe headaches a sign of asthma? YES ☐ NO ☐

14. Is a cough at night a sign of asthma? YES ☐ NO ☐

15. Is wheezing after exercise a sign of asthma? YES ☐ NO ☐

Indicate yes or no with a mark(✓) whether you think this list of things may or may not trigger asthma:

16. Are pets with fur a trigger of asthma? YES ☐ NO ☐

17. Are mosquito bites a trigger of asthma? YES ☐ NO ☐

18. Is dampness a trigger of asthma? YES ☐ NO ☐

19. Are cockroaches a trigger of asthma? YES ☐ NO ☐

20. Is a poor diet a trigger of asthma? YES ☐ NO ☐

21. Is pollen a trigger of asthma? YES ☐ NO ☐

State whether true or false with a mark(✓)

22. Hospitalizations for asthma are preventable. TRUE ☐ FALSE ☐

23. Asthma symptoms can be prevented with the right medications. TRUE ☐ FALSE ☐

24. People with asthma who get relief from over the counter drugs still need to see their doctor. TRUE ☐ FALSE ☐

25. Asthma is a serious health problem in South Africa TRUE ☐ FALSE ☐

26. Asthma care is expensive TRUE ☐ FALSE ☐

27. When a person has a attack they should see a doctor immediately. TRUE ☐ FALSE ☐

28. The emergency room is the best place to get treated for an asthma attack. TRUE ☐ FALSE ☐

29. People can get addicted to their asthma medicines TRUE ☐ FALSE ☐

30. Children with asthma have overprotective mothers. TRUE ☐ FALSE ☐

31. People without medical aid do not get asthma care

TRUE ☐ FALSE ☐

32. Stress makes asthma worse

TRUE ☐ FALSE ☐

Thank you very much for your time.

You have been a great help.

APPENDIX A

Asthma Quality of Life Questionnaire

Thank you for taking this questionnaire. It is part of a research project to learn about the way asthma affects people's lives. All your answers will be treated confidentially. The information will not be entered into your medical record. What follows is a series of statements describing the way in which asthma (or its treatment) affects some people. You are asked to tick the response to each statement, which applies to you over the **past four weeks.**

1. I have been troubled by episodes of shortness of breath

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

2. I have been troubled by wheezing attacks

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

3. I have been troubled by tightness in the chest

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

4. Were you restricted in doing light (easy) activities because of asthma for example walking down the street on level ground or doing light housework

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

5. **Were you restricted in doing heavy (difficult) activities because of asthma for example to walk up hills or doing heavy housework.**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

6. **I have felt tired or a general lack of energy**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

7. **I have been unable to sleep at night**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

8. **I have felt sad or depressed**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

9. **I have felt frustrated with myself**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

10. I have felt anxious, under tension or stressed

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

11. I have felt that asthma is preventing me from achieving what I want from life

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

12. Asthma has interfered with my social life

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

13. I have been limited in going to certain places because they are bad for my asthma

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

14. I have been limited in going to certain places because I have been afraid of getting an asthma attack and not being able to get help

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

15. **I have been restricted in the sports, hobbies or other recreations I can engage in because of my asthma**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

16. **I have felt generally restricted**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

17. **I have felt that asthma is controlling my life**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

18. **I have been worried about my present or future health because of asthma**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

19. **I have been worried about asthma shortening my life**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

20. **I have felt dependent on my asthma sprays**

[1] ☐ Not at all
[2] ☐ Mildly
[3] ☐ Moderately
[4] ☐ Severely
[5] ☐ Very Severely

ASTHMA CONTROL QUESTIONNAIRE

PATIENT ID: _____ DATE: _____

Please answer questions 1 – 6

You are asked to tick (✓) the response that best describes how you have been feeling during the past week.

1. On average, during the past week, how often were you **woken up by your asthma** during the night?

[0] ☐ Never
[1] ☐ Hardly ever
[2] ☐ A few times
[3] ☐ Several times
[4] ☐ Many times
[5] ☐ A great many times
[6] ☐ Unable to sleep because of asthma

2. On average, during the past week, how **bad were your asthma symptoms when you woke up** in the morning?

[0] ☐ No symptoms
[1] ☐ Very mild symptoms
[2] ☐ Mild symptoms
[3] ☐ Moderate symptoms
[4] ☐ Quite severe symptoms
[5] ☐ Severe symptoms
[6] ☐ Very severe symptoms

3. In general, during the past week, how **limited were you in your activities** because of your asthma?

[0] ☐ Not limited at all
[1] ☐ Very slightly limited
[2] ☐ Slightly limited
[3] ☐ Moderately limited
[4] ☐ Very limited
[5] ☐ Extremely limited
[6] ☐ Totally limited

PATIENT ID: _____ DATE: _____

4. In general, during the past week, how much **shortness of breath** did you experience because of your asthma?

[0]	☐	None
[1]	☐	A very little
[2]	☐	A little
[3]	☐	A moderate amount
[4]	☐	Quite a lot
[5]	☐	A great deal
[6]	☐	A very great deal

5. In general, during the past week, how much of the time did you **wheeze**?

[0]	☐	None
[1]	☐	Hardly any time
[2]	☐	A little of the time
[3]	☐	A moderate amount of time
[4]	☐	A lot of the time
[5]	☐	Most of the time
[6]	☐	All the time

6. On average, during the past week, how many **puffs/inhalations of short-acting bronchodilator** (Ventolin/Berotec) have you used each day?
(If not sure how to answer this question, please ask for help)

[0]	☐	None
[1]	☐	1 – 2 puffs/inhalations most days
[2]	☐	3 – 4 puffs/inhalations most days
[3]	☐	5 – 8 puffs/inhalations most days
[4]	☐	9 – 12 puffs/inhalations most days
[5]	☐	13 – 16 puffs/inhalations most days
[6]	☐	More than 16 puffs/inhalations most days

To be completed by a member of the clinic staff

7. FEV_1pre-bronchodilator.....

FEV_1predicted.....

FEV1%predicted.....

(Record actual values on the dotted lines and score the FEV_1% predicted in the next column)

[0]	☐	>95% predicted
[1]	☐	95 – 90%
[2]	☐	89 – 80%
[3]	☐	79 – 70%
[4]	☐	69 – 60%
[5]	☐	59 – 50%
[6]	☐	<50% predicted

ADDENDUM C

PERMISSION TO CONDUCT THE STUDY – UNIVERSITY OF STELLENBOSCH

26 April 2001

Sr ZA Williams
Dept of Internal Medicine

Dear Sr Williams

RESEARCH PROJECT: "A SURVEY TO EVALUATE THE QUALITY OF LIFE OF ADULT ASTHMATICS AT TYGERBERG ACADEMIC COMPLEX"
PROJECT NUMBER : 2001/C049

It is a pleasure to inform you that Subcommittee C of the Research Committee has approved the above-mentioned project on 24 April 2001, including the ethical aspects involved.

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in all further correspondence.

Patients participating in a research project in Tygerberg Hospital will not be treated free of charge as the Provincial Administration of the Western Cape does not support research financially.

Due to heavy workload the nursing corps of the Tygerberg Hospital cannot offer comprehensive nursing care in research projects. It may therefore be expected of a research worker to arrange for private nursing care.

Yours faithfully

CJ VAN TONDER
RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG)
Tel: +27 21 938 9207 / E-mail: cjvt@sun.ac.za

CJVT/ev

ADDENDUM D

PERMISSION TO CONDUCT THE STUDY – TYGERBERG ACADEMIC HOSPITAL

Dr J P Müller

938-4141

24/1

13 Augustus 2001

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FAKULTEIT GESONDHEIDSWETENSKAPPE

Geagte Me Williams

NAVORSINGSPROJEK: PROJEKNOMMER 2001/C049
"A SURVEY TO ASSESS THE QUALITY OF LIFE OF ADULT ASTHMATICS AT TYGERBERG ACADEMIC HOSPITAL COMPLEX".

Hiermee word toestemming verleen dat bovermelde navorsingsprojek by Tygerberg Hospitaal uitgevoer mag word.

Vriendelike groete

DR. J.P. MÜLLER

HOOFDIREKTEUR

ADDENDUM E

ACADEMIC YEAR DAY ABSTRACT 2002

70. QUALITY OF LIFE IN ADULTS WITH ASTHMA: A REVIEW OF THE LITERATURE

Sr ZA Williams, Dr EM van Schalkwyk, Prof EM Irusen,
Respiratory Research Unit, University of Stellenbosch.

Quality of life (QOL) is a concept rooted in the social sciences. It relates to productivity at work, role and social functioning, self-care, rest and sleep and the ability to enjoy recreational activities. These are items identified by patients as important in their day to day lives. Asthma is a chronic, inflammatory respiratory disease that influences QOL through respiratory impairment. It causes great anxiety in patients because of its unpredictability. In recent years there has been an increased interest in the study of quality of life in asthma. There is good evidence that asthma is a cause of impaired QOL. Although it has become a standard criterion for measuring response to treatment during clinical trials it is still not utilised during clinical practice. Nothing in current practice obliges the health care worker to address the differences between what we do and what the patient may want [Rockwood 2001]. Various validated QOL Questionnaires have been developed. These include the SF-36, Juniper's and Woolcock's. Although there is a relatively weak correlation between asthma QOL scores and objective measures of asthma severity and control, it captures those perceptions that are unique to the asthma experience such as a patient's ability to cope with his disease and satisfaction with health care delivery. Quality of life in asthma is an under-researched area in South Africa. Long-term pulmonary care demands greater responsibility from the patient as well as health care workers. Information on QOL in asthmatic patients may be valuable in the clinical setting to direct intervention strategies and may aid health care planners in setting priorities for health care resources.

ADDENDUM F

SCREENING CHECKLIST

Afdeling / Section C

Insluitings kriteria / Inclusion Criteria

1. Simptome van Asma / Asthma Symptoms:

		Yes	No
1.1	Herhaalde episodes van hoes, fluitbors, toebors en kortasemheid. / Recurrent episodes of coughing wheezing, chest tightness and breathlessness.	☐	☐
1.2	Simptome kom voor of vererger in aand. / Symptoms occur or worsen at night.	☐	☐
1.3	Simptome kom voor of vererger in die teenwoordigheid van / Symptoms occur or worsen in the presence of oefening / exercise	☐	☐
	virusinfeksies/viral infections	☐	☐
	diere met pels/animals with fur	☐	☐
	huisstof/house dust	☐	☐
	stuifmeel/pollen	☐	☐
1.4	Positiewe veltoets vir algemene allergene./Positive skintest to common allergens.	☐	☐
1.5	Familiegeskiedenis van asma, hooikoors en/of ekseem. /Family history of asthma, hay fever and or/eczema	☐	☐

2. FEV_1 ☐ Absolute value / Absolute waarde ☐ % predict/ % voorspel

Mild (>80%)	Moderate (60-80%)	Severe (<60%)
☐	☐	☐

3. **Longfunksie voor BD / Lung function pre BD**

	Absoluut Absolute	% Voorspel % Predict
FEV_1		
FVC		
FEV_1/FVC		

4. **Longfunksie na BD / Lung function post BD**

FEV_1		
FVC		
FEV_1/FVC		

5. **Longfunksie na kursus steroiede / Lung function post course steroids**

FEV_1		
FVC		
FEV_1/FVC		

6. **FEV_1 Omkeerbaarheid / Reversibility**
