

An Evaluation of Parental Knowledge of Childhood Asthma in a Family Practice Setting

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ABSTRACT

The purpose of this study was to measure and evaluate parental knowledge and misconceptions with regard to asthma and its treatment, to identify parental concerns with regard to the disease and its effects on their children, and to identify selected socio-demographic and medical correlates of the above. A cross-sectional survey was conducted among 54 families with a child with asthma.

The sample comprised all the parents of a consecutive series of asthmatic patients between the ages of two to eighteen years attending a family practice in Mandalay on the Cape Flats. Data were collected by means of a structured questionnaire administered to 52 mothers and 48 fathers, reflecting a 95.2 per cent response rate. Respondents completed the questionnaire in their homes. A 55 item Asthma Knowledge Test was developed and validated to assess medical knowledge. Parents obtained an average score of 72%. Scores of over 70% were obtained in the sub-sections of aetiology, symptomatology, pathophysiology, precipitants and environmental control. Parents were less informed in the sub-sections of asthma prognosis, general medical knowledge and asthma therapy. Misconceptions and deficiencies in asthma knowledge which could lead to inadvertent non-compliance were identified. The following misconceptions were shared by a significant number of parents: inhaler therapy weakens the heart, regular administration of medication leads to addiction and medicines becoming ineffective, and folk remedies are effective in asthma therapy. Parental educational status was the only significant correlate with performance on the Asthma Knowledge Test. There was no significant difference

in the performances of mothers and fathers. 47% of parents smoked but there was no significant difference in the scores of smokers and non-smokers.

Parental concerns centred predominantly on their lack of confidence to manage acute asthma attacks, followed by concern as to whether their children will out grow asthma. Dependence on asthma medication and its perceived harmful effect on the heart and lungs were other concerns.

The findings suggest the need for systematic asthma education especially with regard to acute attack management and preventive medications. The aims of such education should be to increase asthma knowledge, develop skills, improve attitudes, and develop positive expectations toward the outcome and effectiveness of treatment. An effort should be undertaken to discourage parental smoking in asthmatic families. Attention should be given to dispel misconceptions during educational programmes. The increased information needs of parents with a lower education should be addressed by health professionals. Parents should receive adequate information during the early stages of the disease to minimise their insecurity in coping with the illness and prevent the development of misconceptions that undermine their confidence in medications and care givers.

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NOTES

1. For the ease of reading the text, sentences start with percentages written as numerals, e.g. 52 per cent and not fifty-two percent.
2. Standard English terminology is used throughout, e.g. "per cent" and not "percent".
3. The increasingly popular term "family practice" is used for what is traditionally known as "general practice".

CHAPTER ONE

1. Introduction

Childhood asthma is the commonest chronic condition in developed communities.(1) In developing countries, possibly as a result of rapid urbanisation and the effects of industrialisation, childhood asthma is becoming a significant problem.(2) Moreover, children under the age of 15 years constitute about 40-50 per cent of the population in developing countries compared to approximately 22 per cent in developed ones.(2) In South Africa the estimated prevalence of childhood asthma is between 3-6 per cent.(1,2) Poverty, with its multitude of associated problems, is a major impediment to effective asthma care especially with regard to access to health services and the inadequate use of preventive strategies. (2)

Asthma treatment has improved significantly over the past two decades with the widespread use of new and specific medications inducing a sense of control over the disease. Hence, it is disturbing to read and hear reports of increased deaths from asthma.(3) Further to its worldwide increase in prevalence, asthma utilises an increasing share of the health care budget with more contacts of patients with medical doctors and escalating admissions to hospitals. (4,5)

Paradoxically, asthma is a disease defined by its reversibility, yet it can be fatal; it is characterised by being episodic, yet it is a chronic disease; newer medications are more efficacious, but most fatalities are considered due to undertreatment and the burden of illness is increasing.(4) Under-diagnosis and under-

treatment of asthma by the medical profession is one factor; the other is poor self-management by a large number of patients and/or parents with non-adherence to medications and environmental control strategies.

Inadequate knowledge about the disease results in inappropriate management strategies, faulty decision-making and delayed care.(4) Providing information regarding inter alia the nature of the disease, the rationale for treatment, the correct use of inhaler devices and avoidance of precipitants and triggers should contribute towards improving compliance if it is linked with bringing about attitudinal and behavioural changes in patients and parents who should share in the responsibility for their own or child's health and illness.(6) Clinical experience in family practice has indicated that many myths and misconceptions about asthma are prevalent in the general community and amongst families with asthmatic children in particular. Researchers have shown that misconceptions negatively influence compliance and attitudes towards the disease.(7,8)

The management of asthma presents a challenge to family practitioners. If they are to care for patients with asthma, they must accept responsibility to be educators and narrow the gap between what is known about assessment and effective therapy and the unwarrantedly high morbidity and mortality.(4) Unlike the hospital out-patient doctor, the family doctor is strongly placed to offer continuity of care.(9) This is not only of value for consistent medical care, but should also lead to a strong and positive relationship between doctor and patient with the potential for optimal self-management of the disease.(9) But the challenge is even greater in the face of the evidence of doctors' own lack of knowledge

about childhood asthma and gaps in the hallowed doctor-patient relationship.(7,8,10)

To date, however, there is a dearth of local research which has examined the disease-related knowledge of families of asthmatic children who are managed in family practice settings. Such information is particularly important if more asthmatic children are to be optimally managed in primary care settings.

In an attempt to address some of the above in a South African family practice context, this study was undertaken to assess parental disease-related knowledge, misconceptions and concerns regarding childhood asthma.

1.1 Study Aim

The overall aim of the present study was to assess parental knowledge of childhood asthma in a family practice setting.

1.2 Study Objectives

More specifically, the purpose of the study was to:

1. Measure and evaluate parental knowledge and misconceptions with regard to childhood asthma and its treatment.
2. Identify parental concerns with regard to the disease and its effects on their children.
3. Identify selected socio-demographic and medical correlates of the above.

CHAPTER TWO

2. LITERATURE REVIEW2.1 Childhood Asthma: an introduction

Asthma is a common illness that has afflicted mankind for many centuries. The word "asthma" has its first recorded use in the Iliad of Homer, referring to panting or shortness of breath.(11) Hippocrates described it in the fourth century BC and through his school it acquired the meaning of paroxysmal dyspnoea.(11)

The cause of asthma is unknown. There is a genetic component to the disease but the mode of inheritance is unclear. The evidence suggests that asthma is a disease in which a genetic predisposition to the asthmatic diathesis is expressed only when the at-risk individual comes in contact with an environmental trigger.(12) This stimulus either sets off or aggravates an inflammatory reaction that is localised to the airways.

Asthma is a disease characterised by variable airflow obstruction in which the sufferer's airways are very sensitive to a variety of irritants that readily lead to their narrowing.(12) This airways obstruction or bronchoconstriction is due to a combination of oedema of the bronchial wall, plugging of the lumen with inspissated mucus, and spasm of the bronchial smooth muscle.(12) The underlying mechanism for these events is airways inflammation.(12)

The severity of asthma can vary from occasional attacks of mild wheeziness and breathlessness, to severe life-threatening episodes that require emergency

hospitalisation, and to chronic debilitating breathlessness that constantly interferes with quality of life. The severity may vary within an individual so that mild asthmatics can have severe attacks or the disease may remit for months or years and then return for no apparent reason.(12)

The narrow airways of children mean that small degrees of airways narrowing due to mucosal oedema can have a marked effect on respiratory function.(12) A large proportion of children have what is termed atopic asthma, in which a sensitivity to generally airborne allergens is thought to play an important part in the aetiology of childhood asthma. (12). Treatment of childhood asthma follows the same general principles as adult asthma. However, many children under two years of age respond poorly to bronchodilators as the airway narrowing is thought to be predominantly due to mucosal oedema and not bronchial smooth muscle spasm.(12)

The long term effect of poorly controlled asthma is persistent changes in small airway lung function and lung elastic recoil, similar to those in early chronic obstructive bronchitis and emphysema.(13,14) Even during symptom-free intervals, hyperinflated lungs already have enlarged alveolar spaces.(13) Hence, a consequent therapeutic approach should aim to normalise the child's pulmonary function even when symptoms or signs are lacking.(13)

2.2 Prevalence of childhood asthma

Childhood asthma is the commonest chronic condition in developed countries.(1) Evidence suggests that asthma prevalence may have increased over the past 20 years,

that it is imposing an increasingly large burden on the health services and is claiming an ever greater number of lives each year.(1,3,4) Progress in the field of its epidemiology has been hindered by the lack of standardized instruments and uniform protocols.(3) This has caused difficulties in comparing studies conducted in the same areas over time and in different geographical areas because of differences in methodology and diagnostic criteria.(1) Increases have been reported from national samples in Sweden, England, and Finland, and increases have been recorded not only in the prevalence of diagnosed asthma but also in the prevalence of an airway response to exercise and in symptoms.(3)

Apart from the concerns of the comparability of studies, other researchers are sceptical as to whether the overall prevalence has increased.(4) They ascribe increases to the readiness of doctors to label viral respiratory infections with wheeze as asthma rather than bronchitis with wheeze. However, the use of day care centres along with increased mobility and social interaction, have resulted in an increased number of respiratory and gastrointestinal infections at earlier ages.(15) Physicians are also now more aware that recurrent cough may represent asthma and the awareness and availability of diagnostic tests help identify patients not previously diagnosed.(4)

The prevalence of asthma in Europe, North America and Australia is approximately 10-15 per cent.(1) Prevalences in Scandinavia have been reported as low as 5 per cent and here too evidence indicates that it is growing.(1) There has been a notion that asthma prevalence is lower in developing countries but recent international comparisons refute this.(1)

2.3 Prevalence of asthma in Africa

In 1969 Wesley and others (16) published one of the earliest reports on childhood asthma based on hospital admissions in black, Indian and white children in Durban, South Africa. During a 5-year period they determined the admission incidence amongst black children to be 0,02 per cent compared to 0,79 per cent amongst white children. They predicted an increase in asthma amongst black children with increasing exposure to the socio-economic conditions similar to white children.

Community prevalence studies in Africa include those of Carswell and others (17) among rural Tanzanian school children in whom they found a prevalence of 3.3 per cent and Godfrey's (18) survey in rural Gambia which found a similarly low prevalence. In 1979 Van Niekerk and colleagues(19) verified Wesley's prediction by showing that the prevalence of exercise-induced bronchoconstriction in urban and rural Xhosa children to be 3.2 and 0.1 per cent respectively. Keeley and co-workers (20) in their Zimbabwean study found strikingly similar results. In a second urban study among children of higher socio-economic status, Keeley's group reported a prevalence of 5,8 per cent, with no differences between white and black children.(20) Urbanisation and higher material standards of living appear to be associated with a higher prevalence of reversible airways obstruction.

The prevalence of asthma amongst black urban South African children appears to be rising.(1) At Baragwanath Hospital, Johannesburg, asthma accounted for 3.8 per cent of the paediatric hospital admissions for 1992 and 1993, which represents a 200-fold increase in paediatric asthma admissions when compared with the figures presented by

Wesley's group.(1) There has been an increase in hospital admissions for acute childhood asthma in Cape Town as determined from the records of the Red Cross War Memorial Children's Hospital from 1978 to 1990.(22)

It can be concluded that urbanisation or urban dwelling is a significant risk factor for bronchial hyper-responsiveness and that a similar prevalence of asthma exists among different race groups of the same socio-economic status.

2.4 Natural History Of Childhood Asthma

The natural history and prognosis of asthma for persons suffering from this condition are extremely variable.(23) This is in part related to the existence of different sub-groups of patients diagnosed with asthma. Even within such subgroups, the natural history of asthma varies greatly among individuals.

About one-quarter of all children wheeze at some time in their lives with a peak incidence in the second year of life.(3) Childhood asthma resolves by young adulthood in 20 to 50 per cent of cases.(4) Two thirds of children with mild symptoms will outgrow their disease but 70-90 per cent of those with more troublesome asthma continue to have symptoms in mid-adult life.(15,24) Severe disease, reflected by onset after age two, more than ten attacks throughout childhood, lower peak flow rates in childhood and signs of atopy, which are themselves related with each other, are associated with persistence of asthma.(3,15,23) Children who cough in early childhood have three times the risk of developing persistent wheeze than those who are asymptomatic.(3) The need for treatment tends to decline around puberty and

those whose need for treatment declined before the onset of puberty do best.(3) If the increase in the prevalence of childhood asthma continues into adult life this will create substantial health care problems with potentially important economic consequences through time off work and cost of treatment.(24)

The natural history of asthma in some cases appears to include the development of irreversible airway obstruction and adults with asthma may experience a more rapid decline in ventilatory function with increasing age than non-asthmatics.(23) Children with wheezing symptoms that eventually resolve appear to have normal pulmonary function as adults. However, persistence of wheezing into young adulthood is associated with persistence of ventilatory impairment.(23) It has been observed that many who have improved during adolescence relapse, particularly in the third and fourth decades.(4) The relapse is likely to be persistent and associated with an increased loss of lung function which may be irreversible.(4) The impact of treatment on the "natural" course of asthma remains to be fully determined, especially in those at greater risk of persistent disease. An early study(24) seems to indicate that prolonged use of inhaled corticosteroids failed to alter permanently the long term course of moderately severe asthmatics whilst another(25) suggests that delaying the introduction of inhaled steroids may result in irreversible changes to the airways.

2.5 Morbidity from childhood asthma

Asthma is a relatively infrequent cause of death, the greater problem is the burden of illness.(23) The disease exacts an enormous toll on patients, families and

the health care delivery system. While it is not possible to quantitate the personal suffering caused by asthma, some aspects of the burden that this condition imposes on some populations has been estimated.

In the United States a reported 2.7 million children younger than 18 years were reported by an adult in the household to have asthma in 1988.(26) These asthmatic children experienced the added burden, when compared with non-asthmatic children, of 10.1 million days missed from school, 12.9 million contacts with medical doctors, and 200 000 hospitalisations.(26) Almost 30 per cent of children with asthma had some limitation of activity, compared with only 5 per cent of children without asthma.(26) 10 per cent of children had severe disease as measured by frequency of symptoms and limitations of function; these children accounted for 35 per cent of hospitalisations for asthma and 77 per cent of the days in hospital.(26)

In the home environment, asthma has a significant and wide-ranging impact on the child and family (refer table 2.1). About 50 per cent of parents report that asthma has an adverse emotional effect on their children who feel restricted socially, embarrassed about taking medications, and fearful about attacks.(4) This stress is aggravated by emergency room visits and night-time attacks when both parents and child lose valuable sleep. Asthmatic children often worry about death and have doubts regarding their physical abilities.(4,7)

In the school setting several significant problems exist for asthmatic children and their families.(4,27) School officials often lack the necessary information concerning the management of the asthmatic child at

TABLE 2.1

MORBIDITY FROM ASTHMA: RESPONSES OF PARENTS CONCERNING THE
IMPACT OF ASTHMA.

	% POSITIVE RESPONSES
Adverse effect on emotional life	46
Worries about death	21
Worries about medication	10
Perceive asthma as life-threatening	
Overall	47
For mild asthma	41
Visits to physician for care of asthma*	89
Single emergency room visit*	48
Multiple emergency room visits*	30
Hospitalisation*	21

*In the previous 12 months.

Data from the American Asthma Report, in which 250 parents of children suffering from asthma were interviewed over the phone in 1988. (Modified from Bloomberg GR, Strunk RC: Crisis in Asthma Care. *Pediatric Clinics of North America* 39(6): 1225 - 1241, 1992).

school.(27) Children are often not allowed to keep or use their inhaler in the classroom.(4) Having to ask permission to leave the room may delay the treatment of individual attacks and increase the probability that the child will leave the school because of asthma.(4) Participation in physical education classes is another problem area with either unnecessary restrictions or inadequate rest periods.(27) Teachers often do not know that all exercise to the limit of the child's tolerance is beneficial.(27) All of this sets the child apart from his/her peers and often reduces his/her self esteem.

The impact of childhood asthma on parents is considerable. Each acute attack disrupts their lives especially if emergency room visits or hospitalisation are required.(4) Mothers perceive themselves as playing the major role in controlling medications and making decisions regarding attendance at school.(7) They feel that the burden and worry of the illness is on their shoulders, with other members of the family, including the father, bearing very little of the responsibility and often failing to show concern.(7)

Hospitalisation rates for asthma have increased dramatically in the past two or three decades.(4) The increase in hospitalisation for children with asthma in the United States, 112 per 100 000 in 1970 to 279 per 100 000 in 1980, contrasts sharply with the stable rate of hospitalisation for all other diseases in children.(4) Children less than four years of age have been disproportionately affected, accounting for 46 per cent of childhood asthma admissions in 1979 and 54 per cent in 1987.(4) All studies indicate a large increase in cost per admission, increasing by 30 per cent from 1972 to 1983.(4) 35 per cent of hospitalisations for asthma and 24 per cent of the hospital expenditure are utilised by

children under the age of 18 years.(4) In South Africa, a similar trend has been described.(22) Asthma admissions have shown a sharp upward rise from 1978 to 1984, a slower rise through 1987 and levelling off since.(22)

The reasons for these increases have not been fully accounted for. Possible factors include the increased prevalence and severity of the disease, changes in the preference of disease classification and discharge diagnosis, changes in admission criteria and increased numbers of readmissions.(4) Increased self-referral to hospital and improved access to hospital by a larger population than previously are other contributing factors.(22) In the United Kingdom, general practitioners admit more patients from the emergency room than in previous years for the same severity of disease.(28) Small changes in case-management practices could produce large increases in admission rates given the high prevalence of asthma and frequency of attacks.(28)

2.6 Mortality trends in childhood asthma

Asthma is not usually a fatal condition. In fact, improved medications have increased the potential to prevent attacks. Asthma mortality studies are beset with numerous problems.(3) Studies indicate that there are significant differences in death-certification practices between countries and that the underreporting of asthma deaths affects the recorded mortality rates for asthma for the different countries.(3) Changes in the clinical definition of disease and coding of deaths can also affect mortality trends.(3) Studies since the 1940s have determined the death rate from severe asthma to range

from 1 to 3 per cent.(4) In the United States, death due to asthma in all age groups rose from 0.8 per 100 000 in 1977 to 1.9 per 100 000 in 1988.(4) The deaths in 1988 totalled 4597 of which 119 were under the age of 15 years.(4) Advances in medications for treatment of asthma have not prevented deaths. In fact, there is concern that medications may be playing a role in increasing death rates due to asthma.(4) Studies from New Zealand and Canada suggest a relationship between death and beta-agonist overuse.(4) However, studies into the circumstances surrounding deaths from asthma are handicapped by the lack of comparative information on those who survived asthma attacks.(3) Such studies report on the poor ability of patients and doctors to recognise serious symptoms, undertreatment with steroids and the presence of psychosocial problems, but the degree to which they are responsible for the deaths is difficult to determine.(3) Questions relating to mortality have been difficult to resolve as the reliance on uncontrolled audits is not acceptable.(3) Case-control studies are an improvement but the lack of a credible independent marker of severity limits their conclusions.(3)

In summary, the rising prevalence of childhood asthma, the documented increases in the burden of the illness on the family, and the increase in mortality, together underscore the need to improve the disease-related knowledge and self-management skills of parents and patients.

2.7 Parental knowledge of chronic childhood illness

An in-depth review of the literature regarding knowledge of chronic illness in parents and the main correlates of this knowledge has recently been described by Henley.(29) The disease-related knowledge of patients and parents regarding diabetes, cystic fibrosis, cancer, epilepsy, juvenile chronic arthritis and asthma was reviewed.

Parental status is a consistent correlate of knowledge with mothers being better informed than fathers. It is speculated that the mothers' greater contact with health care providers and their involvement with daily decision-making and care necessitated them to enquire more about the illness. Social class is an inconsistent correlate of parental knowledge but problems in measurement could account for this. No significant correlation exists between parental educational level and knowledge. The ability to understand a disease, researchers suggest, is more an emotional than a cognitive phenomenon and the degree of emotional resistance is dependent on the nature of the illness, its cultural desirability, the acceptability of its outcome, and whether acknowledgment of the reality of the illness forces drastic changes in preplanned parental functioning.(30) No significant relationships have been detected between knowledge and duration of illness, number of clinic attendances or hospitalisations.

The interpretation of correlational evidence between parental knowledge and chronic illness requires caution as studies reveal complex relationships between variables that are best dealt with using multivariate analysis.(29)

2.8 Parental knowledge of childhood asthma

A review of published research on parental knowledge of childhood asthma was undertaken following a Medline search using the keywords "asthma", "parents", and "knowledge". Six studies have evaluated parental knowledge of childhood asthma with contrasting results. A chronological summary of these studies is presented in Table 2.2.

In New Zealand, Reddihough and co-workers(7) (1976) evaluated the understanding of the disease and its treatment amongst the parents of 41 children attending a children's hospital and managed by paediatricians and chest physicians. They found the level of knowledge to be poor with deficiencies in the area of drug treatment. Misconceptions about asthma and its treatment were common and adversely influenced compliance. Parents expressed significant anxieties and uncertainties which, in their view, good doctor-patient communications should have alleviated.

Hilton and colleagues(31) (1982) in a preliminary pilot study to a controlled trial reported on the level of knowledge of patients as well as a morbidity assessment. Patients' level of knowledge was low and no significant correlation was found between patients' level of knowledge and level of morbidity.

Spykerboer and others(32) (1986) in an Australian hospital-based case-control study of 128 families, determined that parents' knowledge of childhood asthma was satisfactory but detected a significant amount of misconceptions about asthma amongst them. They conclude that attempts at improving self-care of the disease by focusing on knowledge alone was not sufficient and

TABLE 2.2

KNOWLEDGE OF CHILDHOOD ASTHMA IN PARENTS: A SYNOPSIS OF RESEARCH STUDIES

REFERENCE	SAMPLE CHARACTERISTICS		SAMPLING METHODS	MEASURING INSTRUMENT
	SIZE	AGE OF CHILDREN (YEARS)		
Reddihough, Landau, Jones and Rickard (1978)	41 Families	9 - 11	Attenders at a specialist clinic and general medical clinic	Questionnaire and interview. No psychometric data.
Hilton (1982)	50 patients	5 - 65	Random general practice sample.	Questionnaire
Spykerboer, Donnelly and Thong (1986)	128 parents 110 controls	1 - 31	Randomly selected from children admitted to hospital with a definite diagnosis of asthma. Controls recruited from children who were hospitalised for minor surgical complaints.	Questionnaire administered by trained interviewers

Continued ...

Table 2.2 Continued

Van Esperen, Jandera, De Neef, Hill and Law (1986)	30 parents 10 controls	1 - 12	Randomly selected from children attending paediatric casualty. Controls from parents attending casualty.	Questionnaire.
Fitzclarence and Henry (1990)	70 parents 84 controls	not stated	Randomly selected from asthma clinic attenders and asthma support group members. Controls from non-respiratory clinic attenders.	Questionnaire.
Mesters, Pieterse and Meertens (1991)	42 parents	1 - 6	Non-randomly recruited from general population and pediatrician's practice.	Questionnaire and focus group interview.

misconceptions must be actively dispelled. They found, moreover, that improved attitudes towards asthma would enhance preventive and promotive health behaviour. Using data from the same study, Donnelly and co-workers(33) (1987), reported on the parents' attitude to compliance and treatment. They highlighted the parents' conflict regarding long-term drug treatment. Whereas both control and study groups agreed that the advantages of medications outweighed the disadvantages, more than 80 per cent of both groups believed that children should not be given prolonged treatment, and more than 40 per cent considered long-term treatment to be unnatural and harmful, and about 30 per cent thought that children's bodies were too small to cope with medications.

Van Esperen and co-workers(34) (1986) compared parental knowledge of childhood asthma with that of controls. They determined the mean score of the asthmatic group to be 69.1 per cent (range 44 to 86 per cent) and that of the control group to be 53.6 per cent (range 44 to 66 per cent). The considerable overlap between the two groups casts doubt as to the discriminatory validity of their questionnaire as a measuring instrument.

Fitzclarence and Henry(35) (1990), in an attempt to validate an asthma knowledge questionnaire, studied 70 parents of asthmatic children and compared them to 84 controls. The parents had a mean score of 81.6 per cent (range 58 to 100 per cent) whilst the controls had a mean score of 41.9 per cent (range 0 to 67.7 per cent). The study was able to determine, indirectly through the responses of the controls, the level of knowledge of childhood asthma in the background community. The general community perceived asthma as being managed by treatment of acute attacks rather than prophylaxis, allergy and outdoor air pollution were named as prominent

triggers rather than infection and exercise, both asthma and the drugs used to treat it were regarded as damaging the heart, a milk-free diet was thought to be necessary for most children with asthma, and antibiotics were regarded as an intrinsic part of asthma therapy. A weakness in their study was that the study group, compared to controls, was better educated, older and engaged in more professional occupations which limits the overall generalisation of the findings. Although the mean score increased marginally from 41.9 to 45.8 per cent when the professionals' performances within the control group were evaluated, no mention was made as to their total number within each group.

In a study from the Netherlands, Mesters and colleagues(8) (1991) determined the level of knowledge and misconceptions of parents, and their experience of satisfaction with health care providers, using a questionnaire and focus group interview. Parents were reasonably well informed on aetiology and triggers of asthma but misconceptions existed as to what preventive actions to take. A lack of confidence amongst parents in performing preventive actions was mainly a result of not knowing why, when and how these should be performed. Non-compliance with prescribed medications was ascribed to negative outcome expectations about the effectiveness of medications by parents. The proper understanding of using inhalers was found wanting. Parents reported about difficulties with their general practitioners (GPs) especially during the early stages of their children's asthma. Dissatisfaction was expressed in the quality and quantity of care and information received from their GPs. Parents perceived that GPs did not take the symptoms seriously, that GPs often hesitated to diagnose asthma in the first place, and on more than one occasion initiated antibiotic therapy instead of asthma therapy. Parents

felt "deserted" by their GPs and would change doctors or seek a referral to a specialist. Shortcomings of this study were the small and non-random sample, and the overrepresentation of more highly educated respondents with a possible selection bias to dissatisfied parents with bad experiences as 38 parents were recruited in response to a newspaper advertisement.

In summary, the research literature reflects a general trend towards an increase in parental knowledge of childhood asthma over time. However, several studies noted gaps in parental knowledge regarding drug therapy, management of acute attacks and the presence of misconceptions especially with regard to drug usage.

2.9 Asthma self-management programmes

An in-depth literature review of asthma self-management programmes was beyond the scope of this study. Moreover, this literature has recently been reviewed.(36) An overview of self-management programmes follows.

As already mentioned, morbidity and mortality from asthma have increased over the past decade despite improved understanding and significant advances in medical therapeutics. Because poor compliance with prescribed medical regimens is a contributing factor, considerable attention has been directed to this issue and to the role of health care providers in fostering improved adherence.(37)

In 1988 the National Asthma Education Program (NAEP) was initiated in the United States of America. One of its goals is to encourage education as a routine part of medical care.(37) This was in response to the huge

burden asthma imposes on patients, their families, and the health care system.(4) Several centres have developed effective asthma self-management programmes. These programmes were designed to assist families learn how to lessen the impact of asthma on the family and become active partners with their physicians in managing the disease. The aim of self-management programmes extends beyond fostering improved compliance and includes the development of self-monitoring skills, decision-making, and communicating about both symptoms and treatment regimens.(38) Being such a variable disease, asthma necessitates that parents and patients make key observations and exercise considerable judgement. Hence, they must be educated and trained to take appropriate action under a wide variety of circumstances.(37) Developed and tested in a variety of clinical settings with patients and families from different social, educational, and economic backgrounds, the programmes have, for the most part, been shown to be effective, although none has been shown to have superiority.(37)

The use of the term "self" may result in the misconception that self-management means self-treatment, removed from a physician's guidance.(23) Rather, the health care provider, patient, and family should deal with asthma as a team, communicating frequently so that decisions are made with complete information. Hence, the term "co-management" was introduced to reflect the co-operative team approach which is important in the self-management process.(23)

Most of patient education occurs in the physician's office, with formal courses supplementing that process.(37) When families return from a formal course, they usually have a better base of knowledge and understanding on which the physician can build a

realistic care plan. The process must be regarded as a continuum, with ongoing re-evaluation and reinforcement of knowledge and appropriate self care.(37) One of the positive effects of asthma education programmes is often an improvement in the doctor-patient relationship. This is in part due to parents being assisted to develop reasonable expectations, both for their child and the medical care team. A positive doctor-patient relationship enhances patient compliance.(37)

In the management of chronic childhood illnesses such as asthma, the health care provider and the family should work in an active partnership, each having distinct as well as overlapping responsibilities.

2.9.1 Components of an effective programme

Health care professionals tend to equate the transfer of information with health education.(6) The critical issues of bringing about behavioural change in patients, making patient education a planned learning experience and having patients share in the responsibility for their health and illness do not feature prominently in medical training.(6) An effective self-management programme must involve participants actively with emphasis on the acquisition of skills. The ability to make valid observations, use good judgement, and make appropriate decisions must be fostered. The four essential features of effective programmes are reaching agreement on goals, rehearsal, repetition and reinforcement.(37)

2.9.1.1 Reaching agreement on goals

Before parents can have appropriate expectations about an asthma treatment programme, physicians must reach

consensus.(37) Currently there seems to be a considerable gap between the unacceptably high level of morbidity experienced by many, if not most, children with asthma and the degree of control of symptoms that the expert panel of the NAEP considers to be attainable, namely, that asthmatics should lead normal lives.(37) This goal is only attained by a small minority of school-aged asthmatics and adolescents. Part of the reason that both parent and physician accept more morbidity than necessary is that they think of asthma not as a chronic disease but as an episodic illness. Consequently the emphasis is on symptomatic use of medications rather than continuous preventive environmental measures and drug usage.(37)

2.9.1.2 Rehearsal

Parents and children should be expected to discuss and demonstrate the elements of good care within the asthma education programmes and doctor's office. A written crisis plan is essential, and parents should know when to increase therapy, when to call the doctor or when to go immediately to an emergency centre. The proper use of metered dose inhalers, symptom diaries, peak flow meters and nebulisers must be demonstrated, and parents and children should be able to show that they have acquired competency with these skills.(37)

2.9.1.3 Repetition

Repetition, from both the educator and doctor, is necessary to ensure that the material presented is understood and accepted by parents and patients.(37)

2.9.1.4 Reinforcement

Positive reinforcement in the form of praise from the educator, doctor and ancillary staff can assist people to learn and acquire new skills. But success and seeing the improvement in the quality of their lives is perhaps the most effective reinforcer. (37)

2.9.2 Tasks of a self-management programme

Several tasks have been identified as part of a self-management programme. (23) They are: attack prevention, attack management and improving social skills related to asthma management. Recent studies have focused on family and patient behaviours needed for effective asthma management and have used strategies derived from social learning theory and principles of instructional technology which have proven effective in altering behaviour. (23,38)

2.9.2.1 Attack prevention

The patient must recognise early signs of an attack, act on these signs in appropriate ways, identify and avoid triggers to wheezing and take prescribed preventive medications properly and on time.

2.9.2.2 Attack management

This involves practising efforts to rest and staying calm, maintaining adequate hydration, using prescribed medications, seeking assistance as warranted and following other steps outlined by the doctor.

2.9.2.3 Asthma-related social skills

These refer to communicating with the doctor and handling problems at work, school, home and with friends.(23)

2.10 Conclusion of literature review

The last two decades have seen significant medical improvements in the understanding and treatment of asthma. Nonetheless, the incidence and prevalence appear to be rising especially in the urban areas. Asthma morbidity continues to rise and its load on the providers and financiers of health care is taking on alarming proportions. Parental knowledge especially relating to therapeutics can be improved. Self-management programmes can make an impact on improving disease-related knowledge, attitudes and skills. In South Africa, the recently launched National Asthma Education Programme has as one of its objectives to improve the knowledge and attitudes of patients about the detection, treatment and control of asthma. Such a co-ordinated strategy should hold the key to reducing the burden of illness on patients, families and communities.

CHAPTER THREE

3. Method**3.1 Study design**

A cross-sectional analytic and descriptive survey design was adopted.

3.2 Study population

The study was conducted from the researcher's family practice located in Mandalay, a suburb close to Mitchell's Plain on the Cape Flats. The first residences were built in the area during the late 1970s but a large housing development from 1986 onward contributed to its present size. The family practice was started in 1989 and is one of three practices serving approximately 2000 homes. The local population is a mixture of working- and middle-class families and includes many working mothers.

3.3 Study sample

The sample comprised the parents of a complete consecutive series of all children between the ages of 2 to 18 years with the diagnosis of asthma and who had attended the practice between January 1989 to February 1993. The diagnosis of asthma was made whenever the patient responded to bronchodilator therapy for recurrent episodes of coughing and wheezing. A minimum of two

illness episodes was required. Children under two years of age were excluded as the diagnosis of asthma is often difficult in this age group.

3.4 Data collection

Data collection took place over a four month period (March to June 1993). 75 patients were identified. 16 families had relocated and were not contacted. All parents of the remaining 59 patients were informed of the theoretical and practical importance of the study. They were given a guarantee of complete confidentiality. The parents of 5 patients declined to participate as they did not consider their child deserved to be labelled "asthmatic". In addition to recurrent episodes of mild bronchospasm, two of these latter patients had moderate eczema.

Questionnaires were personally delivered to parents at their homes or when they attended the practice during the study period. Within three to four weeks of delivery, parents were telephonically re-contacted to establish whether the questionnaires had been completed. These were either personally collected or returned by the parents to the practice.

105 questionnaires were issued to the parents of 54 patients, 3 of whom were single mothers. This personalised approach resulted in 100 of the original 105 questionnaires being returned - 95.2 per cent response rate (or 85.5 per cent if the total of 59 patients is considered). 48 fathers and 52 mothers comprised the final sample.

3.5 Questionnaires

Data were collected by means of a self-administered questionnaire i.e. respondents completed the questionnaire unsupervised. Each parent was issued with an identical questionnaire (Appendix 1).

The questionnaire consisted of three major parts, the first containing socio-demographic items concerning parents' level of education, age and gender. Included in this section were the medical characteristics of the children, such as present therapy, previous hospitalisations and exposure to pets and cigarette smoke.

The second part, consisting of 55 questions, was a measure of parental knowledge and possible misconceptions. Parents were asked to make one choice from three options.

In the third part of the questionnaire, parents were asked to evaluate the patients' present asthma status, to express their main concerns regarding their child's asthma and to indicate the areas in which they would like more information. Part of this section was open-ended.

Part two of the questionnaire which measured parental knowledge of childhood asthma was developed as follows:

Following a search of the literature, an initial pool of 110 questions was collected, from which 57 were selected for the preliminary questionnaire. These were then submitted to two senior consultant paediatricians in the Allergy Clinic at the Red Cross War Memorial Children's Hospital (RCWMCH) to evaluate the accuracy and

appropriateness of item content. The final draft included 55 of these items assessing parental knowledge covering the following eight content areas:

1. General medical knowledge
2. Aetiology
3. Symptomatology
4. Pathophysiology
5. Prognosis
6. Precipitants
7. Environmental control
8. Therapy

3.6 Reading levels of the questionnaire

The reading levels of the questionnaire were assessed according to the Flesch formula.(39) This is an assessment of the complexity of written material and provides a numeric value. A high score (over 69) indicates an easy reading level, while lower scores indicate more difficult levels.

An average Flesch score was calculated from two separate paragraphs on page one, namely paragraphs two and six. An average score of 70.68 was calculated which would indicate that an intelligence quotient of 86 or more was required for questionnaire comprehension i.e. an easy reading level.

3.7 Psychometric properties

3.7.1 Reliability

Reliability is the extent to which an instrument measures a construct in a consistent manner.(40) Reliability is traditionally assessed using the test - retest method and if respondents achieve similar scores on a test within a reasonable time scale, the test is considered reliable. However, in this study, none of the respondents was asked to repeat the Asthma Knowledge Test as it would have unduly increased the response burden. In addition, a second attempt could have been influenced by the "learning process" involved in completing the original test.(40)

3.7.2 Validity

Content validity refers to the representativeness of the questions included in the measuring instrument.(40,41) This was established by the process of test construction during which items were sampled from the professional and lay literature and the questions evaluated by experts in the field.

Face validity refers to the extent the questions make logical and common sense.(40) This was established by the process of questionnaire construction, the evaluation by experienced paediatricians and the questionnaire exposure to different criterion groups (see construct validity).

Construct validity refers to the ability of the measuring instrument to measure the specific construct it was designed to measure.(40) It was necessary to determine if the test was indeed measuring knowledge of asthma.

The asthma knowledge test was administered to the following groups who were thought to possess varying levels of knowledge, namely:

- 9 medical doctors
- 16 fifth year medical students
- 12 parents without asthma or asthmatic children
- 13 parents of children attending the asthma clinic at Red Cross War Memorial Children's Hospital.

The performances of these groups are contained in table 3.1

As was to be expected, the non-asthmatic parents scored considerably lower than parents with exposure to asthma. The asthma-clinic parents scored better than the asthma study parents. It is likely that the clinic-based patients have more severe asthma than the family practice-based sample since the clinic functions as a referral centre. Educational endeavours at the clinic would most likely be intensive and consistent. Parents of more severely affected children would probably enquire and ask more questions to assist them to cope.

Medical students scored on average 5.2 per cent more than the medical doctors, probably indicating their greater awareness of recent developments in the understanding of asthma, with the emphasis on the chronic inflammatory nature of the illness, the use of long-term anti-inflammatory drugs in all but the mildest type of asthma, the use of beta-agonists for symptom relief only and not on a regular daily basis as previously practised.

TABLE 3.1

TOTAL MEAN SCORES (PERCENTAGES) ON THE ASTHMA KNOWLEDGE TEST

CATEGORY	N	SCORE
Medical students	16	95.3%
Medical doctors	9	90.1%
Asthma clinic parents	13	78.5%
Asthma study parents	100	72.1%
Non-asthma parents	12	49.5%

The Asthma Knowledge Test was able to discriminate between persons with specialized knowledge of asthma and those with a more general medical knowledge. All medically trained criterion groups received some total scores of one hundred percent. The test was therefore able to detect differences in asthma knowledge.

3.7.3 Threats to validity

The validity of the questionnaire as a true measure of knowledge of childhood asthma was threatened in the present study by the possibility of "cheating" and guessing. Parents were requested to complete the questionnaire in the privacy of their own homes which meant that there was no control over whether family members exchanged answers or looked up answers in a book or pamphlet. Written instructions on the questionnaire motivated parents to provide spontaneous and independent answers. This was emphasised verbally when the parents received the questionnaires. It was hoped that guessing, the 'examination anxiety' feeling and possible emotions of inadequacy that the evaluative component of the test could cause, would be reduced by the use of the "I don't know" option. Since the researcher was the continuous health-care provider to the patients and parents, they were not told that he would be evaluating the data so as to reduce the possibility of parents providing answers to suit the doctor.

3.8 Analysis

Statistical analysis of the data was undertaken with the assistance of a statistician in the Department of Community Health, University of Cape Town, using EPI Info 5 statistical software. Since the variables used in this

study were either categorical or ordinal, the most commonly used statistical procedures were non-parametric. These included the Wilcoxon-Two sample test and Chi-square analysis. Results are given as percentages unless otherwise stated. Responses to open ended questions were analysed by the author, using qualitative methodology. (21)

CHAPTER FOUR

4. Results4.1 Description of study sample

59 patients satisfied the entrance criteria to the study. The parents of 5 patients declined to participate. 105 questionnaires were handed out to the parents of the remaining 54 patients. 100 of these were returned - a 95.2 per cent return rate (or 85.5 per cent if the total of 59 patients is considered). Both parents of 46 patients returned questionnaires. 3 patients were from single-parent families and in 5 families only one spouse returned his/her questionnaire.

4.2 Socio-demographic and medical characteristics

Part one of the questionnaire sought socio-demographic and medical data on the families. The relevant socio-demographic characteristics are summarised in table 4.1.

4.2.1 Age, gender, marital status and parental education.

Parental ages ranged between 21 and 52 years with a mean age of 34.8 years. 52 per cent of respondents were female and 48 per cent male. 97 per cent of respondents were married. 56 per cent of parents had been to high school and 42 per cent to a tertiary institution. Only 2 parents had only primary school education.

TABLE 4.1

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF STUDY SAMPLE
(Percentages)

Parental age	Mean 34.8 years (SD 6.25) Range 21 - 52 years	
Gender	Female Male	52 48
Marital status	Married Single	97 3
Parental education	Primary school only High school only College / Technikon / University	2 56 42
Parental smoking	Male smokers Female smokers Non-smokers	28 19 52

4.2.2 Parental smoking

47 per cent of parents smoked (28 fathers and 19 mothers). In 13 of the 46 families who had returned both questionnaires, both parents smoked.

4.2.3 Pets

27 families had dogs, 7 families had birds and 6 families had cats. 10 families had two pets. 25 families had no pets.

4.2.4 Number of asthmatics, age of onset, asthma admissions

85 per cent of parents had one asthmatic child whilst 15 per cent had two i.e. 9 families. The mean age of onset was 2.4 years with a range of 1 to 9 years. 43 per cent of parents has had a child admitted to hospital for asthma.

4.2.5 Parental asthmatics, asthma deaths

12 per cent of parents were asthma sufferers and 15 per cent of respondents had lost a family member due to asthma.

4.2.6 Medications

61 per cent of parents reported that their children took no preventive medication, and the remaining 39 per cent reported that their children took one or more of such drugs.

21 per cent of parents reported that their children took no relieving medications at present, 36 per cent reported one drug only and 43 per cent reported two or more.

4.3 Results of the Asthma Knowledge Test

Medical knowledge and misconceptions were examined in part two of the questionnaire using 55 multiple choice questions (Appendix 1). Completed tests were received from 100 parents (52 mothers and 48 fathers).

Knowledge scores were obtained by adding the correct responses on each item. *Composite* knowledge scores, reflecting overall test performance, and 8 *Sub-Section* scores reflecting the dimensions of this knowledge, were calculated for each respondent. Sub-section analyses were undertaken to accurately identify specific areas of knowledge. This was necessary since respondents could well have obtained the same composite scores yet have different gaps in their knowledge.

4.3.1 Composite scores of the Asthma Knowledge Test

The overall test performance of fathers and mothers is presented in table 4.2. Average composite scores of 71.3 per cent and 72.9 per cent were obtained for fathers and mothers respectively. 3 mothers (1.9 per cent) and 3 fathers (4.2 per cent) obtained scores of 90 per cent or more, and 23 mothers (40.2 per cent) and 17 fathers (25.4 per cent) received scores above 80 per cent. Towards the lower end of the spectrum 19 mothers (36.5 per cent) and 21 fathers (43.8 per cent) obtained scores of less than 70 per cent. Scores of below 50 per cent were found in less than 10 per cent of parents.

TABLE 4.2

MEANS, SD'S AND RANGES (PERCENTAGES) ON THE ASTHMA KNOWLEDGE TEST (Composite test - 55 items)

ASTHMA KNOWLEDGE	N	MEAN	SD	RANGE
Fathers	48	71.3	14.6	36.4 - 92.7
Mothers	52	72.9	14.4	34.5 - 92.7

4.3.2 Mean sub-section scores on the Asthma Knowledge Test

Parental performances on the 8 sub-sections are presented in table 4.3. Fathers received scores of over 80 per cent on the three sub-sections of aetiology, asthma symptomatology and environmental control. Mothers obtained scores of over 80 per cent on the four sub-sections of aetiology, asthma symptomatology, asthma precipitants and environmental control. Both fathers and mothers demonstrated low knowledge on the sub-sections of general medical knowledge (57.3 and 52.4 per cent respectively), asthma therapy (66.2 per cent and 64.4 per cent respectively) and asthma prognosis (61.5 per cent and 65.3 per cent respectively).

4.3.3 Association between socio-demographic and medical variables and the Asthma Knowledge Test scores.

The associations between the socio-demographic and medical variables and the Asthma Knowledge Test are summarised in table 4.4. There was a small statistically significant difference in the knowledge score of parents who had obtained high school education only and those who have had a tertiary education (71.8 and 80.0 per cent respectively, $p = 0.0368$). There was no significant differences in the knowledge scores of fathers and mothers (77.9 and 73.6 per cent respectively, $p = 0.5850$), nor between the scores of parents with one and two asthmatic children (74.5 and 72.7 per cent

TABLE 4.3

MEAN SUB-SECTION SCORES (% CORRECT RESPONSES) ON THE ASTHMA
KNOWLEDGE TEST

CATEGORY	NO. OF ITEMS	FATHERS	MOTHERS
1. General medical	4	57.3	52.4
2. Aetiology	4	87.0	92.3
3. Symptomatology	7	80.6	82.4
4. Pathophysiology	5	73.4	73.8
5. Prognosis	2	61.5	65.3
6. Precipitants	10	74.8	80.8
7. Environmental control	4	88.0	91.3
8. Therapy	19	66.2	64.4

TABLE 4.4

**ASSOCIATIONS BETWEEN SOCIO-DEMOGRAPHIC AND MEDICAL VARIABLES
AND THE ASTHMA KNOWLEDGE TEST SCORES.**

VARIABLE	N	MEDIAN	RANGE	P*
High school only	56	71.8	34.5-92.7	0.0368
Tertiary	42	80.0	41.8-92.7	
Mothers	52	77.4	34.5-92.7	0.5850
Fathers	48	73.6	36.4-92.7	
One asthmatic child	85	74.5	34.7-92.7	0.2872
Two asthmatic children	15	72.7	56.4-92.7	
Parents asthmatic	15	74.5	34.5-92.7	0.2374
Non-asthma parents	83	74.5	34.5-92.7	
Parents under 35 yrs	47	74.5	36.4-92.7	0.9201
Parents over 35 yrs	53	75.5	34.5-92.7	
Smokers	47	76.4	34.5-92.7	0.4018
Non smokers	52	71.8	36.4-92.7	

* P = Wilcoxon Two Sample test

respectively, $p = 0.2877$), nor between the scores of parents under and over thirty five years of age (74.5 and 75.5 per cent respectively, $p = 0.9200$).

4.3.4 Individual sub-section performances on the Asthma Knowledge Test

In order to accurately identify areas of high and low knowledge, a comprehensive analysis of each sub-section was undertaken for fathers and mothers (Table 4.5). These findings are presented in the remainder of this section.

4.3.4.1 General medical knowledge

This section included four general medical questions which have relevance to asthma management. Not surprisingly about 95 per cent of parents knew that asthma is a disease of the lungs and over 80 per cent knew that the common cold had a viral aetiology. Knowledge of antibiotic usage was low with 64.6 per cent of fathers and 57.7 per cent of mothers incorrectly believing that viral infections could be effectively treated with antibiotics while a further 9 per cent were uncertain. Only 20.8 per cent of fathers and 7.7 per cent of mothers correctly identified the childhood prevalence of asthma as 10 per cent.

4.3.4.2 Aetiology

Knowledge was high in this section with an approximate score of 90 per cent on each item. Parents knew that asthma causes the airways to be sensitive, that exposure to cigarette smoke can bring on asthma attacks, that

TABLE 4.5

ASTHMA KNOWLEDGE TEST (% CORRECT RESPONSES) FOR FATHERS AND MOTHERS ACCORDING TO SUB-SECTION AND ITEMS, AS THESE APPEAR IN THE ORIGINAL QUESTIONNAIRE (n = 48 fathers, n = 52 mothers)

GENERAL MEDICAL			PROGNOSIS			THERAPY		
ITEM NO.	FATHERS	MOTHERS	ITEM NO.	FATHERS	MOTHERS	ITEM NO.	FATHERS	MOTHERS
1	95.8	94.2	20	54.2	51.9	37	91.7	92.3
2	85.4	80.8	21	68.8	78.8	38	52.1	40.4
3	27.1	26.9				39	45.8	44.2
22	20.8	7.7				40	50.0	44.2
						41	56.3	57.7
						42	27.1	32.7
						43	83.3	80.8
						44	89.6	88.5
						45	89.6	82.7
						46	95.8	94.2
						47	12.5	11.5
						48	97.9	100.0
						49	97.9	90.4
						50	93.8	100.0
						51	93.8	86.5
						52	41.7	40.4
						53	20.8	25.0
						54	22.9	36.5
						55	29.2	36.5
SYMPTOMATOLOGY								
ITEM NO.	FATHERS	MOTHERS						
8	87.5	96.2						
9	95.8	96.2						
10	95.8	94.2						
11	83.3	80.8						
12	91.7	95.0						
13	50.0	65.4						
14	60.4	69.2						

TABLE 4.5 Continued

AETIOLOGY			PRECIPITANTS			PATHOPHYSIOLOGY		
ITEM NO.	FATHERS	MOTHERS	ITEM NO.	FATHERS	MOTHERS	ITEM NO.	FATHERS	MOTHERS
4	91.7	96.2	23	77.1	80.8	15	91.7	82.7
5	79.2	88.5	24	89.6	90.4	16	10.4	17.3
6	89.6	88.5	25	60.4	57.7	17	93.8	90.4
7	87.5	96.2	26	72.9	90.4	18	89.6	92.3
			27	70.8	88.5	19	81.3	86.5
			28	50.0	65.4			
			29	91.7	96.2			
			30	75.0	82.7			
			31	75.0	76.9			
			32	85.4	78.8			
ENVIRONMENT								
ITEM NO.	FATHERS	MOTHERS						
33	95.8	100.0						
34	93.8	98.1						
35	87.5	90.4						
36	75.0	76.9						

asthma runs in families and that asthma is more likely to occur in children who are allergic to pollen and house dust mite.

4.3.4.3 Symptomatology

Parents exhibited high knowledge in this section with an average score of approximately 80 per cent. Parents identified the common symptoms of night-time coughing and wheezing and exercise-induced shortness of breath. Alarmingly, only 50 per cent of fathers and 65.4 per cent of mothers knew that severity of an attack is best determined by blowing into a peak flow meter. Approximately 20 per cent of parents believed that asking the child how tight his chest is feeling is the best assessment and a further 20 per cent of parents did not know. 60.4 per cent of fathers and 69.2 per cent of mothers knew that a cough which is responsive to asthma treatment is likely to be asthma.

4.3.4.4 Pathophysiology

An acute attack of asthma is characterised by airway narrowing due to mucosal inflammation, smooth muscle contraction and mucus secretions. Parents exhibited high knowledge but approximately 80 per cent incorrectly identified asthma as an inspiratory difficulty.

4.3.4.5 Prognosis

Only 50 per cent of parents knew that breast feeding delayed the onset of asthma. 68.8 per cent of fathers and 78.8 per cent of mothers knew that the prognosis of asthma is unpredictable.

4.3.4.6 Precipitants

Knowledge in this section was high with scores of 74.8 per cent for fathers and 80.8 per cent for mothers. Feathers, colds and flu, worry, and being unhappy or upset were correctly identified by over 80 per cent of parents. Regarding exercise and asthma, approximately 80 per cent of parents knew that asthmatics can play sport, that swimming was better than running, that taking a puff from an inhaler pump before exercise may prevent asthmatic symptoms and that a physically fit child will have fewer attacks of asthma. The lowest scores in this sub-section were received for items 25 and 28. Only 60 per cent of parents were aware that cold air can precipitate asthma and a high percentage of parents (50 per cent of fathers and 35 per cent of mothers) failed to recognise excessive laughter as a precipitant.

4.3.4.7 Environmental control

Knowledge of the environmental control of asthma was high with over 90 per cent of parents being aware of the beneficial effects of a dust free bedroom, frequent vacuuming of carpets and mattresses, and exposing them to the sun. Only 12 per cent of fathers and 9 per cent of mothers were incorrect regarding the suitability of cats and dogs as pets for asthmatic children. Approximately 75 per cent of parents correctly regarded a move to a dry, hot climate as beneficial to asthmatic children.

4.3.4.8 Asthma therapy

This sub-section included interventions for acute attacks as well as routine ambulatory care. Both fathers (66.2 per cent) and mothers (64.4 per cent) demonstrated fairly low knowledge in this sub-section. More than 90 per cent

of parents knew that medications only allow for control of asthma, not cure, but more than 50 per cent did not know that inhalers provide a lower dose and less side-effects than tablets and syrups. Low scores were obtained relating to the use of preventer medications (items 40,41,42). Approximately 50 per cent did not know that preventers reduce airway swelling (inflammation), and should be taken for a long time, taking a few weeks to come into effect. Surprisingly, 80 per cent knew that the frequency of acute attacks is reduced with daily use of preventers (item 43).

Higher scores were received for items 44, 45, 46 and 50 relating to reliever medications. More than 80 per cent of parents knew that relieving medications are only used when a child is coughing and wheezing which may be the start of an acute attack (items 44 and 45). Most parents correctly responded that initially the night-time cough should be treated with relieving medicines (item 46) and a sudden attack of asthma requires relieving as opposed to preventive medications (item 50). More than 90 per cent correctly responded that during a sudden attack of asthma both parent(s) and child should try to be calm, that the child should breathe slowly and regularly and medical assistance should be sought if the regular medications did not bring relief within one hour (items 48, 49 and 51).

Much uncertainty and confusion are reflected in the responses to items 52-55 relating to popular misconceptions in asthma therapy. Only about 40 per cent of parents knew that inhalers do not weaken the heart (item 52). Approximately 75 per cent of parents felt that regular administration of medications can lead to addiction (item 53) and to medicines becoming ineffective (item 55). As many as 77.1 per cent of fathers and 63.5

per cent of mothers believed that folk remedies were effective in treating asthma.

At the end of the Asthma Knowledge Test parents were requested to describe their child's asthma at present (item 56). 59 per cent of parents considered the asthma to be fairly well to well controlled. 34 per cent regarded the asthma as very well controlled. Only 2 per cent of parents considered their child's asthma to be poorly controlled whilst a further 5 per cent did not know.

4.4 Parental concerns

In part three of the questionnaire parents were asked to express in their own words what worries them most about their child's illness. Their responses were classified into the following four categories:

4.4.1 Acute asthma attacks

50 per cent of parents expressed a concern regarding acute attacks. These ranged from being uncertain of the onset of an attack, attacks occurring at night or at school, no medicine being available or the effects of a delay in therapy, a fatal asthma attack and the patient's anxiety during an attack.

4.4.2 Prognosis of asthma

41 per cent of parents indicated some concern regarding their child's future health. The majority expressed a hope that the asthma will not worsen but would improve as the child grows older. Others hoped that a cure would be found.

4.4.3 Asthma therapy

5 per cent of parents expressed concern that their children can or have become dependent on their medication. The cost of medication and the long term effects of treatment (and illness) on the heart and lungs were other concerns.

4.4.4. Miscellaneous

Parents raised concerns regarding sport, restricting their child's activity and their child's inability to keep up with peers. Parents expressed a sense of guilt ("what did we do wrong") and helplessness during acute attacks. Others expressed concern as to the effect of the chronic "cough and phlegm" and the child being continuously sick and having constant colds.

4.5 Additional information

Item 58 requested parents to indicate in which areas of asthma they would like more information. The majority requested general information. Parents also wanted further information on self-help techniques, prevention, medication, diets and non-drug/alternative therapies.

CHAPTER FIVE

5. Discussion5.1 Socio-demographic and medical characteristics

The study sample was limited to mostly well-educated parents. This is mainly due to private family practice attracting predominantly patients with medical aid cover i.e. from the middle- to upper middle-class groups. Although the mainly middle-class nature of the sample limits generalisation of the findings, it does allow for ready comparison with published studies, most of which had samples of similar socio-economic and educational standing. (8, 32, 34, 35)

There was a small statistically significant difference in the knowledge scores of parents who had obtained high school education only and those who have a tertiary education (71.8 and 80.0 per cent respectively, $p = 0.0368$). It could be deduced that education, and by extrapolation, social status, may be a significant correlate of disease-related knowledge amongst parents of childhood asthmatics. Whereas Henley(29) found social class to be a highly significant correlate of disease-related knowledge amongst the parents of cystic fibrosis patients, Spykerboer and co-workers(32) as well as Fitzclarence and Henry(35) found no association between knowledge of asthma and socio-demographic variables. The implications from the findings of this study are that parents with less education are slightly less informed about their child's illness which could, in turn, have a direct bearing on the quality of their decision-making and compliance with medical advice. Given, however, that only 2 per cent of parents in this study had less than

high school education, the association between knowledge of asthma and parental education needs further investigation in future research. This research should include parents with a wide range of educational levels. Nonetheless, it is important that health care workers make an extra effort to communicate disease-related information to parents with less formal education, the more so since they may ask fewer questions and consequently receive less information from doctors.(50)

47 per cent of parents smoked and 54 per cent of families have pets that are known to be deleterious to asthmatics i.e. dogs, cats and birds. Smokers performed marginally better than non-smokers on the Asthma Knowledge Test with scores of 76.4 per cent and 71.8 per cent respectively ($p = 0.4018$). Respondents performed well on item 5 with more than 80 per cent being aware that exposure to cigarette smoke increases the likelihood of an acute asthma attack. More than 80 per cent of parents are also aware that cats and dogs are unsuitable pets for asthmatic children, but 54 per cent of families had such pets. Donnelly and co-workers(33) found that 50 per cent of parents of asthmatics smoke and 66 per cent had household pets. Only 20 per cent of parents would give up smoking whilst 90 per cent would get rid of the pets. This study confirms that parents are aware of the harmfulness of certain personal habits and family lifestyles but these are resistant to change even if good health reasons exist. Dogs also have a family security function and parents are often reluctant to get rid of them.(2) Parental knowledge notwithstanding, they still need to be constantly reminded of the harmful effects of smoking on their asthmatic child's health. In addition, family practitioners may need to offer practical advice on how parents might give up their addiction.

5.2 The Asthma Knowledge Test

Children depend on their parents for care and decision-making regarding their health and illnesses. Parents' ability to cope with their children's asthma depends to a certain extent on their knowledge and understanding of the disease. An important aim of the study was to assess how much parents knew about the medical aspects of asthma. Responses to the 55 multiple choice questions on the Asthma Knowledge Test revealed that parents were far more knowledgeable about aetiology, asthma symptomatology, pathophysiology, precipitants, and environmental control than they were about general medical knowledge, prognosis and asthma therapy.

Parents obtained an average total score of 72.0 per cent which compares favourably with scores obtained by Fitzclarence and Henry(35) namely, 81.6 per cent and Van Esperen and colleagues(34) whose asthmatic sample scored 69.1 per cent. Spykerboer and co-workers' sample(32) scored approximately 66 per cent.

Asthma knowledge was determined under 8 sub-sections. A degree of overlap in the discussion between the respective sub-sections is unavoidable.

5.2.1 General medical knowledge

Parents are aware that colds are caused by viruses (item 2) and the majority of parents consider antibiotics as being effective against viral infections (item 3) and necessary when their children catch a cold (items 47). Parental expectations and their satisfaction have important implications for an agreeable doctor-patient relationship. Parents complain that doctors treat their children with antibiotics especially in the early stage

of the illness when doctors appear hesitant to diagnose asthma.(8) Doctors, in turn, feel pressurised by parents to prescribe antibiotics for viral infections and often yield to such demands rather than explain their rational use and indications. Antibiotics are widely reported on in the lay press and their curative abilities often lauded. Parents may naturally have come to regard them as a panacea for every infection whilst not clearly understanding the difference between viral and bacterial infections. Other studies have confirmed the inability of parents to distinguish between viral and bacterial infections.(8,29,32) There is a definite educational need to explain to parents about the correct use of antibiotics and the potential harmful effects of their indiscriminate use. That responsibility rests with family doctors and primary care givers who should be motivated to take the often more time-consuming route of explanation and education than the issuing of a prescription. The long term gains from such a course would have positive health and financial implications.

5.2.2 Aetiology

In keeping with previous studies(8,32) parents performed well in this section obtaining an approximate score of 90 per cent on each item. Parents are aware of the familial nature of asthma, that external agents such as cigarette smoke, pollen and house dust mite have a role in asthma, and that asthmatic airways are sensitive to such agents. As already noted (section 5.1), knowledge regarding the harmful effects of smoking does not necessarily translate into behavioural change in as much as 48 per cent of parents reported that they were smokers. The relationship between knowledge and behaviour has recently been elucidated in studies of asthma(38) and cystic fibrosis.(43)

5.2.3 Symptomatology

In keeping with previous studies(32,35) parents scored well in this section. Approximately 40 per cent of parents were, however, unaware that the peak flow meter is the best measure of the severity of an attack, of whom 20 per cent considered the child's subjective feeling of "tightness in the chest" as an adequate measure of an attack. The importance of an objective measure of airways obstruction such as peak expiratory measurements was highlighted by Couriel and colleagues(44) in their study of severe asthmatic children with frequent symptoms. The subjects were found to be poor perceivers of airways obstruction and they recommended the need for objective measurements in such patients. The authors suggested that it may be possible that children with less frequent symptoms may be better or worse at perceiving airways obstruction accurately and that further studies would be required to establish this. Creer(38) emphasises that patients using objective measurements, such as the peak flow meter, were not only able to predict the likelihood of future attacks but could also decide what actions to take to bring an incipient attack under control. Thus, they are able to better use self-management skills to either prevent attacks or keep ongoing attacks from becoming more severe. Although the present study sample was made up of predominantly mild asthmatics, who might not use a peak flow meter, it is important that all parents are well informed regarding its advantages.

Approximately 35 per cent of parents were unaware that a cough, responsive to asthma therapy, is likely to be asthma. In practice, doctors often institute such a trial of therapy when faced with doubtful cases. It would be useful for parents to be informed of such

practices as they often think that specialised tests need to be performed to make the diagnosis of asthma.

5.2.4 Pathophysiology

Similar to the findings in other studies(32,35), parents exhibited high levels of knowledge in this section. Unlike the study by Spykerboer and colleagues(32), fewer parents exhibited misconceptions in this section. Only 3 per cent of parents believed that the lungs become filled with water during an attack, 5 per cent thought that the chest muscles become paralysed, and only 1 per cent considered wheezing to be due to closure of the throat. Only 14 per cent of parents were aware that asthma is an expiratory difficulty but it is questionable as to whether knowing the subtle difference between inspiration and expiration has a significant role in helping parents to cope.

5.2.5 Prognosis

About 65 per cent of parents were unaware that breast feeding delayed the onset of asthma. There is, however, little consensus within the medical profession on the effects of infant feeding on the incidence of atopy, although some studies suggest a protective effect from breast feeding.(3) A study of breast milk amongst premature neonates demonstrated a reduction in atopic disease in early life but only among those with a family history of atopic disease whilst, by way of contrast, a study among older children showed a trend to more atopic disease in those breast-fed for the longest.(3) Although the protective role of breast feeding in asthma may remain unproven, it is essential that family practitioners continue to encourage breast feeding given its many proven advantages in other areas of child

health. The unpredictable nature of asthma is well known among parents.

5.2.6 Precipitants

Parents performed well in this section and were knowledgeable about the common precipitants of asthma and compared favourably with the results of Spykerboer and colleagues(32) and Mesters and co-workers.(8) About 40 per cent of parents were unaware that cold air could precipitate asthma whilst 73 per cent of Spykerboer's sample responded correctly. Laughter is not well known among parents as a precipitant whilst stress and unhappiness are. Whilst 30 per cent of Spykerboer's sample regarded the swallowing of a hard object as a precipitant, only 1 per cent of parents in this study responded in that way.

The unawareness of common precipitants does have practical implications for parents as the inadvertent exposure of children to cold air or allowing excessive laughter could precipitate an attack. Clearly parents cannot be expected to control how much their asthmatic child laughs, but it is, however, partially their responsibility to ensure that such knowledge is passed over to their children. Similarly, all parents need to know that cold air may induce an asthma attack and caution their children in this regard.

5.2.7 Environmental control

Parents exhibited a high level of knowledge in this section with scores of about 90 per cent. Parents were aware of the benefits of a dust free bedroom, frequent vacuuming and the correct choice of pets. In contrast, Mesters and colleagues(8) found that parents only knew

half of the environmental preventive actions mentioned in their questionnaire. In addition, they detected misconceptions in this area at an average of 1.5 misconceptions per parent. These misconceptions included letting the child sleep near an open window, decorating indoors with dried flowers and natural furnishings, all of which may actually aggravate asthma. Moreover, Spykerboer and colleagues(32) found that 30 per cent of parents incorrectly believed that moving to the seaside would improve asthma. In contrast, three quarters of parents in this study correctly knew that a move to a hot, dry climate could be beneficial to their child's asthma. Furthermore, 40 per cent of parents in their study considered restriction of the child's activity beneficial whereas 80 per cent of parents in this sample regarded swimming as an appropriate sport for asthmatics and correctly responded that a physically fit child has fewer attacks. Ideally, given the importance of environmental control in the management of asthma, it can be argued that all parents should be fully informed regarding its practical benefits.

5.2.8 Therapy

Parents performed less than satisfactorily in this section with scores of 66.2 and 64.4 per cent for fathers and mothers respectively. Their knowledge of the mode of action of the drug as well as the indications for usage appears deficient. Understanding of preventive drugs is especially lacking. The majority of parents were unaware as to how preventive drugs work and that they only become fully operative after prolonged use of a few weeks. 24 per cent responded that preventers can be stopped as soon as the child feels better and another 41 per cent said preventers give immediate relief to symptoms. Yet surprisingly, 80 per cent of parents knew that preventers

reduce the frequency of acute attacks with daily use. Such variable responses could be reflecting uncertainty or confusion among parents regarding these drugs. Mesters and colleagues(8) commented that parents appeared to be confused about medication effectiveness. Parents considered preventive medications as ineffective as children still suffered occasionally from asthma symptoms. It is also worth noting that almost two-thirds (61 per cent) of children in the present study were not using preventive medication which might explain lower parental performance in this area. It is vitally important that this deficiency in understanding of preventers be corrected especially in view of the increasing evidence of the beneficial effects of early and prolonged treatment with anti-inflammatory agents.

Furthermore, asthma has an enormous economic impact. Costs that are directly incurred from the disease i.e. drugs and hospitalisation, consume 1-2 per cent of the health budget in industrialised countries, calculated at more than 6 billion dollars per year for the USA.(5) Even in this sample of predominantly mild asthmatics, 43 per cent of parents reported that their child had been admitted for asthma. Therefore, if anti-inflammatories can reduce the number of acute attacks, a lot of money will be saved. Given the impact of the disease(4), parents should be aware that effective anti-inflammatory treatment in patients with asthma not only reduces morbidity and improves quality of life, but can contribute considerably towards reducing the total cost of asthma.

Higher scores were obtained on items relating to reliever medications. More than 80 per cent of parents were aware that a night-time cough could be the start of an acute attack and responded appropriately with reliever

medications and observation of the child's progress. Parents managed acute attacks correctly at home with 90 per cent of respondents administering the child's usual reliever medication and observing the response over the next hour. Regarding the mode of administration of drugs, less than half the respondents were aware that inhaler therapies utilised a smaller dose and exhibited fewer side effects. Ultimately parents are dependent on health care providers for this, somewhat technical, information. Doctors need to prescribe the most appropriate medications as well as provide suitable explanations regarding their use. This is even more important given parents' misconceptions towards drugs in general, and inhalers in particular.

Parents performed very well on items referring to first aid actions during an acute attack. More than 90 per cent correctly kept the child calm and breathing slowly and regularly. Similarly, Mesters and colleagues(8) found that parents knew on average five out of their seven adequate actions during an acute attack. Once again, all parents should be well informed in this regard, even more so given parents' open-ended concerns regarding acute attacks and their management.

Parents exhibited a large number of misconceptions regarding asthma therapy. About 60 per cent held that inhaler therapy weakened the heart, 75 per cent felt that regular therapy can lead to addiction and medication becoming ineffective, and approximately 70 per cent believed that folk remedies are effective asthma treatment. Similar findings are reported in the literature. Spykerboer and colleagues(32) found that 30 per cent of parents considered natural and herbal food beneficial, with the ability to improve asthma. Mesters and colleagues(8) determined from their focus group

interviews that parents believed asthma medications were addictive and were concerned that their children would need increasing dosages. Parents were, in turn, disappointed when medication dosages had to be increased despite their efforts. They were, however, unaware that dosages are calculated according to the child's weight and continuously increased as the child grew. Parents developed their own explanations for the increase in medications. Donnelly and colleagues(32) found that although the majority of parents felt that the advantages of medications outweighed the disadvantages, more than 80 per cent felt that children should not get medicines for long periods, more than 40 per cent believed that any long term medications are unnatural and harmful, and 30 per cent thought that children's bodies are too small to cope with medications.

It is apparent that misconceptions regarding asthma therapy are widespread and numerous. Parents seem to have an ambivalent relationship towards drug therapy. They know that their child needs therapy but fear its potential harmful effects. They would use "natural" and "herbal" and "folk" remedies, probably because they consider them to be innocuous or less harmful. Donnelly and colleagues(45) found that 45 per cent of asthmatic families had consulted an alternative practitioner at some time. Neither did their results support the view that patients who use alternative medicines are those who are disgruntled with orthodox medicine. Stern and colleagues(46) evaluated the use of non-medical practices among cystic fibrosis patients and families. 66 per cent used at least one such practice, predominantly of a religious type. They found these treatments rarely interfered with medical care. On the contrary, perceived benefits from such practices included the reduction of symptoms, emotional comfort, overall well-being and

security, and the prevention of feelings of guilt for not having "tried everything". Since parents in this study requested more information regarding non-drug/alternate therapies, it seems opportune to follow the advice of Stern and colleagues. They suggest that physician openness and empathy towards patients' beliefs might enhance the doctor-patient relationship and facilitate discussion of the non-medical treatment.

The newer medications in use today are significantly safer with fewer side-effects but this message has not yet been accepted by parents. An element of denial of the severity of the illness may exist in parents' reluctance to use prolonged medications. This explanation gains some support from the finding that only 2 per cent of parents evaluated their child's asthma as being poorly controlled.

5.3 Parental concerns

The third part of the questionnaire included an open-ended question to which parents could respond by writing in their own words what worried them most about their child's asthma. A number of these concerns reflected parental responses in the Asthma Knowledge Test.

The most common concern, mentioned by 50 per cent of respondents, related to acute asthma attacks. The wide range of concerns included uncertainty about the onset of attacks, nocturnal and school time attacks, the availability of medications and delays in therapy, fatal acute attacks, and the child's own anxiety during attacks. Similar concerns were expressed by the parents in the study by Mesters and colleagues.(8) These parents mentioned the perceived unavailability of information,

the lack of specific guidelines for what to do and the lack of criteria to estimate severity of symptoms.

The Asthma Knowledge Test results indicate that, in general, parents know what asthma is and what aggravates asthma and, importantly, how to react during acute attacks. Yet, they openly expressed their lack of confidence in handling acute attacks. The ability to confidently execute behaviour required in a particular situation has been described as self-efficacy.(49) Self-efficacy is important in the self-management of asthma as it influences the development of skills necessary to manage the illness. Self-efficacy is highly correlated with a person's performance and research indicates that its assessment permits behaviour to be predicted with impressive accuracy.(48)

Although parents in this study had the "theoretical" knowledge on how to manage acute attacks, in practice, it seems that they lacked confidence (self efficacy). Parents' lack of confidence to perform treatment-related activities at home has significant morbidity implications. Acute attack mismanagement, caused by poor judgement and decision-making skills, results in a delay in seeking assistance.(6) It has been estimated that only about 10 per cent of hospital admissions for asthma are for severely affected children whilst the vast majority represent a failure of home management.(47) To this financial burden must be added the suffering of parents and patients.(4) These concerns underscore the need for effective education of parents and the acquisition of skills to allow them to manage the acute situation adequately.(38) This study confirms recent findings(50) that knowledge and self efficacy are both necessary for optimal management of a child with a chronic disease.

The second most common concern related to the child's future health. 41 per cent of parents expressed a hope that the asthma will improve with age or that a cure will be found. From the Asthma Knowledge Test it can be gleaned that three quarters of respondents know that improvement with time is unpredictable and that medications are only able to control the illness, not cure it (items 21,37). Mesters and colleagues(8) also report that many parents appear to have been informed or thought that their child would probably grow out of asthma. This is, strictly speaking, not true as the symptoms may disappear but the asthmatic disposition will remain and relapses can occur in adult life.(4) It is apparent that despite knowing the natural course of childhood asthma, parents have a deep-seated desire to see improvement that could have been reinforced by sympathetic doctors.

Other concerns raised by parents were the issue of dependence on medications and their long term effect on the heart and lungs. It is apparent that parental attitudes to asthma medication are dominated by anxiety regarding negative physical consequences of the use of medication in general and especially of the use of long term therapy which a chronic illness such as asthma would require. Donnelly and colleagues(33) also comment on this psychological resistance to the use of medications as a direct influence on non-compliance which may be amenable to educational programmes directed at modifying attitudes. Education to dispel these misconceptions is essential for optimal care.

Finally, the combined findings of section 5.2 and 5.3 have important implications for inadvertent non-compliance with therapy, which is said to occur when a patient or parent believes that he or she is adhering to

recommended treatment but, because of poor understanding, misconceptions about the disease and its treatment, and a complex treatment regimen, is actually non-compliant.(49) In as much as knowledge of preventive medications and acute asthma attack management can be considered a prerequisite for optimal compliance, it can be considered essential knowledge and should be known by all parents.

5.4 Parental information needs

The majority of parents requested more general information about asthma. The more specific requests included information on self-help techniques, preventing asthma, medications, diets and non-drug/alternate therapies.

Parental informational requirements should be viewed within the global context of an asthma self-management programme. Such a programme is different from the strict transfer of knowledge to promote compliance only but "it includes the complex cognitive-behavioral skills of self-monitoring, decision-making, and communicating about both symptoms and treatment regimens" (page 1524).(50) As already noted, a critical determinant of learning and performance is self-efficacy which determines whether a person or parent will attempt a task or not and for how long he or she will persevere.(50) Enhancing self-efficacy through health education is considered crucial to learning and performing home care routines.(50)

Moreover, Parcel and colleagues(43) suggest that intervention strategies need to be specific for targeted behaviour. Knowledge should be focused on information specific to the performance of the self-management behaviour.(43) Education programmes that focus on

increasing knowledge alone are unlikely to be successful because of the important role self-efficacy appears to play in the performance of self-management behaviour.(43)

Recent studies on asthma(38) and cystic fibrosis(43) suggest that individuals with knowledge of what to do and how to do it (behavioural capability), confidence in being able to perform the behaviour (self-efficacy) and the belief that their behaviour will result in some favourable outcome (outcome expectation) will be more likely to perform the specified behaviour. These studies lend support for the social learning theory-based assumptions which form the basis of self-management programmes.(43)

Community-based asthma support groups have been successfully established in other countries and should contribute in allowing parents to achieve the aforementioned goals.(37) In addition, the lay media are an important means to provide facts and correct misconceptions. This literature is widely read and could reach specific target groups of people such as specific language or cultural groups.

A summary of the major findings and recommendations is presented in the final chapter.

CHAPTER SIX

6. Summary and recommendations6.1 Summary

A cross-sectional survey was conducted among a sample of 54 families attending a family practice in Mandalay on the Cape Flats. Data were collected by means of a structured questionnaire from 52 mothers and 48 fathers. The study was primarily investigative and exploratory in nature with the main aim to measure and evaluate parental knowledge of childhood asthma and to ascertain some of the misconceptions associated with it. The other goals included an attempt to identify parental concerns with regard to the disease and its effect on their children, and to identify the selected socio-demographic and medical correlates of these measures.

A 55 item Asthma Knowledge Test was developed and validated to assess medical knowledge. Parents obtained an average score of 72 per cent. Scores of over 70 per cent were obtained in the sub-sections of aetiology, symptomatology, pathophysiology, precipitants, and environmental control. Parents were less well informed in the sub-sections of asthma prognosis, general medical knowledge and asthma therapy.

Parental educational status was the only significant correlate with performance on the Asthma Knowledge Test. Parents with a tertiary education were slightly more informed than those with a high school education (80.0 per cent versus 71.8 per cent respectively).

A number of specific gaps exist in parents' knowledge such as their unawareness of a difference between viral and bacterial infections and the tendency to treat all infections with antibiotics. Parents seem to underestimate the potential benefits of breast feeding which, in addition to its numerous other beneficial effects to babies, may play a role in delaying the onset of asthma. Parents are not aware that a recurrent cough that responds to asthma therapy is probably asthma. That the smallest dose of medications with the least observable side effects is to be found in the inhaler delivery form must be promoted. Understanding of the mode of action of preventive medications and the need for prolonged treatment has to be emphasised. This goes hand in hand with the more recent understanding of asthma as a chronic inflammatory illness. The presence of these deficiencies demonstrates a lack of essential knowledge, i.e. knowledge that is a requirement for optimal compliance, and re-emphasises the need for asthma self-management programmes and education.

The following misconceptions were shared by a significant number of parents: inhaler therapy weakens the heart, the regular administration of medications leads to addiction and medicines becoming ineffective, and folk remedies are effective in asthma therapy.

Parental concerns centred predominantly on their lack of confidence to manage the acute asthma attack. This is followed by concerns as to whether the child will outgrow asthma. Dependence on asthma medications and perceived harmful effects on the heart and lungs are other concerns.

The extent to which knowledge translates into behaviour was explored. It seems from the literature that in

addition to knowledge, the management of a chronic disease, such as asthma, requires the integration of a complex series of skills and behaviours that involve co-operation and shared decision-making among health care providers, parents and patients. Increasing knowledge alone is unlikely to be successful as self-efficacy and positive expectations regarding the outcome of therapy play a critical role in behaviour.

It is necessary to consider these findings against the limitations of the study:

1. The reliability of the Asthma Knowledge Test was not psychometrically validated.
2. The sample consisted of mainly middle class and well educated parents which limits generalisation of the findings to other groups of asthmatic patients and their families.
3. The patients were predominantly mildly affected asthmatics which are more typical of a family practice-based population. Caution must be used when generalising these findings to patients with more severe disease.

6.2 Recommendations

Arising from the findings in this study and the insight gained the following recommendations are made:

1. There is a need for systematic asthma education of parents and patients especially with regard to acute attack management and preventive medications. In addition to the transfer of knowledge, these

programmes should aim to build self confidence and positive expectations regarding the effectiveness of treatment. Individualised education should be reinforced by larger awareness campaigns as proposed by the recently launched National Asthma Education Programme.

2. An effort be undertaken to discourage parents of asthmatic children from smoking. If a complete cessation is not possible then a smoke-free home environment is to be emphasised.
3. The increased informational needs of parents with lower education be addressed by health professionals.
4. Parents should receive adequate information during the early stage of the disease to minimise their insecurity in coping with the illness and prevent the development of misconceptions that undermine their confidence in the medications and care-givers.
5. The knowledge, skills and attitudes of family practitioners should be upgraded in a continuum, beginning with principles and theory and concluding with applications to patient care.

6.3 Future research

This study was conceived as an exploratory effort in the local family practice setting and should provide a baseline for future research. The following suggestions for research are made:

1. Further development of the Asthma Knowledge Test with regard to validating reliability and improving content to include more practical problems of daily management.
2. Evaluation of knowledge should be extended to include parents with more severely affected children, different language and cultural groups, different socio-economic groups, and of the children (i.e. the patients) themselves.
3. The knowledge of school teachers needs to be evaluated as they are the other main caretakers of children.

APPENDIX 1: QUESTIONNAIRE

CHILDHOOD ASTHMA INFORMATION STUDY

It is not always possible for doctors to know what kind of information about asthma you, as parents, are wanting. In the questions that follow we, therefore, hope to find out what you already know about asthma, and in which areas you might want further information and advice.

Because the questionnaire is quite long, we have tried to make it as easy as possible to answer. Most questions simply require a circle or short answer. Should you find that the space provided for your answer is not enough to fully explain your opinions and feelings, there is a section for additional comments on the last page.

Please take your time answering the questionnaire.

We would rather you did not discuss your answers with the rest of your family until you have fully answered all the questions. It is **YOUR** answers and opinions that we want.

Everything that you tell us will be completely confidential, so please be as frank and honest as possible.

We hope you find the questionnaire interesting and enjoyable to answer (in spite of its length). We are looking forward to receiving your replies. For ease of reading only the male gender 'he' is used in the questionnaire.

The questionnaire begins with a few questions about you and your family.

Should you come across any questions which you cannot answer, simply circle the 'I DON'T KNOW' response

Please don't look up on any answers in books or pamphlets because I'm interested in your immediate responses.

**PLEASE ANSWER ALL THE QUESTIONS IN THIS SECTION
BY PLACING A CIRCLE AROUND THE ANSWER YOU CHOOSE**

HERE IS AN EXAMPLE:

THE LUNGS ARE PART OF THE:

- | | |
|--------------------|---|
| Respiratory system | 1 |
| Digestive system | 2 |
| I don't know | 3 |

RESPIRATORY SYSTEM is the correct answer, so you would place your circle around Number One.

REMEMBER THIS IS NOT A TEST!

**IT IS ONLY TO HELP US FIND OUT
WHAT YOU UNDERSTAND ABOUT ASTHMA**

1. Asthma is a disease of the
 - a. Heart 1
 - b. Lungs 2
 - c. I don't know 3

3. The common cold is caused by
 - a. Viruses 1
 - b. Bacteria 2
 - c. I don't know 3

3. Antibiotics are very effective in treating
 - a. Viral infections 1
 - b. Bacterial infections 2
 - c. I don't know 3

4. Asthma is a disease that
 - a. Is contagious i.e. can be caught from other people 1
 - b. Causes the airways (tubes in the lungs) to be sensitive 2
 - c. I don't know 3

5. A child is more likely to get attacks of asthma if he
 - a. Is exposed to cigarette smoke 1
 - b. Does not wear a vest 2
 - c. I don't know 3

6. A child is more likely to get asthma if
 - a. The mother drinks alcohol during pregnancy 1
 - b. Both parents are asthmatic 2
 - c. I don't know 3

7. Asthma is more likely to occur in children who are
 - a. Allergic to substances like pollen and house dust mite 1
 - b. Born prematurely 2
 - c. I don't know 3

8. Children with asthma commonly have the following symptom
- a. Coughing at night 1
 - b. Sore throat 2
 - c. I don't know 3
9. Children with asthma are more likely to
- a. Become short of breath when they exercise 1
 - b. Vomit when they exercise 2
 - c. I don't know 3
10. Wheezing in children with asthma occurs most commonly
- a. At night 1
 - b. During the day 2
 - c. I don't know 3
11. Asthmatic children often also have
- a. Hay fever and eczema 1
 - b. Throat infections 2
 - c. I don't know 3
12. When an asthmatic child has coughed and wheezed at night he often wakes up in the morning
- a. With a stomach ache 1
 - b. Feeling tired and irritable 2
 - c. I don't know 3
13. In the older child, the severity of an asthmatic attack is **best** determined by
- a. Asking the child how tight his chest is feeling 1
 - b. Performing a blowing test using a peak flow meter 2
 - c. I don't know 3
14. A child is very likely to have asthma if his cough
- a. Responds to asthma treatment 1
 - b. Does not respond to asthma treatment 2
 - c. I don't know 3

15. During an asthma attack the
- a. Lungs become filled with water 1
 - b. Mucous lining of the airways becomes inflamed (swollen) 2
 - c. I don't know 3
16. A child with asthma has difficulty
- a. Breathing in 1
 - b. Breathing out 2
 - c. I don't know 3
17. The asthmatic child wheezes because the
- a. Throat closes 1
 - v. Airways in the lungs are swollen and narrowed 2
 - c. I don't know 3
18. The symptoms of asthma may be worse
- a. At lunch time 1
 - b. After midnight and in the early morning 2
 - c. I don't know 3
19. During a sudden asthma attack the child's
- a. Chest muscles become paralysed 1
 - b. The airways (tubes) in the lungs become very narrowed 2
 - c. I don't know 3
20. The onset of asthma may be delayed by
- a. Breast feeding 1
 - b. Feeding the baby cow's milk products e.g. SMA, NAN 2
 - c. I don't know 3
21. The improvement of a child's asthma as he grows older
- a. Is unpredictable 1
 - b. Always occurs 2
 - c. I don't know 3

22. What percentage of children have asthma
- a. 10% 1
 - b. 40% 2
 - c. I don't know 3
23. A child is more likely to have an asthmatic attack if he sleeps on
- a. Foam pillows 1
 - b. Feather pillows 2
 - c. I don't know 3
24. An asthmatic attack can be brought on by
- a. Colds and flu 1
 - b. Hot baths 2
 - c. I don't know 3
25. Which of the following can commonly bring on asthma
- a. Eating too fast 1
 - b. Breathing in cold air 2
 - c. I don't know 3
26. Asthma can be brought on by
- a. Swallowing hard objects 1
 - b. Excessive worry before examinations 2
 - c. I don't know 3
27. Asthma can be brought on by
- a. Playing barefoot 1
 - b. Being unhappy or upset 2
 - c. I don't know 3
28. Asthma can be brought on by
- a. Laughing too much 1
 - b. Eating too much 2
 - c. I don't know 3

29. Children with asthma
- a. Should not play any sport 1
 - b. Can play certain sports 2
 - c. I don't know 3
30. The **BEST** sport for an asthmatic child is
- a. Swimming 1
 - b. Running 2
 - c. I don't know 3
31. The wheezing and coughing that may occur during exercise can be prevented by
- a. Taking a puff from the inhaler pump **before** the exercise 1
 - b. Drinking water **before** the exercise 2
 - c. I don't know 3
32. A physically fit child will have
- a. Fewer attacks of asthma 1
 - b. More attacks of asthma 2
 - c. I don't know 3
33. The asthmatic child's bedroom should be kept
- a. As dust free as possible 1
 - b. Closed and dark, allowing in no air or sunlight 2
 - c. I don't know 3
34. House dust mite which irritate the airways of the asthmatic child and live in mattresses and carpets are best removed by
- a. Not changing the bedding frequently 1
 - b. Frequently vacuuming the carpet and mattress and exposing them to the sun 2
 - c. I don't know 3
35. Which of the following is a suitable pet for an asthmatic child
- a. A goldfish 1
 - b. A dog or a cat 2
 - c. I don't know 3

36. When children with asthma move to a dry, hot climate e.g. the Karoo, their asthma will
- Improve in most children 1
 - Remain the same in most children 2
 - I don't know 3
37. Medicines used in asthma can
- Cure the illness 1
 - Control the illness to allow for a normal lifestyle 2
 - I don't know 3
38. Fewer side-effects of asthma medicines are experienced by using them in
- Tablet or syrup form 1
 - Inhaler pump form 2
 - I don't know 3
39. The smallest dose of medicine is used in the
- Tablet or syrup form 1
 - Inhaler pump form 2
 - I don't know 3

In general, all asthma treatments can be divided into two groups, namely, the 'PREVENTERS' that keep asthma attacks away e.g. Becotide, Lomudal, Zaditen and the 'RELIEVERS' that give instant relief to symptoms e.g. Ventolin, Venteze, Solphylin etc.

40. The 'preventers' e.g. Becotide, Lomudal, Zaditen etc. work by
- Reducing the swelling (inflammation) of the airways (tubes) of the lung 1
 - Relaxing the muscles of the airways 2
 - I don't know 3
41. The 'preventers' e.g. Becotide, Lomudal, Zaditen etc
- Should be taken regularly for a long time 1
 - Can be stopped as soon as the child feels better 2
 - I don't know 3

42. The 'preventers' e.g. Becotide, Lomudal, Zaditen etc
- Take a few weeks to come into effect 1
 - Give immediate relief to symptoms 2
 - I don't know 3
43. Acute asthma attacks will occur less often if the child takes the 'preventers' e.g. Becotide, Lomudal, Zaditen etc
- Daily 1
 - Only when he feels like it 2
 - I don't know 3
44. Relieving medicines e.g. Ventolin, Venteze, Solphylin etc are used
- When a child is not coughing or wheezing 1
 - Only when the child is coughing and wheezing 2
 - I don't know 3
45. When an asthmatic child starts to cough at night, it usually means that
- He's got a sore throat 1
 - He may be starting an acute attack 2
 - I don't know 3
46. In the case of a child who is starting a cough at night, the parents should
- Give the child a 'relieving' medicine e.g. Ventolin, solphylin and observe the child's progress 1
 - Rush the child to hospital or doctor 2
 - I don't know 3
47. If a child with asthma catches a common cold, he
- Should be treated with an antibiotic 1
 - Should not be treated with an antibiotic 2
 - I don't know 3
48. When a child has a sudden attack of asthma you should
- Stay calm and keep your child calm 1
 - Make the child cry 2
 - I don't know 3

49. When your child has a sudden attack of asthma, you should let him
- a. Breathe slowly and regularly 1
 - b. Breathe fast 2
 - c. I don't know 3
50. When your child has a sudden attack of asthma, you should give him a dose of
- a. Relieving medicine 1
 - b. Preventing medicine 2
 - c. I don't know 3
51. When your child has a sudden attack of asthma, you should
- a. Take him to the doctor or hospital if his usual medicine does not help within a half or one hour 1
 - b. Continue giving more medicines at home 2
 - c. I don't know 3
52. Inhaler pumps taken for asthma as the doctor has prescribed
- a. May weaken his heart 1
 - b. Do not weaken the heart 2
 - c. I don't know 3
53. Children who are taking medicines for asthma regularly
- a. Can become addicted to the medicines 1
 - b. Cannot become addicted to the medicines 2
 - c. I don't know 3
54. Folk remedies e.g. Dutch medicines are effective in treating asthma
- a. True 1
 - b. False 2
 - c. I don't know 3
55. If you use the same asthma medicines for a long time, they become ineffective
- a. True 1
 - b. False 2
 - c. I don't know 3

(You are almost finished)

56. How would you describe your child's asthma at present?
- a. Poorly controlled 1
 - b. Fairly well controlled 2
 - c. Well controlled 3
 - d. Very well controlled 4
 - e. I don't know 5

57. What worries you **MOST** about your child's illness?

Answer in your own words.

58. In which areas of asthma do you want more information?

59. General comments:

*Many thanks for completing the questionnaire,
it is much appreciated*

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