PARENTS' MANAGEMENT OF CHILDHOOD ASTHMA: THE RELEVANCE OF PSYCHOSOCIAL FACTORS

VOLUME ONE

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November 1998
# VOLUME ONE

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ABSTRACT

Asthma is the most common chronic disease experienced by children in Australia and accounts for the greatest number of admissions to paediatric hospitals. Although parents carry the major responsibility for the management of children with asthma, little information is available about the specific management approaches parents employ when caring for their children. Few direct measures of parental behaviour have been available to investigate differences in parental management practices. This has limited our understanding of how recommendations made by health professionals are interpreted and implemented by parents.

The principal aim of this thesis was to develop a tool to measure approaches parents use to manage children's asthma. The second aim was to identify the influence of psychosocial factors on parents' management of childhood asthma. The new questionnaire developed in this thesis asked parents to describe their management approaches to typical asthma scenarios. For each scenario, parents rated their likelihood of carrying out different behaviours including giving medication, monitoring children's symptoms and seeking medical help. Behaviours which parents considered important as well as behaviours that health professionals advocate were included in the questionnaire. Factor analysis was used to derive subscales for the questionnaire. The medical assessment subscale describes parents' tendency to take their children for medical assessment when their children experience asthma symptoms. The external advice subscale describes parents' tendency to seek assistance from knowledgeable others. The home management subscale describes parents' approaches to monitoring and treating children at home.
One of the principal findings of this thesis was that psychosocial factors accounted for a large proportion of the variance in parental asthma management. The two most important independent factors were, parental perceptions of children’s vulnerability and family socioeconomic status. Parents who perceived their children to be more vulnerable to illness and parents from lower socioeconomic groups, reported a greater tendency to take children to be medically assessed, to seek external advice and to actively monitor their children’s clinical status at home. These relationships were present even after controlling for the effect of asthma severity. These findings have important clinical and public health implications.
DECLARATION

I certify that this thesis does not contain material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text. I consent to the thesis being made available for photocopying and loan if accepted for the award of degree of Doctor of Philosophy.

Nicola J Spurrier
November, 1998
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<td>Asthma Management Questionnaire</td>
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<td>ASI</td>
<td>Asthma Severity Index</td>
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<td>CFA</td>
<td>Confirmatory factor analysis</td>
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<td>CVS</td>
<td>Child Vulnerability Scale</td>
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<td>BHR</td>
<td>Bronchial hyperresponsiveness</td>
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<td>EIA</td>
<td>Exercise induced asthma</td>
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<tr>
<td>EFA</td>
<td>Exploratory factor analysis</td>
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<td>ER</td>
<td>Emergency room</td>
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<tr>
<td>FAD</td>
<td>Family Assessment Device</td>
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<tr>
<td>GP</td>
<td>General practitioner</td>
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<td>ISAAC</td>
<td>The International Study of Asthma and Allergies in Childhood</td>
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<td>NAC</td>
<td>National Asthma Campaign</td>
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<td>SE</td>
<td>Standard Error</td>
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<td>Standard Deviation</td>
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<td>URTI</td>
<td>Upper respiratory tract infection</td>
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<td>VCOP</td>
<td>Vulnerable Child Overprotectiveness Scale</td>
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CHAPTER ONE

INTRODUCTION

AIMS AND HYPOTHESES

INTRODUCTION

Childhood asthma is a significant public health problem in Australia. Asthma affects up to 20% of Australian children [Crocket, Cranston and Alpers, 1995; Robertson et al., 1998; Volkmer, Ruffin, Wigg and Davies, 1995]. Despite gains in the pharmaceutical management of asthma and extensive attempts to educate patients and parents about asthma, the morbidity and mortality from childhood asthma worldwide remain high [Robertson et al., 1998; Morbidity and Mortality Weekly Report, 1996].

Parents of children with asthma have the major day to day responsibility for managing childhood asthma. This is particularly so with younger children. Management includes giving children preventive medication, recognising and treating acute symptoms and adopting strategies to negotiate with teachers and other caregivers [Clark & Starr-Schneidkraut, 1994]. Much research has focused on possible reasons for the ongoing morbidity and mortality from childhood asthma. There is indirect evidence that parental behaviours affect outcomes of children with asthma. For example, socioeconomic differences in the severity of children's asthma has been interpreted by some authors as evidence that there are differences in the way parents of different educational levels manage children's symptoms [Anderson, Cooper, Bailey and Palmer, 1981; Bauman, Young, Peat,
Hunt and Larkin, 1992; Evans, 1992; Mitchell, 1991. In addition, a number of studies examining antecedents of fatal or near-fatal asthma episodes have suggested that parents of these children have delayed seeking medical care when their children have symptoms [Martin et al., 1995; Strunk, Mrazek, Wolfson Fuhrmann and LaBrecque, 1985]. Parents' management of children's asthma therefore appears an important factor in maximising health outcomes for children. However, a lack of reliable and valid measures has meant that often studies have used indirect indicators of parental behaviour such as the number of hospitalisations or visits to general practitioners for asthma.

One area of parental behaviour which has received considerable attention in asthma and in other chronic illness research, is compliance to medical therapies. Generally this research has concentrated on medication taking behaviour and there is much less information available on other aspects of asthma care. These broader areas include parents' ability to anticipate symptoms, monitor children's symptoms and communicate with other care-givers about their children's asthma. Because, medical compliance or adherence is, by definition, interested in the extent to which patients or parents follow the advice of medical professionals, behaviours which parents feel are important have often been excluded from assessments of parental asthma management. There have been few previous attempts to measure the broader aspects of parental asthma management directly and no attempts to quantitatively assess behaviours which parents themselves consider important.

The initial focus of this thesis was therefore to develop a direct measure of parents' management of childhood asthma. The two guiding principles adopted in the development of the new measure were that behaviours considered important by both parents and clinicians would be included and the measure would be suitable for use in clinical practice and in epidemiological studies. The new questionnaire
developed in this thesis was called the Asthma Management Questionnaire (AMQ). The questionnaire measures the degree of action or intervention parents intend to take when their children develop symptoms of asthma.

The second focus of the thesis was to investigate the relationship between psychological variables and parents' asthma management, measured by the AMQ. In addition to considering sociodemographic factors, parental perceptions of children's medical vulnerability, parental overprotectiveness and family functioning were included as potential explanatory factors. These particular variables were chosen for inclusion in the study after conducting focus group interviews with parents and reviewing the available literature.

AIMS

The study had three primary aims.

1. To develop a new questionnaire to measure parental approaches to manage children's asthma.

2. To assess the psychometric properties of the new questionnaire.

3. To assess the association between independent psychological and social factors and parental asthma management approaches.

HYPOTHESES

To support these aims a series of hypotheses were proposed. These are listed below in the order they are addressed in the thesis.
The first two hypotheses relate to the psychometric properties of the new questionnaire.

1. Parental responses to the new parental Asthma Management Questionnaire will be stable over time (i.e., test-retest reliability).
2. Parental responses to the new parental Asthma Management Questionnaire will closely reflect approaches used by parents in real-life asthma situations experienced by their children (i.e., criterion validity).

The next hypotheses refer to the relationships between psychological and social factors and parental asthma management.

1. Higher levels of parental perceptions of children’s medical vulnerability will be associated with higher levels of asthma intervention as measured by the parental Asthma Management Questionnaire.
2. Higher levels of parental overprotectiveness towards their children will be associated with higher levels of parental intervention.
3. Parents from well functioning families will report higher levels of intervention compared to parents from dysfunctional families.

The following hypotheses describe the anticipated direction of the relationships between disease-specific variables and parental asthma management.

1. Greater levels of background asthma severity will be associated with higher levels of asthma intervention as measured by the parental Asthma Management Questionnaire.
2. Parents with greater familiarity with asthma symptoms and asthma treatments will report lower levels of asthma intervention.
The final hypotheses describe the anticipated direction of relationships between demographic variables and parental asthma management.

1. Parents will manage younger children with greater levels of intervention as measured by the parental Asthma Management Questionnaire compared to older children.

2. Parents will manage girls with greater levels of intervention compared to boys.

3. Parents in lower socioeconomic groups will report lower levels of intervention compared to parents in higher socioeconomic groups.

**THESIS STRUCTURE**

The main body of this thesis is divided into 9 chapters which outline the development of the new questionnaire. The text for these chapters is contained in Volume One. Tables, figures, a complete reference list and appendices are contained in Volume Two. Chapter 2 provides an overview of the literature, focusing on both the public health implications of childhood asthma and the importance of assessing parental asthma management. Chapter 3 describes how the new questionnaire evolved from a previously published, semi-structured parent interview developed by Taylor et al. [1991]. The limitations of the measure of Taylor et al. and the steps taken to overcome these limitations are described in this chapter. Chapter 4 describes the sampling method, the subjects and general statistical approaches used in subsequent chapters of the thesis. Chapter 5 reports the frequency distribution of individual items for the new questionnaire. Chapter 6 describes how factor-based scores were derived for the AMQ using exploratory factor analysis. Chapter 7 presents data to support the reliability and validity of the questionnaire. Chapter 8 describes the relationships between responses to the AMQ and a number of important psychosocial factors. These factors included parental perception of child vulnerability, parental protectiveness, family functioning
and socioeconomic status. Both the clinical and public health implications of these results are discussed. Chapter 9 concludes the thesis by summarising the major findings, discussing the strengths and limitations of the study and highlighting further research questions which were generated from the results of this study.
CHAPTER TWO

LITERATURE REVIEW

INTRODUCTION

The literature review is divided into two sections. The first section is an overview of the epidemiology of childhood asthma in Australia and reviews the trends in prevalence and severity of asthma in children over time and between different groups of children. Comparisons are made between Australia and other countries. The impact of this common disease on children, families and society is also described. The second section describes the concept of parental asthma management and highlights areas of controversy particularly with regard to differences in medical and parental perspectives of chronic childhood disease management. Methods available to assess asthma management approaches of parents are also reviewed in this section. Articles were chosen for inclusion in this review if they were contemporary and were the larger studies undertaken in a particular area. In addition, Australian studies are highlighted because the prevalence of asthma and the medical management of asthma differs between countries. Parental approaches to asthma management in Australia are best understood within the context of these differences.
PART I. ASTHMA: A MAJOR PUBLIC HEALTH PROBLEM IN AUSTRALIA

Defining Asthma

Asthma is a chronic respiratory disorder which varies widely in severity and can be fatal. Asthma is typically characterised by episodic symptoms. As a result, making a diagnosis of asthma is not straightforward even in a clinical setting. Difficulties defining asthma are further magnified in epidemiological studies. Definitions of asthma are based either on physiological changes or clinical characteristics. The International Consensus Report on Diagnosis and Treatment of Asthma defined asthma as a,

....chronic inflammatory disorder of the airways in which many cells play a role, including mast cells and eosinophils. In susceptible individuals this inflammation causes symptoms which are usually associated with widespread but variable airflow obstruction that is often reversible either spontaneously or with treatment, and causes an associated increase in airway responsiveness to a variety of stimuli. [National Heart, Lung, and Blood Institute, 1992, p. 603].

In clinical practice, a more useful definition of asthma is, "episodic wheeze and/or cough in a clinical setting where asthma is likely and other rarer conditions have been excluded" [Warner et al., 1989, p. 1065]. The clinical diagnosis of asthma, particularly in children, is often based on a history of typical symptoms. Clinical signs of a prolonged expiratory phase and typical expiratory wheeze are usually present only during an exacerbation. Occasionally, children with severe asthma will have signs of long standing airway obstruction such as chest deformity.

Physiological markers of airway obstruction have been used to facilitate the diagnosis of asthma [Van Asperen, 1995]. These have included the presence of atopy, bronchial hyperresponsivness (BHR) and changes in spirometric measurements of pulmonary function. Atopy is defined as the presence of immunoglobulin E antibodies to common allergens in the patient’s environment and
has been considered to be the strongest risk factor in the development of asthma [Burrows, Martinez, Halonen, Barbee and Cline, 1989; Martinez et al., 1995; Sears et al., 1991]. Bronchial hyperresponsiveness describes an abnormally pronounced bronchoconstrictor response to inhaled physical or chemical airway irritants. Although a positive relationship exists between typical symptoms of asthma and hyperresponsiveness, laboratory assessed BHR is not significantly sensitive nor specific to be used diagnostically [Pattemore et al., 1990]. The role of BHR in the diagnosis of asthma has been reviewed by Britton and Tattersfield [1986] and more recently by Pattemore and Holgate [1993]. Pulmonary Function tests using spirometry have largely been used to follow the clinical progress of children diagnosed with asthma. A reduction in ratio of forced expiratory flow to forced vital capacity and a reduction in forced mid-expiratory flow suggests airway obstruction and is helpful to confirm the diagnosis of asthma, but pulmonary function tests in isolation cannot diagnose asthma [Warner et al., 1989]. These tests of airway physiology require the subject to cooperate fully with the test procedure. Many children, even those of primary school age have difficulty coordinating respiratory effort and results are not always reliable.

Population studies of asthma prevalence have relied on self or parent report of symptoms. Surveys have used responses to questions such as having had ‘wheeze’, ‘shortness of breath’, ‘cough’ or ‘a doctor diagnosis of asthma’ to determine which subjects have asthma [Burr, Butland, King and Vaughan-Williams, 1989; Rona, Chinn and Burney, 1995; Mitchell & Asher, 1994; Nystad, Magnus, Gulsvik, Skarpaas and Carlsen, 1997]. There are two major weaknesses to this approach. First, no distinction is made between current symptoms and asthma symptoms in the past. This is of particular relevance in children where symptoms frequently abate with time [Martin, McLennan, Landau and Phelan, 1980]. Second, these definitions are loose and subjective and have created difficulties comparing
prevalence rates of asthma between studies. Most recently, population studies have defined asthma as the presence of wheeze in the preceding 12 months. Standardised questionnaires have been developed for use in different countries to allow valid international comparisons. The ISAAC protocol (International Study of Asthma and Allergy in Children) is a standard set of questions based on symptoms in the preceding 12 months and has been used extensively in Australia, New Zealand and internationally to document the prevalence of asthma in these countries and to allow valid international comparisons [Asher et al., 1995].

The Prevalence of Childhood Asthma

Prevalence of Asthma in Australian Children

Despite difficulties defining and diagnosing asthma, current evidence suggests that asthma is the most common chronic health condition in children in all developed countries. Many individual studies have been conducted over the last 15 years in Australia to quantify the prevalence of childhood asthma. The studies which are most recent, have the largest sample size and which have utilised a clear case definition for asthma are summarised in Table 2.1 [Bauman, Mitchell, Henry, Robertson and Abramson, 1992; Crockett, Cranston and Alpers, 1995; Peat, Gray, Mellis, Leeder and Woolcock, 1994; Robertson et al., 1992; Robertson et al., 1998; Volkmer, Ruffin, Wigg and Davies, 1995]. Considering these studies in total, about one in five children in Australia experience symptoms consistent with asthma. In addition, cohort studies have shown that the prevalence of asthma declines with age [Williams & McNicol, 1969; Martin, McLennan, Landau and Phelan, 1980; McNicol & Williams, 1973].
Studies have demonstrated significant differences in prevalence of asthma between geographic regions within Australia. In South Australia for example, both Crockett et al. [1995] and Volkmer et al. [1995] reported significantly higher rates of wheeze in the past 12 months in rural areas compared to urban centres. Volkmer et al. also reported that the 12 month prevalence of wheezing in four year old children varied considerably across postal areas within metropolitan Adelaide.

**International Asthma Prevalence Rates**

In terms of international comparisons, the most recent study is that of the ISAAC group of researchers, based in Australasia [The ISAAC Steering Committee, 1998]. This study is the largest reported attempt to assess the prevalence of asthma between countries using identical criteria. Using standardised questionnaires and video questionnaires to enhance validity, 463,801 children aged 13 to 14 years in 56 countries were surveyed. Overall, the highest prevalence rates of “wheeze in the last 12 months” were found in the UK, Australia, New Zealand and the Republic of Ireland, followed by countries in Latin America. The lowest prevalence rates were reported from Eastern European countries, Indonesia, Greece, China, Taiwan, Uzbekistan, India and Ethiopia.

**Increases in Prevalence of Childhood Asthma**

Over the last 30 years there has been a steady increase in the prevalence of childhood asthma. This has been documented in both Western countries and developing nations. This appears to reflect true increases in prevalence, rather than changes in diagnostic criteria or heightened awareness of asthma by health professionals and the public [Burr, Butland, King and Vaughan-Williams, 1989; Robertson et al., 1991; Crockett et al., 1995; Mitchell & Asher, 1994; Nystad,
Magnus, Gulsvik and Carlsen, 1997; Peat, van den Berg, Green, Mellis and Leeder, 1994; Rona, Chinn and Burney, 1995. A large number of studies have reported these increases and the major studies conducted in Australia are summarised in Table 2.2. A number of the larger international studies are also included for comparison. Overall, the percentage increases in prevalence of childhood asthma range between 6% and 25%, the size of the difference varying depending on the definition of asthma used and years compared.

**Asthma Mortality**

The number of deaths from asthma has also risen over the last 30 years. This increase in mortality has been considerably more marked in adults than in children, particularly adults over 60 years of age. This trend has been noted in Australia, New Zealand, the United States and the United Kingdom [Evans, Mullally, et al., 1987; Jenkins et al, 1988; Mitchell & Jackson, 1989; Sly, 1984]. The current mortality rate for children in Australia is 0.9 per 100,000 population [Nguyen et al., 1996]. In the United States, black children and children living in poverty, have a significantly higher asthma mortality rate [Evans, 1992; Morbidity and Mortality Weekly Report, 1996]. The relationship between asthma mortality and socioeconomic status has not been examined closely in Australia, although a study of near-fatal asthma deaths in South Australia failed to demonstrate such a relationship [Martin et al., 1995].

**The Severity of Asthma**

**Definitions of Asthma Severity**

The frequency and intensity of asthma symptoms is commonly referred to as asthma severity or functional severity. However, the definition of severity of
children's asthma is not standardised and the approach used to assess asthma severity varies across studies. For example, the term severity is sometimes used to refer to the intensity of symptoms of discrete acute attacks of asthma. The term also is used to refer to the background frequency and intensity of symptoms over a defined period of time. One problem with this latter definition is that current and past drug therapies are often not included in the assessment of severity. As a result, some children may be reported to have minimal symptoms on a questionnaire, but require large and frequent doses of inhaled preventer medications to maintain this level of control. Other parents may report similar levels of symptomatology in their children but these children may require any medications. Bearing these issues in mind, the common clinical classification of childhood asthma in Australia is, mild episodic asthma, frequent episodic asthma and chronic persistent asthma. In Australia it is estimated that approximately 75%, 20% and 5% of children fall into these categories respectively [Isles & Robertson, 1993].

Variations in the Severity of Childhood Asthma

Defining the background severity of asthma in terms of the frequency and intensity of symptoms, there is some evidence that children are experiencing more frequent and intense episodes of asthma in recent years, in addition to there being a higher prevalence of childhood asthma worldwide. An increase in the severity of asthma experienced by children is suggested by the massive increase in hospitalisations for childhood asthma reported over the last 30 years in many countries [Mitchell, 1985]. These increases cannot be explained just by changes in ICD coding, diagnostic transfer, medical management or admission criteria [Anderson, 1978; Anderson, Bailey and West, 1980; Carman and Landau, 1990; Gergen and Weiss, 1990; Kun, Oates and Mellis, 1993; Mitchell & Dawson, 1989; Weitzman, Gortmaker, Sobol and Perrin, 1992]. Others have sought more direct evidence to support an
increase in asthma severity. Dawson [1987] assessed the severity of presentation of acute asthma in children admitted to a Christchurch hospital over 20 years and an increase in the severity of attacks was noted over this time. Similarly, Gergen and Weiss [1990] reported not only a 4.5% per annum increase in hospitalisation rate for childhood asthma in the United States, but found that the proportion of children requiring tracheal intubation and cardio-pulmonary resuscitation had also increased. However, other studies using direct questions pertaining to the frequency and impact of symptoms have shown little change in background asthma severity with time. For example Mitchell and Asher [1994] conducted two studies in 1985 and 1991 in Auckland, New Zealand using identical methodology. Defining severe asthma as “more than 12 wheezy attacks in last 12 months” or “wheeze or breathlessness in the last one month”, there was no significant difference in the rates of these symptoms in children surveyed in 1985 compared to 1991. Similarly, although Weitzman et al. [1992] showed a 200% increase in hospitalisation rate in children less than 17 years of age between 1964 and 1980 in the United States, responses to direct questions about the number of doctor visits with asthma, the bother caused by asthma, the number of bed days in 12 months and the limitation of usual activities because of asthma showed no differences between 1964 and 1980.

There is substantial evidence that children living in disadvantaged families experience more severe asthma. In the United States, children living in inner city slum areas have higher rates of asthma compared to children living in more advantaged areas and hospital discharge rates also suggest that these disadvantaged children have more frequent and severe episodes of asthma [Crain et al., 1994; Halfon and Newacheck, 1993]. Although there is some debate about whether the differences in asthma prevalence and asthma severity reflect poverty or race, most authors recognise that socioeconomic disadvantage is the major
explanatory factor [Gold et al., 1993; Schwartz, Gold, Dockery, Weiss and Speizer, 1990; Weiss, Gergen and Crain, 1992].

Early British studies suggested that asthma was more prevalent in higher socioeconomic groups [Hamman, Halil and Holland, 1975]. The likely reason for this finding was diagnostic bias in that children from higher socioeconomic groups were more likely to have access to medical care where asthma was recognised and diagnosed. More recent studies have reported that the prevalence of wheeze in British children does not vary by social class but that the intensity and frequency of asthma symptoms are significantly greater in disadvantaged children [Strachan, Anderson, Limb, O’Neill and Wells, 1994]. A series of studies undertaken in New Zealand, reported that Maori and Pacific Island children have higher mortality rates and hospitalisation rates for asthma despite having lower levels of bronchial hyperresponsiveness [Mitchell et al., 1989; Mitchell, 1991; Pattmore et al., 1989]. The authors suggested that less effective management of childhood asthma in disadvantaged minority groups was the main reason for these findings. There is limited comparable data, assessing socioeconomic differences in childhood asthma available in Australia. However, national census data from 1989 to 1990 reported that asthma was 33% more prevalent in boys and 26% more prevalent in girls in socioeconomically disadvantaged households [Australian Institute of Health and Welfare, 1996]. The source of this data however was unclear. If these figures were based on hospital separations, the results may have been influenced by selection bias. It is plausible that children from disadvantaged families are admitted more readily with the same level of symptoms than children from more advantaged backgrounds. A study by Bauman, Young, Peat, Hunt and Larkin [1992] reported that the prevalence of current wheeze and cough were higher in children attending a primary school in a disadvantaged area of New South Wales compared to children living in more advantaged suburbs. They also suggested that this group of
children were having less appropriate asthma management because of a lower rate of usage of reliever and/or preventer treatment and because a greater proportion of the parents of these children smoked. Aboriginal children are one of the most economically disadvantaged groups of children in Australia. There is a paucity of published data describing the prevalence and severity of asthma in urbanised Aboriginal children. However the prevalence of asthma in rural Aboriginal children is reported to be very low [Veale et al., 1996].

The Impact of Asthma on the Lives of Children and Families

Although physical symptoms (and at one extreme, mortality) are important health outcomes, asthma can impact on many areas of children’s lives. Health related quality of life (QOL) describes this broader impact of disease or illness on individuals. The domains of interest include not only the physical nature of the condition but the impact of the disorder on psychological, social and occupational or school functioning. These considerations have only recently been addressed in children and there are no prospective studies indicating whether quality of life of children with asthma has improved, declined or remained unchanged. An early study by Robertson, Bishop, Caust et al. [1992] in Australia suggested that childhood asthma considerably interfered with the lives of children, their parents and families. This study relied on parental responses to single items. They reported that 34% of children with asthma experienced interference with sporting activities at school, 12% interference with sleep at least weekly and on average children with asthma missed eight days of school a year. In terms of effects on the family, 16% of parents of children with asthma reported interference with work and 21% of families said that the child’s asthma interrupted social and recreational plans.
A number of validated asthma specific measures of quality of life are now available for children, most of which give total scores on important domains [Bender, 1996; French, Christie, Sowden and West 1993; Juniper et al., 1996a; Juniper et al., 1996b; Sullivan & Olson, 1995; Usherwood, Scrimgeour and Barber, 1990]. Because these measures have only recently been developed there is little information available about, (i) changes in the quality of life of children with asthma over time, (ii) differences between QOL of children with asthma and children without, (iii) differences between children with asthma and children with other chronic illnesses, and (iv) differences in QOL of children living in families of varying socioeconomic status.

The Economic Impact of Asthma

Asthma imposes a significant economic burden on our society. Mellis, Peat, Bauman and Woolcock [1991], summed direct and indirect costs of asthma in Australia. They estimated that the total cost of adult and childhood asthma in the state of New South Wales was A$209 million dollars in 1989 with 68% representing direct health care costs, 9% direct non-health care costs and 22% representing indirect costs. Overall, drugs and the appliances needed for administration of drugs made the largest contribution to costs. The second largest cost was the cost of inpatient care for asthma. Krahn, Berka, Langlois and Detsky [1996] analysed the cost of asthma in Canada. The total cost of asthma was between C$504 and C$648 million dollars. Direct costs accounted for just over half of this amount and the single largest direct cost was that of drugs. Consistent with the study by Mellis et al., the second largest cost was the cost of inpatient care. The cost of asthma was similar to the cost of infectious diseases, perinatal illness, birth defects and haematological conditions but much lower than that associated with cardiovascular disease and cancer. Compared to other respiratory illnesses, the proportion of cost
attributed to drugs was much higher in asthma. Although these results cannot be
used to make direct inferences about the quality of management of asthma in the
community, they indicate that optimal home management of asthma could
potentially reduce the economic burden of asthma.

Summary
Although there are some difficulties with the epidemiological definition of asthma,
current evidence suggests that, (i) asthma is the most common chronic childhood
illness in Australia and other developed countries, (ii) the prevalence of childhood
asthma has increased, (iii) the frequency and intensity of asthma symptoms
experienced by children may also have increased (iv) children from disadvantaged
backgrounds appear to have higher rates of asthma and probably also experience
more severe asthma and (v) asthma contributes significantly to the economic
burden of illness in Australia and elsewhere.

PART II. MANAGEMENT OF CHILDHOOD ASTHMA BY PARENTS AND
HEALTH CARE PROFESSIONALS
Suboptimal ambulatory management of asthma has been identified as a possible
explanation for the increasing rates of hospitalisation for children with asthma and
for the significant asthma symptoms experienced by children despite the availability
of efficacious drug therapies. The next section describes the current medical
recommendations for childhood asthma management. Evidence is then presented
suggesting that these recommendations are not universally practised both by health
care providers and parents. Indirect evidence that parents are not adequately
managing children's asthma is examined.
One way to directly assess the adequacy of parental asthma management is to focus on compliance to asthma medications. However, this approach has been criticised because it emphasises the position of relative power held by health care professionals. Broader definitions of parental asthma management, incorporating parents' abilities to monitor children, parental efforts to reduce children's contact with known precipitating factors (such as allergens) and seek appropriate and timely medical assistance have been advocated. These broader constructs have been considerably more difficult to quantify. Previous approaches to assessing these areas will be described.

Changing Approaches to the Medical Management of Asthma

The medical management of asthma is ideally determined by the frequency and severity of a patient's symptoms. The aims of management of childhood asthma have been summarised in a recent international consensus statement.

1. To achieve rapid resolution of acute symptoms;
2. To employ environmental control where indicated by history and allergy test results;
3. To use prophylactic drugs when morbidity of asthma is sufficient to justify their use, taking into account their potential side effects;
4. To optimize the quality of life with no sleep disturbance and prevent exercise-induced asthma;
5. To use delivery devices that are appropriate to the drug and the patient's age.


Prior to 1980, the mainstay of outpatient management of children with asthma was inhaled bronchodilator medication such as salbutamol or ibratropium bromide, administered with the onset of symptoms. Children with more frequent symptoms were prescribed oral theophylline preparations or inhaled sodium cromoglycate on a daily basis to prevent symptoms. During episodes of exacerbation of symptoms, short courses of oral corticosteroids were given. With the availability of inhaled corticosteroids such as beclamethasone and the realisation that asthma was an
inflammatory condition of the airways, the use of this class of drugs as preventer agents was strongly advocated [Barnes, 1989]. There is good evidence from clinical drug trials that the regular use of inhaled corticosteroids leads to enhanced control of symptoms and reduces the need for bronchodilator therapy [Dutoit, Salome and Woolcock, 1987; Haahtela et al., 1991; Phelan, 1992]. Newer preparations of inhaled steroids have recently become available which are claimed to be associated with reduced side effect profiles. Currently, trials of new leukotriene antagonists are being conducted in Australia in the childhood population [Rachelefsky, 1997; Wenzel, 1998].

Consensus guidelines to help medical professionals treat children with asthma have been widely distributed in Australia, New Zealand and elsewhere summarising current standards for investigation and management of children with asthma [Henry et al., 1990; Isles & Robertson, 1993; Wainwright, Isles and Francis, 1997; Warner, Naspitz and Cropp, 1998]. The majority of these guidelines have been based on currently available scientific evidence in addition to expert opinion. The process of ensuring consistent medical management of asthma in Australia culminated in the National Asthma Campaign (NAC), a national attempt to educate health care professionals, patients and the public about diagnosis and management of childhood and adult asthma [Pierce & Irving, 1991]. A summary of the current medical guidelines for treating children with asthma in Australia is given in Table 2.3 [Wainwright et al. 1997].

Gaps between Guidelines and Practice in the Ambulatory Management of Children’s Asthma

Despite the National Asthma Campaign and numerous local health promotion initiatives, a number of Australian studies have shown that the asthma management
of large numbers of children and adults in the community does not comply with consensus guidelines particularly with regard to the use of preventive strategies. For example, Bauman and Mitchell et al. [1992] surveyed a random sample of primary school children in Sydney, Melbourne, Brisbane and the Hunter Valley. Children with a history of three or more episodes of wheeze in the past 12 months, cough more than once a week or a current diagnosis of asthma were defined as having "probable" asthma. Of these children, only 30% had lung function measured in the past 12 months and only 6% possessed both a peak flow meter and an asthma action plan. The authors felt that under-treatment of children was likely because preventive asthma medications were regularly used by only 25.5% of children with "probable" asthma and by 44.3% of children who had asthma symptoms more than twice per week. Seventeen percent of children with "probable" asthma had not been diagnosed prior to the study, suggesting that a considerable number of children in the community remained undiagnosed.

Similar findings have been reported in adults. Abramson, Kutin, Rosier and Bowes [1995] conducted a random survey of 3095 adults on the Victorian electoral role. Five percent of participants had been diagnosed as having asthma at some time. However, a further 14% of respondents with non-specific respiratory symptoms, consistent with asthma, had never been diagnosed. Of those diagnosed with asthma, 61% of subjects reported using inhaled bronchodilators, 16% theophylline preparations and only 15% and 4% used inhaled corticosteroids and cromoglycate, respectively. This study demonstrated both high levels of undiagnosed adult asthma in the community and low levels of inhaled preventer medication use. Similar results have also been reported in studies from other developed countries [Hodges et al., 1993; Joseph, Foxman, Leickly, Peterson and Ownby, 1996; Mitchell and Asher, 1994].
Ambulatory or home management of childhood asthma is dependent on a number of inter-related factors; expertise and knowledge of medical practitioners (particularly general practitioners), availability of educational materials, equitable access to high quality health services and parental knowledge and skills about asthma management.

Management of Asthma by Health Care Professionals

The management of asthma by medical professionals has been directly assessed in Australia. An audit of doctor's knowledge and reported management of adults and children with asthma was conducted in South Australia in 1989, prior to the instigation of the National Asthma Campaign (NAC) [Coates et al, 1994]. The major finding of this study was that optimal asthma assessment, patient monitoring and medication prescribing was not being employed by general practitioners to manage asthma. A further finding was that the majority of general practitioners surveyed felt that,

patient centred factors such as denial, lack of compliance and continuing to smoke were substantial barriers to the effective treatment of asthma while practitioner factors such as lack of monitoring or labelling, that is informing a patient he or she has asthma, were believed to be less important [Coates et al., 1994, p. 126].

Following the implementation of the NAC in Australia and New Zealand, a survey was undertaken of general practitioners, paediatricians and paediatric respiratory specialists in both countries [Phin and Oates, 1993]. There was general consensus between these groups about what constituted good asthma management although a number of deviations from the NAC guidelines were noted. These included overuse of oral sympathomimetics by general practitioners and a preference to prescribe inhaled corticosteroids rather than sodium cromoglycate by general practitioners and respiratory physicians. A more recent study was conducted in
Melbourne in 1995 [Kourdoulos & Schattner, 1997]. This study demonstrated that general practitioners were complying somewhat better with consensus guidelines although there was still a tendency to over-treat children with mild asthma with inhaled corticosteroids. Similar studies have been conducted elsewhere, particularly in the United Kingdom. These studies show that substantial differences exist in the management of asthma by medical professionals in other countries despite the availability of detailed consensus guidelines [Harrison & Pearson, 1993].

**Parental Asthma Management**

Children spend the majority of their time with their families or at school. Day to day asthma management therefore becomes the responsibility of parents, carers and teachers. Parents and other carers need to recognise the onset of symptoms, know when to initiate treatment, be able to monitor symptoms and determine whether and when medical opinion should be sought. A number of authors have suggested that inadequate management of childhood asthma by parents may be one reason why children have continued to experience significant morbidity from asthma [Clarke, Gotsch and Rosenstock, 1993; Howell, Flaim and Lum Lung, 1992; Wilson, Mitchell, Rolnick and Fish, 1993]. This has been the basis for the widespread development and implementation of patient and parent asthma education programs.

*What Constitutes Parental Asthma Management?*

The term parental asthma management is a child specific form of the term asthma self-management. This phrase, coined in the early 1980’s, reflects the recognition that because asthma is a chronic, episodic condition, patients have to monitor and treat their own symptoms. Asthma is inherently different to other chronic diseases
because for the most part, children are perfectly well with symptoms only occurring episodically. Some parents are able to predict the onset of symptoms which are consistently triggered by respiratory tract infections, exercise or exposure to cold air etc. However, frequently symptoms arise unpredictably. Differences in frequency, severity and quality of symptoms between children and within individual children at different times mean that parents have to adapt management strategies to best meet the needs of each child. In contrast, diseases such as diabetes or cystic fibrosis have a relatively narrower spectrum of symptoms and generally parental behaviours are more easily defined and consistent for different children.

Clark and Starr-Schneidkraut [1994], considered family or parent asthma management to be composed of three facets; (i) preventive behaviours, (ii) attack management and (iii) social skills. By prevention they refer to parents’ ability to recognise early signs of asthma, identify and control trigger factors and to supervise medication taking. Attack management refers to “resting and remaining calm, taking medicines as prescribed, using criteria to seek assistance as needed, and following other steps outlined by the physician” (such as peak flow monitoring) [Clarke and Starr-Schneidkraut, 1994, p.s55]. They also describe social skill behaviours which are strategies used by patients or parents to control the disease and to reduce the impact of the disease on day to day activities. Their model of management highlights some of the factors thought to impact on parental asthma management. This model is shown in Figure 2.1. Parts of the three facets of management have been investigated in previous research as have a number of the antecedent factors. For example, parents' knowledge about asthma has been examined, particularly in the context of evaluating asthma education programs [Henry, Cooper and Halliday, 1995; Hindi-Alexander and Cropp, 1981; Rubin, Bauman and Lauby, 1989]. Health beliefs and attitudes towards asthma have been addressed in other studies [Gibson, Henry, Vimpani and Halliday, 1995; Lim, Goh,
Tan and Lee, 1996; Rubin, Bauman and Lauby, 1989. However Clarke and Starr- 
chneidkraut argue that these proximal factors should not be used as proxy 
measures for actual behaviour. Limited research has addressed the question of 
what parents actually do to manage their children's asthma and whether this has 
any impact on outcome.

**Indirect Evidence that Parental Asthma Management Influences Health 
Outcomes for Children with Asthma**

There has been longstanding interest in the impact of parents' asthma management 
on the outcome of childhood asthma. Long term hospitalisation of children, the so-
called "parentectomy", was introduced over 60 years ago as a treatment approach 
for children with very severe asthma [Peshkin, 1930]. Although the potential role of 
precipitating allergens in the children's homes was recognised, many authors 
interpreted the resolution of asthma symptoms during these month-long periods of 
separation as evidence of poor parental asthma management and that 
psychological stressors in the families directly exacerbated symptoms. These 
practices were current up until the late 1960's in Australia and elsewhere [Munro 
Ford, 1968; Purcell et al., 1969].

Studies evaluating socioeconomic differences in outcomes for children have 
implicated differences in parental management practices as a major explanatory 
factor for the varying levels of asthma severity across socioeconomic groups. For 
example, an early study reported that parents in lower socioeconomic groups used 
less anti-asthma drug therapy to manage wheezy episodes in their children than 
parents in higher socioeconomic groups [Anderson, Cooper, Bailey and Palmer, 
1981]. A more recent New Zealand study showed that Polynesian children, a racial 
minority group, were less likely to receive asthma medications prior to hospital
admission and were less likely to be taking prophylactic therapy despite having more previous admissions to hospital with asthma [Mitchell, 1991]. One Australian study has reported similar findings by comparing parental reports of anti-asthma therapy used by children attending schools in two different socioeconomic areas [Bauman, Young, Peat, Hunt and Larkin, 1992]. Parental smoking is currently more common in disadvantaged families [Spencer, 1996]. This is an important issue because passive smoking has been considered to play a major causative role in the pathogenesis and exacerbation of asthma [Martinez, Cline and Burrows, 1992]. Parental smoking has been interpreted by some to reflect poor parental management because parents are expected to give up smoking if it is known to cause worsening of asthma symptoms in their children [Bauman, Young et al., 1992; Murray & Morrison, 1993].

Other studies focusing on asthma mortality, have suggested that inadequate parental recognition of asthma symptoms in their children and non-compliance with preventive therapies could contribute to fatal episodes of asthma in children. One of the first studies to examine the relationship between inadequate home management of asthma by parents and death from asthma used a case-control study design to highlight eight factors which were thought to predict death in children with severe asthma [Strunk, Mrazek, Wolfson Fuhrmann and LaBrecque, 1985]. Apart from disease-specific factors, the other significant factors included, conflict between patients, parents and hospital staff regarding medical management of asthma, self-care of asthma in hospital which was inappropriate for age, depressive symptoms and a disregard of asthmatic symptoms. Although this study was useful in highlighting areas for further research, the results were limited because researchers were not blinded to outcome of subjects and ascertainment bias was likely. A similar, more recent study was conducted in South Australia. This study showed that near-fatal episodes in children were associated with poor
self-management, delay in seeking care and significant psychosocial problems in the families [Martin et al., 1995]. However, these factors were not measured directly but were judged retrospectively by a panel of medical experts.

**Do Interventions Aimed at Changing Parental Behaviour Improve Outcomes for Children with Asthma?**

One way of assessing the relative contribution of parental management in determining outcomes for children with asthma is by considering the effectiveness of asthma education programs for parents. Positive relationships have been hypothesised to exist between asthma education interventions, parental behaviours and morbidity and mortality experienced by children with asthma. A large number of interventions have thus been designed to improve parental asthma management behaviour. The success of these interventions however, remains controversial. In general, studies have either measured changes in self-management behaviours or changes in indicators of morbidity (symptoms, health care utilisation, school absences). Many small studies have been published claiming success in changing either behaviour or outcome but are limited by lack of a control group [e.g., Charlton, Charlton, Broomfield and Mullee, 1991; Gillies et al., 1996; Taggart, Zuckerman, Lucas, Acty-Lindsey and Bellanti, 1987].

Clark [1989] has conducted the most extensive review of randomised controlled studies conducted in the United States aiming to improve self-management behaviour. The studies reviewed showed improvement in self-management behaviours [Clark, Feldman, Evans and Duzey et al., 1986; Clark, Feldman, Evans and Levison et al., 1986; Lewis, Rachelefsky, Lewis, de la Sota, Kaplan, 1984; Wilson-Pessano & McNabb, 1985], changes in health care use [Clark, Feldman, Evans and Duzey et al., 1986; Clark, Feldman, Evans and Levison et al., 1986;
Lewis et al., 1984; Maiman, Green and Gibson, 1979, reduction in wheezing episodes [Creer et al., 1988; Evans et al., 1987], improved school attendance [Creer et al., 1988; Hindi-Alexander & Cropp, 1984], increases in physical activity [Hindi-Alexander & Cropp, 1984] and improved attitude towards asthma [Creer et al. 1988; Evans et al. 1987; Parcel, Nader and Tiernan, 1980].

Other studies have reported less encouraging results. For example, Hilton, Sibbald, Anderson and Freeling [1986] conducted a large controlled trial of asthma education provided by general practitioners for adult patients, in the United Kingdom. This study had three separate groups; one group received a maximum education program, the second received a limited education program and the third group acted as the control group. Only patients receiving maximum intervention had significant improvement in knowledge one year later and no group showed any significant difference in self-management ability (assessed by self-report) or asthma morbidity compared to the control group. A similar study, compared the effects of a self-management booklet and audiocassette for children and adults with asthma [Jenkinson, Davison, Jones and Hawtin, 1988]. Although knowledge about drugs was increased in groups receiving the educational material, skill in the use of inhalers, consumption of drugs, consultations with general practitioners and symptoms from asthma were no different compared to the control group.

A large randomised control study conducted in New Zealand reported that the intervention group which received intensive community based asthma education had significantly greater use of preventer medication, were more likely to possess peak flow meters and individualised self-management plans and had greater knowledge about asthma and asthma management [Garrett et al., 1993]. However, there were no differences between intervention and control groups in terms of other types of illness behaviour (compliance with medication, smoking and outpatient...
attendance). Nor were morbidity indices (courses of oral corticosteroids, school or work absences and acute visits to the doctor or hospital) different between intervention and control subjects.

Because behaviour is difficult to evaluate, many intervention studies have simply focused on assessing changes in asthma morbidity. Howland, Bauchner and Adair [1988] conducted a review of paediatric intervention studies of this kind. Their criteria for inclusion in the review were; (i) the study was an educational intervention, (ii) subjects diagnosed with asthma were less than 20 years of age and (iii) the findings reported were final and not subject to revision. Thirteen studies were included, six used pretest-posttest design without controls and seven were randomised control trials. Although most of the studies reviewed reported favourable outcomes, the overall effectiveness of asthma education programs on outcomes such as school absences and health care utilisation was small. Similar conclusions were reached by Bernard-Bonnin, Stachenko, Bonin, Charette and Rousseau [1995] who conducted a meta-analysis to ascertain the impact of asthma education programs on childhood morbidity due to asthma. They searched for all asthma education intervention studies in English or French published between 1970 and 1991 and included only randomised controlled clinical trials in their analysis. Only studies measuring emergency room visits, hospitalisations, hospital days, asthma attacks and school absences were included. Eleven studies were identified which satisfied these criteria. The results of the meta-analysis showed that self-management education programs had little influence on these morbidity outcomes. The authors suggested that although patient education can enhance adjustment to asthma, improve attitudes towards the disease and improve knowledge about management, reduction in morbidity is not necessarily realised. There are a number of possible explanations for these results. First, the education programs developed to date, may not be effective in changing parents' behaviour and second,
parental behaviour may not significantly influence morbidity experienced by children with asthma. Finally, it may be possible that education programs increase parental awareness of asthma and encourage rather than discourage parents to seek medical expertise when their children experience asthma symptoms. Outcomes such as visits to the doctor or emergency room may therefore increase.

Compliance (or Adherence) to Medical Regimens

The construct, compliance is one popular direct approach to measuring disease management behaviour of patients. The concept of medical compliance focuses on how closely patients follow the advice of health care professionals. Research has examined compliance to medications, dietary guidelines, attendance at follow-up appointments and other health related behaviours. The discrepancy between what the patient is told to do by a treating physician and what the patient in fact does is fundamental to defining the concept of compliance. In the most substantial text on the subject, Haynes defined compliance as, “The extent to which a person’s behaviour .... coincides with medical advice” [Haynes, 1979, p. 1]. Research has been directed both at assessing levels of adherence and investigating the significance of antecedent factors. A large amount of literature on compliance exists, spanning the last 30 years. For example, many articles have been published about the merits of different approaches to measuring adherence such as questionnaires, reports of knowledgable others, pill counts, blood levels of drugs etc. [Caron, 1985; Epstein & Cluss, 1982; Rand & Wise, 1994; Vander Stichele, 1991]. Most health psychology text-books include a review of patient adherence with guidelines on how health professionals can improve adherence of their patients [Dunbar & Agras, 1980; Janis, 1984; La Greca, 1988].
The most recent and complete review of compliance behaviour in childhood asthma is by Lemanek [1990]. After reviewing the available literature, she estimated that nonadherence to asthma regimens varied between 17 and 90% in children and adolescents. Factors which influence adherence in childhood asthma can be divided into (i) regimen and illness characteristics, (ii) health care issues (iii) sociodemographic characteristics and (iv) psychological correlates. Regimen characteristics examined have included the complexity of the regimens, complexity of delivery systems and side effects of medications. Illness characteristics have included whether the illness is acute or chronic, self-limiting or fatal and whether medication is for treatment or prophylaxis. Knowledge about asthma appears to be associated with adherence but there is a threshold effect. Over a certain threshold, increasing knowledge does not increase adherence. In terms of asthma, the severity or duration of the diagnosis of asthma does not appear to influence adherence. Health care issues investigated have included satisfaction with care provided, convenience of follow-up appointments and relationship with the health care provider. Sociodemographic characteristics studied have included race, age, socioeconomic status and gender but there is little consistent association between these factors and adherence behaviour. Finally, psychological factors have been given some attention. These have included, child adjustment, family functioning and social supports available to the family. Lemanek strongly emphasises that inconsistent results have been obtained in nearly all areas examined. Some studies have found positive associations, some negative and some, no association at all between possible antecedent factors and adherence to childhood asthma regimens. Similar conclusions have been reached in other reviews of adherence behaviour [Caron, 1985; Fotheringham & Sawyer, 1995]. Reasons given to explain the discrepancies found between studies have focused on methodological problems such as the use of invalid or indirect measures of adherence (e.g., relying on self-
report) and a lack of multivariable approaches to analysing predictors of adherence [Caron, 1985; Lemanek, 1990; Fotheringham and Sawyer, 1995].

An alternate and equally plausible explanation for the discrepancies found across different studies is that the construct, adherence is inherently flawed. The first obvious problem encountered when adherence behaviours are assessed, is that the construct assumes available treatment is effective and all patients respond in the same way. Johnson [1994] argues that, “for many, if not most diseases, this assumption is not true. Indeed, for most diseases, the relationship between health behaviour and health status is imperfect or unknown” [Johnson, 1994, p. 131]. There are two possible explanations for this observation. First, the majority of intervention studies in the past have assessed changes in health status in terms of physiological markers such as blood pressure reduction, control of blood sugar levels, variability in peak flow recordings. Studies assessing adherence and using physiological outcome measures have clearly demonstrated a non-linear relationship between adherence and such physiological outcomes. For example, Johnson [1994] described a study of diabetic patients where levels of glycosylated haemoglobin were used as outcome. Only 30% of subjects classified as good compliers had good diabetic control and 28% of subjects classified as poor compliers had poor control. Twenty four percent of poor compliers had good control and 18% who were good compliers had poor control. Johnson suggested that if quality of life had been used as the outcome measure rather than glycosylated haemoglobin, a stronger relationship may have been found between adherence and outcome.

The second explanation for the imperfect relationship between adherence and outcome however, is that irrespective of the type of outcome assessed (i.e., physiological or quality of life), the treatment may simply not be effective and thus
greater patient adherence will not enhance outcome as hoped. It is also possible that treatment is differentially effective in different patients and in the same patient at different times. Some patients may inherently have an underlying disease process which is more difficult to manage and their outcome is more strongly influenced by this fact, which is out of their control, than by their level of compliance. This explanation is supported by a large, longitudinal study which followed the progress of 2125 adult patients with chronic medical conditions (hypertension, diabetes, recent myocardial infarction, congestive heart failure and/or depression) [Hays et al., 1994]. Specific and general adherence were measured at the commencement of the study and outcomes in terms of quality of life (physical, emotional and social components) and physiological indicators were extensively assessed four years later. Only 11 of 132 comparisons between adherence and outcomes showed a significant positive relationship and seven of these comparisons would have occurred by chance alone. The authors concluded that, "it may be time to turn the focus toward documenting what really works in medicine rather than spot-lighting the failure of patients to follow recommendations that may or may not be therapeutic" [Hays et al., 1994, p. 357].

The second intrinsic problem with the concept of adherence is the assumption that only one health care professional provides individual patients with advice and information. Some researchers have taken considerable effort to measure what patients are specifically told by their physician and then assess how closely they follow this advice [Kravitz et al. 1993]. Others have used diseases such as diabetes as models for compliance research because they can assume that all patients in a clinic are given exactly the same information. As previously noted, discrepancies exist in the management of asthma between health professionals in Australia and elsewhere and so it is likely that patients receive different opinions and advice from different doctors [Coates et al, 1994; Harrison & Pearson, 1993;
Kourdoulos & Schattner, 1997; Phin & Oates, 1993]. In addition, patients may also actively seek information from other sources, such as friends, magazines or more recently from the world wide electronic web. Because parents and patients receive advice from more than one source and this advice may vary, the concept of compliance which seeks to measure how closely patients follow advice of a health care provider, has limited value.

The third limitation of the concept of medical compliance, is that according to compliance studies, at least half, and probably even more patients are non-compliant. As pointed out by Donovan and Blake [1992], if noncompliance is more common than compliance, then non-compliance is basically normal and cannot be considered deviant behaviour as portrayed by the compliance literature. These authors argue that rates of "non-compliance" are high simply because the concepts of compliance and noncompliance are meaningless to patients.

The final and arguably the strongest justification against the use of the concept compliance, which investigate why patients "don't do what they have been told to do" is that this approach implies that patients are passive recipients of health care. Trostle [1988] noted that compliance,

.... is better approached as an ideology supporting the authority of medical professionals. The basic problem with research on medical compliance is that it is dominated by a series of ideological conceptions of the proper roles of patients and physicians. Though presented as a literature about improving medical services, the research literature about compliance is preeminently, although covertly, a literature about control. It is written largely by medical professionals about themselves and their clientele, and it reveals the medical profession's worldview: the problem lies in patients' behaviour or in doctor/patient interaction; the solution lies in patient education, behavioural reinforcements, and better doctor/patient communication. [Trostle, 1988, p. 1299]

Trostle described the social history of patient compliance, at least as recorded in the United States. He suggested that medical interest in compliance occurred long before medicine had developed effective therapies. In the late 19th century and
early 20th century government authorities and the medical profession in the United States began to take steps to regulate pharmaceutical advertising. For example, the American Medical Association (AMA) decided in 1905 not to accept advertisements for patent medicine in its journal and adopted a role of approving drugs as medically efficacious or not. Trostle suggested that this was not just to provide better medical care for patients but also to increase health care professional authority over pharmaceuticals and other health related products. He described early marketing of infant feeding formulas and vitamin supplements which were regulated by the government only to be prescribed by doctors. In 1932 the AMA resolved to grant AMA approval to infant formulae producers that advertised solely to physicians and not directly to the public. Trostle further supported his argument with a selection of pharmaceutical advertisements from medical journals in the 1930’s which showed the physician in the position of power and the patient as a grateful receiver of care. He concluded, “The concern for compliance is a cultural phenomenon intimately connected with the self-image of physicians, and with their organised (and often successful) attempts to define the limits of their own discipline” [Trostle, 1988, p. 1303].

*The Patients’ Perspective of Medical Compliance*

In the last 20 years, there has been increasing recognition of patient autonomy and consumer rights and a much greater emphasis placed on providing patients and parents with clear, concise and correct information. Despite this move to make the medical profession more consumer orientated, articles about patient compliance are regularly published in scientific journals. There has been a sustained focus on the importance of the doctor-patient relationship even though patients with chronic illness only spend a small fraction of their lives in the doctor’s office, assuming the role of the patient.
In contrast, there is a small but growing literature focusing on patients' health behaviours and the meaning of medications and therapies to patients. This perspective can be described as patient-centred and the patient is seen to play the active role in managing illness and regaining health. This approach has resulted in a much better understanding of the difficulties faced by patients and parents of children with medical conditions. Such studies, which aim to describe the experience of patients with chronic illnesses, have generally used qualitative methods. Examples of these types of studies were reviewed by Stockwell Morris and Schulz [1993]. Despite differences in patient characteristics and illnesses (epilepsy, hypertension, rheumatoid arthritis etc), a number of common themes were found when patients were directly interviewed [Chubon, 1989; Conrad, 1985; Donovan & Blake 1992; Hunt, Jordan, Irwin and Browner, 1989]. The first theme was that in general, people do not like taking medications even though many considered medication a useful resource to allow better functioning with a disease. This dislike was not because of lack of time, inconvenience nor laziness, but because of one or more of the following reasons. (i) Patients described feeling a loss of control because of their illness. They felt stigmatised and abnormal and taking medication in effect, acknowledged and strengthened the fact that they were in some way different. (ii) Patients were also extremely concerned about side-effects, potential and experienced. (iii) Patients expressed concerns about feeling addicted to medication even when they knew that the particular medication prescribed, medically speaking, was known to be non-addictive. For example, patients likened themselves to being pill 'junkies' and feeling addicted because their bodies were dependent on medication to maintain normal functioning.

The second theme that emerged from the review of Stockwell Morris and Schulz was that people self-regulate medications to maximise their own life-style and aims
[Chubon, 1989; Conrad, 1985; Donovan & Blake 1992; Hunt et al., 1989]. This self-regulation was considered rational and intentional and was found to have little association with perceived inadequacies in the doctor-patient relationship. Patients self-regulated medications for one or more of the following reasons. (i) Patients altered doses and frequency of medication and also ceased taking medication altogether to see if symptoms had resolved or could be controlled at a lower dose. When taking medication regularly in the absence of symptoms, it is impossible to know if the disease process has resolved or if the medication is controlling symptoms. This is certainly true of diseases such as epilepsy or asthma where there is a chance (considerable in childhood asthma) of spontaneous resolution. (ii) Patients also self-regulate medications in an attempt to balance side-effects and symptom control. Many medications are known to have unpleasant and potentially dangerous side-effects and it is the patient and not the prescribing health professional who experiences these side-effects. At least one study found that the side-effects of most concern to patients were those interfering with social and workplace functioning such as drowsiness, impaired memory, dizziness and slurring of speech [Conrad, 1985]. Adjusting medications for these reasons appears entirely rational and moreover mirrors how medical professionals adjust drug dosages. The difference between the testing done by patients and that by doctors is that patients use different outcome criteria to gauge effectiveness. Patients are most interested in tradeoffs between improved functioning in day to day life and side-effects of medications whereas in general, doctors are interested in changes in physiological parameters. (iii) Lastly, patients alter medications in response to changes in their environmental and social factors. For example, patients with epilepsy increased medication if in "high stress" situations such as undertaking school or university examinations or stopped medication temporarily if they were going to drink alcohol because of a perceived interaction between the two [Conrad, 1985].
These studies show that patients self-regulate medications and other medical therapies in rational and often systematic ways, allowing them to regain some control over the disease process. The construct of compliance fails to recognise this rational basis to self-management. Focusing more on a parental rather than a medical perspective of childhood asthma may provide a better understanding of why parents vary in their management of children's asthma. One previous study has been reported which specifically focused on the difficulties associated with the use of the construct compliance in childhood asthma. Deaton [1985] rated the adaptiveness of parents' compliance decisions based on the activeness and clarity of parental decisions not to comply, their knowledge of their children, their knowledge of the asthma regimen and how well parents evaluated their decision not to comply. For example, reducing the amount of preventer medication by parents when children were not being exposed to trigger factors would have been rated as adaptive. Deaton found that greater adaptiveness of parents was associated prospectively with better quality of life outcomes for children whereas degree of compliance was not. This study suggests that further research into parental asthma management should give recognition to parental expertise and that non-compliance can, in some situations, be adaptive.

**Direct Measures of Parental Asthma Management**

As previously described, the use of indirect measures, such as the level of asthma symptoms or health care utilisation rates, as proxies of parental or patient asthma management can give misleading results [Vollmer, Osborne and Buist, 1994]. These variables may be influenced by factors other than parents' or patients' behaviour. For example, the level of children's asthma symptoms can fluctuate, and children with mild asthma can experience a substantial reduction in the number
of symptoms with time [Howard and McNicol, 1969; Martin et al., 1980; McNicol and Williams, 1973]. Asthma symptoms also can vary depending on seasonal variation in trigger factor exposure. Health care utilisation, such as doctor visits, emergency room visits and hospitalisations may be influenced by local health care policy (insurance status, admission criteria etc.), availability of transport and hours open for business.

Although directly measuring people’s behaviour can, from a practical view point, be extremely difficult, a number of studies have used novel approaches to assess parental asthma management. There have been four major direct approaches used to assess parental asthma management; qualitative approaches which have generated extensive typologies or lists of behaviours, quantitative self-reports from parents, semi-structured interviews with parents and the use of hypothetical scenarios. The following sections describe these attempts to assess constructs of parental management which are broader than that of compliance. In terms of asthma management this has included assessing parents’ ability to monitor children’s symptoms, reduce children’s exposure to trigger factors, communicate to other carers about children’s treatment and seek medical help when their children experience symptoms. However, despite examining this broader range of behaviours, most measures of parental asthma management have only included behaviours which health professionals consider important, and not behaviours that are considered useful by parents.

1. **Typologies of behaviours.**

A small number of studies have used qualitative methods to generate typologies of behaviours used by parents and children to manage symptoms of asthma. For example, McNabb, Wilson-Pessano and Jacobs [1986] collected 1,300 reports of
occasions on which a child with asthma took some action which affected the management of his or her condition. Using the 'critical incident technique' they judged which management behaviours made a difference in terms of the child's symptoms and condition. The critical incident technique was developed in 1954 and was initially used to define critical job skills or professional competencies [Flanagan 1954]. The procedure allows identification of behaviours which make a difference to outcomes in defined areas. The presence of a relationship (positive or negative) between behaviour and outcome is judged by someone who is considered to have the competence to do this. The study by McNabb et al. identified an extensive list of behaviours which children use to manage asthma. McNabb et al. divided these behaviours into four groups; preventive behaviours (avoiding allergens, taking preventive medicines, keeping medication accessible etc.), intervention (actions taken when symptoms begin), compensatory behaviours (dealing with peers, cooperating with the regimen, avoiding manipulative behaviours etc.) and external controlling factors (the child's ability to deal with authority figures who deny treatment, family problems that precipitate attacks etc.). The same research group conducted a similar study in children from 12 months to six years of age [Wilson, Mitchell, Rolnick and Fish, 1993]. In this study, 238 ineffective and 336 effective behaviours were recorded. The authors also described a 'small number' of parental behaviours which were thought effective by the reporting parent but ineffective by the research team. One of the few behaviours of this sort described, was placing the child in a steamy shower. Parents felt this was effective in helping symptoms settle but the authors stated that this behaviour could even be detrimental to children because of possible exposure to mould spores. However, there is no scientific evidence that steamy showers are detrimental to the health of children with asthma. In fact, all the behaviours considered to be effective by parents but ineffective by the research team were left out of the final typology. This judgemental approach to measuring self-management behaviours has meant that
we only have information about parental behaviours which health professionals consider important and not about all behaviours which parents use to manage children's asthma.

The qualitative component of a study conducted in the Netherlands by Mesters, Pieterse and Meertens [1991] described asthma management behaviours reported by parents in focus groups. For example, parents reported letting their children sleep by an open window, keeping the indoor air moist, not having fresh flowers in the house, using natural furnishings in the house and having good sanitary facilities. Despite the fact that parents thought these behaviours were important, the authors labelled these behaviours as misconceptions. Misconceptions were defined in this study as parental beliefs or behaviours characterised by "medical irrelevance and inaccuracy" (p. 25) as judged by a paediatrician specialising in lung diseases. Similarly, parents in this study expressed concerns about the long term use of medications in their children, particularly the potential for stunting growth. The authors considered this theme a parental misconception as well. However, there is no long term follow-up data to provide parents with complete reassurance about the safety of inhaled corticosteroids and recent studies in fact suggest growth delay can occur in some children at relatively low doses [Doull, Freezer and Holgate, 1995]. In addition, some parents were disappointed when the dose of medication was increased because they felt that despite all their efforts they were unable to control symptoms. The authors explained that doses of asthma medications are determined by children's weight and therefore parents should expect doses to increase with time. This is not in fact true for asthma, where initial doses are determined mostly by initial response of symptoms [Wainwright, Isles and Francis, 1997]. This study does provide insight into problems faced by parents but again demonstrates a comparatively medicocentric view of chronic disease management.
Although consideration of self-management rather than compliance is an important conceptual development, much of the literature on self-management has tended to focus only on those behaviours considered important by health care professionals. The criticisms of the compliance research described previously, therefore also apply to much of the self-management literature.

2. Quantitative self-report measures.

Another approach to assessing parental asthma management is the use of quantitative measures. Clark and Starr-Schneidkraut [1994] reviewed quantitative self-report measures of asthma self-management. Seven scales of measurement which had been used in previous research were described [Clark, Feldman, Evans and Duzey et al., 1986; Evans, Clark et al., 1987; Fish, Wilson, Starr-Schneidkraut, Loes and Page, 1992; Hindi-Alexander & Cropp, 1984; Mesters, Pieterse and Meertens, 1991; McNabb, Wilson-Pessano, Hughes and Scamagas, 1985; Taggart, Zuckerman, Sly, et al., 1991]. The majority of measurement scales reviewed had been specifically designed to evaluate new asthma education initiatives. For example, Clark et al. developed a simple index of behaviours based on interviews of children with asthma, their parents and physicians [Clark, Feldman, Evans and Duzey et al., 1986]. They divided these behaviours into three subscales: seeking information and support, behaviour during an asthma attack and preventive measures. Mesters et al. assessed asthma management behaviours of parents quantitatively as well as qualitatively [Mesters et al. 1991]. The quantitative assessment consisted of a questionnaire developed by the research team which tested parents knowledge and sought to highlight misconceptions regarding treatment and prevention of asthma. The content of questions was published but actual items, scoring and psychometric data were not
provided, making it difficult to reproduce the study. In general, the questionnaires used in the studies reviewed by Clark and Starr-Schneidkraut have not been published and are therefore difficult to obtain for use in future research.

3. **Semi-structured interviews.**

Two groups of researchers have recently attempted to measure asthma management behaviours using semi-structured interviews. Kolbe, Vamos, James, Elkind and Garrett [1996] used structured interviews to assess the behaviour of 137 adult patients admitted acutely to hospital with severe asthma. Very detailed histories of symptoms and subsequent actions taken by patients were recorded within 24 to 72 hours of admission to hospital. The authors scored the self-management behaviours used by patients in the index attack as adequate or inadequate. A similar approach was used by Klinnert, McQuaid and Gavin [1997] to develop an assessment tool called the Family Asthma Management System Scale (FAMSS). This is a semi-structured interview which takes about one hour to administer. Eleven domains critical to asthma self-management were assessed in the interview: family's perceived alliance with medical caregivers; collaborative relationship between family and caregiver; knowledge of asthma and medications; adherence with asthma medications; adherence with environmental recommendations; knowledge and assessment of child's symptoms; balance of responsibility between parent and child; appropriateness of action plan and emotional response to asthma symptoms; parent-child interactions on domain of asthma care; parental resources; and balanced integration of asthma and family life. The authors indicated that there were standard questions for each of these domains and that a scoring system had been devised. The interviews were audiotaped and scored by paediatric psychologists. Specific details of these
questions and procedures have not been published to date, making this approach currently difficult to apply in other settings.

4. The hypothetical scenario approach.

The use of hypothetical scenarios or vignettes has been used by a number of authors to assess self-management behaviour in asthma. The scenario or analogue technique involves presentation of a story or situation to respondents, with the description of the situation made as concrete and detailed as possible. Respondents are asked to say what they would do, think or feel if confronted with the situation. The advantages of this approach are that real-life decision making situations are approximated whilst ensuring a degree of uniformity and control over the stimulus [Alexander & Becker, 1978]. The scenario approach has been used to assess behaviours, attitudes and beliefs in children and parents in diverse areas including maternal perceptions of vulnerability in preterm infants, parental approaches to managing children’s fear, children’s attitudes towards mentally retarded peers and coping behaviours of children with sickle cell disease [Sharpe, Brown, Thompson and Eckman, 1994; Siperstein & Chatillon, 1982; Stern & Karraker, 1988; Zabin & Melamed, 1980].

One reason why patient or parental asthma management has been difficult to assess is that asthma can differ in quality and intensity between different children and in the same child at different times. The scenario approach offers potential benefits over other self-report measures because it presents every parent with a standardised stimulus. The first published use of the scenario technique in asthma research was by Avery, March and Brook [1980]. A series of hypothetical asthma situations ranging from descriptions of mild, moderate and severe attacks were devised to assess the self-management skills of adults with asthma. Participants
also kept daily diaries for 14 days, beginning when they had an acute episode of asthma, and recorded symptoms, medication use and physician contact. Unfortunately, because the number of subjects experiencing symptoms and thus able to complete the diary was small, it was impossible to compare responses to hypothetical situations to diary recorded actual behaviour. Sibbald [1989] also used hypothetical scenarios to assess the self-management of adults when confronted with an acute asthma attack. She asked patients to describe actions they would take in response to two hypothetical attacks, one increasing gradually in severity and the other developing very rapidly. Responses were scored as appropriate or otherwise using criteria adapted from the earlier work of Avery et al.

The method used by Sibbald was developed further by Kolbe, Vamos, James, Elkind and Garrett [1996]. They used the same asthma scenarios described by Sibbald but changed the scoring system to better reflect the recommendations of the Thoracic Society of Australia and New Zealand and the British Thoracic Society in terms of the significance of various patient management strategies. Most important however, was this research group's interpretation of responses to scenarios as reflecting patients' knowledge not patients' behaviour. This represents a major conceptual difference between the study of Kolbe et al. and previous studies assessing asthma management. Kolbe, Vamos, Fergusson, Elkind and Garrett used two approaches to collect information about the asthma self-management behaviours of adult patients admitted to hospital with an acute severe attack of asthma. The first approach was to collect patient reports of behaviours they had used in response to the recent episode of acute severe asthma, using a semi-structured interview. The authors considered this to represent behaviour. Second, they used hypothetical scenarios describing similar severe attacks of asthma, to collect information on what patients thought they ought to do in these situations. These scores were considered to represent patient knowledge about
asthma. They found that reports of actual behaviour differed significantly to
responses to hypothetical scenarios and that explanatory factors for each of these
variables were also significantly different. The authors concluded that in adults,
simply having knowledge about what to do in asthma situations does not
automatically mean that patients will undertake appropriate behaviours in actual
life-threatening attacks of asthma. However, an alternative explanation is that
behaviours used by patients in the index attack were found to be ineffective and
therefore subjects in the study changed their opinion about what they would do in
future situations. These patients may therefore have reported more appropriate
behaviours in response to the hypothetical scenarios.

Finally, the scenario approach has been used to assess parental management of
children's asthma. A semi-structured interview measure was developed by Taylor
et al. [1991] in New Zealand. This measure was described as "a tool for measuring
the asthma self-management competency of families" [Taylor et al., 1991, p.1].
The interview contains three representative asthma scenarios describing exercise
induced asthma, asthma symptoms developing in the context of a respiratory tract
infection and a severe precipitous asthma attack. Each scenario presents a typical
time progression of symptoms and parent's are asked what they would do in
response to these symptoms. The authors actively encouraged parents and
children to reflect back on what they had actually done in past, similar situations.
This was an attempt to overcome the limitations of self-report in terms of measuring
actual behaviours rather than knowledge. Responses were scored according to a
predetermined schedule which was judged more or less appropriate by the
research team. The interview measure of Taylor et al. was used as the basis for
the quantitative self-report questionnaire developed in this thesis. The limitations of
the original measure and the steps taken to overcome these limitations in the
current study will be discussed in Chapter 3.
Summary

The relationship between asthma self-management or parental management and outcomes for asthma is complex and factors enhancing self-management are poorly understood. The inherent severity of the disease, varying exposure to environmental trigger factors and differing access to high quality medical care may all potentially impact on outcomes for children with asthma. Despite the fact that parental asthma management appears an important factor in determining the outcome of children with asthma, few studies have attempted to directly assess behaviours that parents adopt when managing children’s asthma. There are few valid and reliable published measures of parental asthma management available to further understand the complex relationship between knowledge, attitudes and beliefs about asthma, management behaviours and health outcomes. Furthermore, the measures that are available are limited because they rely on assessing only those behaviours which medical professionals consider important. Behaviours which parents actually use and consider important have generally not been assessed.
CHAPTER THREE
DEVELOPMENT OF THE NEW PARENT ASTHMA
MANAGEMENT QUESTIONNAIRE

INTRODUCTION

The management of many chronic diseases requires patients (including parents and children) to monitor symptoms, make decisions and carry out a multitude of different behaviours. Some authors have implicated poor patient and parental management as a significant factor in the continuing morbidity and mortality experienced by adults and children with asthma [Clarke, Gotsch and Rosenstock, 1993; Howell, Flaim and Lum Lung, 1992; Martin et al., 1995; Strunk, Mrazek, Wolfson Fuhrman and LaBrecque, 1985; Wilson, Mitchell, Rolnick and Fish, 1993]. Others have also suggested that differences in parental asthma management explain the differences in asthma severity observed between social and racial groups [Anderson, Cooper, Bailey and Palmer, 1981; Bauman, Young, Peat, Hunt and Larkin, 1992; Heard et al., 1997; Mitchell, 1991]. Some attempts have been made to assess how parents manage children's asthma however, more often, indirect variables such as hospitalisations and emergency room visits have been used as proxies for parents' management practices. The direct measures of parental management have generally only assessed the use of behaviours which are considered important by health care professionals. As a result, behaviours which parents, but possibly not clinicians, consider useful to manage their children's asthma have not been assessed. This study aimed to develop a self-report measure of approaches used by parents to manage children's asthma. The measure specifically included both behaviours which were considered important by parents and health care professionals.
In brief, a previous parent report measure of asthma management behaviours, developed by Taylor et al. [1991], was used as a basis for the new measure developed in this thesis. The limitations of the original semi-structured interview developed by Taylor et al. are addressed in this chapter and the approaches taken to overcome these limitations are described. The most important limitation of the measure developed by Taylor et al. was that it assumed a medical perspective by only measuring behaviours that doctors considered to be important or critical to outcome. To ensure that parents' views were reflected in the new measure, a wide range of parental behaviours that parents themselves cited as important were included in the questionnaire. Prior to drafting the new questionnaire in the present study, direct information was obtained from parents in focus groups and individual interviews. This chapter describes how a draft version of the new parental asthma management questionnaire was given to a small sample of parents of children with asthma and the results of this data lead to the resultant 53 item pencil and paper questionnaire.

THE SEMI-STRUCTURED INTERVIEW MEASURE DEVELOPED BY TAYLOR ET AL. [1991]

The semi-structured interview developed by Taylor et al. was used as the basis of the new parental Asthma Management Questionnaire (AMQ). The former used hypothetical scenarios to collect parents' and children's reports of their own management of asthma symptoms. The questions used in the interview of Taylor et al. are given in Appendix I. The measure was designed for parents of children, aged five to 12 years of age, living in the North Island of New Zealand. The hypothetical scenarios described exercise induced asthma, asthma symptoms developing with a respiratory tract infection and a severe precipitous attack of
asthma. The measure was designed to be administered to parents and children in semi-structured interviews. Parents and children were asked to reflect back on what they had done in past similar situations so that behaviour rather than knowledge was assessed. Responses were rated by trained interviewers according to a predetermined schedule. Possible scores ranged from 2 to 32. Higher scores were considered to represent more appropriate asthma management.

There were a number of reasons why the measure developed by Taylor et al. was used as a basis for the new questionnaire developed in this thesis. First, the measure developed by Taylor et al. was published, items were available and in addition, the authors could be directly contacted. Second, the measure was based on hypothetical scenarios. This approach appealed as a practical way of making standardised assessments of the decision-making behaviour of parents when they are confronted with asthma situations in their children. Asthma symptoms may arise sporadically, sometimes infrequently and attacks may differ in severity between different children and in the same child at different times. Presenting the same hypothetical situation to all parents would control for some of these potential confounding variables because all parents would respond to questions about the same event. As described in the literature review, other methods of assessing parental behaviour have included yes/no responses to lists of behaviours presented without a contextual framework. However, responses to lists of behaviours are difficult to interpret and can be relatively meaningless without a situational reference point. Diaries are another practical way of obtaining situation-specific parental behaviour. Diaries have been used in asthma and other chronic disease research in the assessment of symptoms [Freer, 1980a; Freer, 1980b; Hyland, Kenyon, Allen and Howarth, 1993; Roghmann & Haggarty, 1972]. Diaries however, rely on the fact that symptoms occur with some frequency and also require a high level of participant cooperation for successful completion [Freer, 1980a; Verbrugge, 1980].
Finally, behaviour can be measured by direct observation. The direct observation of parental behaviour is impractical in asthma research because of the unpredictability and infrequency of asthma episodes in children. Subjects may change their behaviour because they are being observed and this can potentially bias the validity of this approach (i.e., the Hawthorne effect) [Last, 1988]. In addition, observers need to be specially trained to ensure that the ratings of behaviour are reliable and objective.

The measure developed by Taylor et al. was designed to be given to a population similar to the Australian childhood population proposed for the present study, in terms of age, asthma morbidity, socioeconomic status, availability and quality of health care and possibly culture. The major difference between the Auckland and Adelaide childhood populations are the much greater numbers of Maori and Pacific Island children living in Auckland. Medical guidelines for the management of asthma are also the same in Australia and New Zealand [Woolcock et al., 1989]. It was therefore likely that Australian parents would be able to identify with the scenarios used in the original measure of Taylor et al.

Finally, information on the validity of the scenario interview developed by Taylor et al. was available. Watkins [1992] undertook an observational study of 12 families in Auckland. She compared scores on the scenario measure with observed exercise related behaviours of children at school. Nine of 12 children showed significant agreement between responses to the exercise scenario and observed behaviour at school at the 5% level of statistical significance. Parents were also telephoned on a regular basis. If children were experiencing or had recently experienced an upper respiratory tract infection, an indepth, nonjudgemental interview was conducted with the parent. Parental actions taken in response to such episodes were compared to their responses to hypothetical scenarios. All 16 episodes of infection showed
statistically significant agreement between parental responses to scenario and reported actual behaviours. This suggests that responses to the scenario approach reflect parents' and children's actual behaviour in asthma situations.

The measure of parental asthma competencies developed by Taylor et al. was a useful starting point for the current study. However, the original measure had a number of significant limitations. The first and most important limitation was that responses only attracted positive scores if parents mentioned so-called critical asthma management behaviours as defined by McNabb, Wilson-Pessano and Jacobs [1986]. As discussed in the Chapter 2, behaviours which parents consider to have positive effects on children's health may not be considered to do so by a team of experts. To better understand parental asthma management, all behaviours which parents employ to manage children's asthma need to be assessed. The measure of Taylor et al. collects only information on behaviours which are deemed critical by the research team. This important limitation was emphasised by Watkins [1992] whose dissertation also reported behaviours which parents volunteered in the semi-structured interviews but which were not used to calculate total scores for the scenario measure. These parental behaviours included giving the child vitamin preparations, encouraging fluid intake, communicating with health care professionals and teaching children breathing and relaxation techniques. These behaviours were considered helpful by parents but were not included in the scoring schedule proposed by Taylor et al.

The second limitation of the measure developed by Taylor et al. was that it potentially assesses two different constructs, depending on whether parents have previously experienced the situation described in the scenario or not. If parents have experienced the situation before (e.g., their children regularly develop exercise induced asthma symptoms), the interviewer asks them to reflect back on
the last time this happened and say what they did in this situation. This is an attempt to measure actual past behaviour. If parents have not experienced the situation, the interviewer prompts them to say what they would do if the situation arose. This is an attempt to measure behavioural intention. Despite the clear difference between past behaviour and behavioural intention, the measure of Taylor et al. does not distinguish between these two constructs when scoring parental responses.

The two final limitations of the Taylor et al. measure are that it is a semi-structured interview rather than a self-report instrument and that it includes two questions addressed to children rather than parents. These factors reduce the ease of data collection, particularly if the measure is to be used in epidemiological studies.

**ADDRESSING THE LIMITATIONS OF THE SEMI-STRUCTURED INTERVIEW MEASURE DEVELOPED BY TAYLOR ET AL. [1991]**

**Obtaining Information Directly From Parents**

One of the major differences between the approach used to assess parents’ management in this thesis compared to previous work was that a broad range of parental behaviours were included in the questionnaire, irrespective of whether these behaviours were specifically considered appropriate by medical professionals. To ensure a true representation of parental behaviour in the questionnaire developed in the present study, information was sought directly from parents who had actually experienced the situations described in the scenarios. Three approaches were used to collect this information; (i) focus groups, (ii) individual interviews and (iii) cognitive interviews.
1. **Focus group interviews.**

Three focus group interviews were conducted with parents of children with asthma who attended the Women's and Children's Hospital (WCH) pulmonary medicine clinic. Focus groups are a useful research tool for collecting large amounts of qualitative information in relatively short periods of time [Folch-Lyon & Trost, 1981; Bender & Ewbank, 1994]. A total of 16 parents attended the three focus groups. Their children with asthma were aged between 3 and 17 years. Because children were attending a specialist clinic they tended to have more severe, chronic asthma. It was envisaged that more information about management behaviours would be obtained from parents of these children because of the higher frequency of asthma symptoms experienced. In the developmental stages of questionnaire design it is important to seek breadth of information rather than representativeness of data [Streiner & Norman, 1994]. The focus groups were conducted as semi-structured forums, where parents were encouraged to talk freely about what they did to manage their children's asthma. Each focus group lasted approximately 90 minutes. The groups were run by a facilitator (the first by M. Sawyer and the others by N. Spurrier) whilst an assistant took notes and tape-recorded the sessions (with the written consent of participants). The tape-recordings were professionally transcribed. These transcriptions were not formally analysed in the qualitative sense but were used along with the notes taken during the focus group sessions to expand the original scenarios of the measure of Taylor et al. Information on the types of behaviours that parents used in asthma situations and situations which posed specific management difficulties for parents was obtained. As described later, the choice of explanatory factors assessed in the second part of this study (Chapter 8) was also influenced by themes that were identified in focus groups.
2. **Individual interviews.**

Three semi-structured interviews were conducted with parents who were accompanying their children in hospital with an acute asthma episode. This approach was adopted because these parents would have experienced an asthma situation with their children in the preceding one to two days. Individual interviews provide greater privacy for parents to air their opinions about asthma management. Some parents may find group settings threatening and be less prepared to share experiences within a group. The parents approached in hospital wards were selected by convenience because again breadth of information rather than representative information was required at this stage. Behaviours which parents used in the asthma situation prior to their child's hospitalisation and other behaviours used in the past were recorded. Four parents who were unable to attend a focus group interview because of other commitments, were contacted and provided information by telephone about approaches they employed to manage their children's asthma.

3. **Cognitive interviews.**

Initial drafts of the AMQ were given to six parents of children hospitalised with asthma. Parents were asked to provide verbal feedback on technical aspects of the questionnaire including readability, length, ambiguity of items, use of jargon and layout. These parents were also asked if any behaviours had been overlooked and these additional items were noted.

A typology of behaviours used by parents to manage their children's asthma was generated from the three types of interviews conducted with parents. Parental behaviours could be grouped into the same categories described by Clark and
Starr-Schneidkraut [1994]; preventive behaviours, attack or symptom management behaviours and social skills (Tables 3.1 to 3.3).

During the parent interviews, information was also collected about problems encountered by parents when managing children's asthma. These difficulties are summarised in Appendix II. Information about specific difficulties faced by parents was not used directly to obtain items for the new questionnaire but was used later in the thesis to decide which explanatory factors would be examined (Chapter 8). Such factors included heightened parental anxiety about their children and parents making changes in approaches to management with increasing age of children. In addition, parents participating in focus groups reported that not infrequently parents and medical staff differed in opinion about the severity of children's asthma symptoms and about how these symptoms should be treated. Again, this provided additional support for the need to assess parental asthma management from a parental or non-judgemental perspective. The following quotations taken from the focus group interviews with parents, illustrate this important point.

'I sometimes have a problem in umm, in emergency, because I'm dealing with doctors who obviously know more about medicine than I do, but they do not sometimes know as much about asthma as I do, or they don't pick up the individual child's problem'

'well there's an interesting thing about the management of asthma in that there is about umm, as many opinions as there are doctors and err, and parents, because there is, there is probably not one child ... in this room, that is on the same medication at the same time, and that is very bewildering to a first time parent, it really is. There are some who are on this particular regime, there are some on that regime, and it changes constantly, and you know, one we're doing this and the next we're doing that. Now that is very bewildering, especially for a parent'

**Designing a Self-Report Measure**

The typology of behaviours generated in focus groups and individual interviews was used to develop a 120 item self-report questionnaire. The first draft of the parental asthma management questionnaire (AMQ) is given in Appendix III. The initial draft
contained nine scenarios. The content of the scenarios was taken from the semi-structured interview of Taylor et al. The first three scenarios in the new asthma management questionnaire described exercise induced asthma, four scenarios described asthma symptoms developing with an acute respiratory illness, one scenario described an acute life-threatening asthma attack and one scenario described a symptom free period. The scenarios described typical progression of symptom severity over time. Parents responded to a list of possible management behaviours using a four point Likert scale with end points labelled very likely to very unlikely. Some items such as, "use a peak flow meter" and "give child preventer medication" included a not applicable option because these approaches are not medically indicated for all children [Wainwright, Isles and Francis, 1997]. The questionnaire required parents to circle the response which corresponded most closely to what they would do in the situation described.

Each scenario included the item, “give my child inhaled Tobramycin”, a medication which is not used in the treatment of asthma. This was included to assess the extent of social desirability bias. Questionnaires with fixed option answers may encourage subjects to give what are perceived to be a socially desirable responses [Streiner & Norman, 1994]. An open-ended question "please specify any other things that you would do in this situation" was included in the first version of the questionnaire in order to identify any behaviours which had been over-looked.

**Behavioural Intention versus Behaviour**

The new parental asthma management questionnaire was designed specifically to assess behavioural intention, that is, what parents intend to do when confronted with particular asthma scenarios. This is in contrast to measuring actual behaviour. As described previously, measuring behaviour directly is difficult. This is particularly
so with asthma management behaviours because the symptoms of asthma are intermittent and unpredictable.

Parents' behavioural intention was therefore used as a practical alternative to measuring actual behaviour in this study. As well as being considerably easier to measure, theory and research suggests that a close relationship exists between behavioural intention and future behaviour. A number of psychological theories or models have been developed to explain differences in health behaviours. The more well known models are, (i) The Health Belief Model, (ii) Fishbein's theory of Reasoned Action, (iii) Triandis' Theory of Social Behaviour and (iv) Social Learning Theory [Becker & Maiman, 1975; Ajzen & Fishbein, 1980; Triandis, 1979; Rotter, Chance and Phares, 1972, respectively]. Wallston and Wallston [1984] reviewed and compared these theories and concluded that the strongest predictors of behaviour were the Triandis theory and the Fishbein Theory of Reasoned Action. The Triandis model is shown in Figure 3.1. Intention to carry out a behaviour and habit are the major predictors of the behaviour being performed. Habit is a more important determinant when behaviours are regularly carried out. When a behaviour is new to an individual however, the act has to be deliberately considered and thus behavioural intention is of central importance. In terms of parental asthma management, routine behaviours include giving preventive medication. The behaviours of interest in this study were those conducted in response to asthma situations and are therefore not routine behaviours. The Triandis model suggests that behavioural intention will have a close relationship with parents' actual behaviour in these situations. Additional evidence for the presence of a strong relationship between behavioural intention and behaviour exists in compliance research where one of the strongest predictors of future compliance behaviour is self-reported intention to comply [Kaplan & Simon, 1990].
The version of the AMQ used in the initial pilot phase of questionnaire development, contained introductory phrases similar to those used in the original measure of Taylor et al. Scenarios were described and parents were instructed to indicate, *how likely is it that you would do each of the following.* However, parents were not asked to reflect back on past situations, nor to imagine the situation actually happening. To even more clearly assess behavioural intention, the final draft of the new questionnaire used the following wording; *if you found yourself in this situation tomorrow, how likely is it that you would do each of the following (behaviours) at that point in time.* This was to encourage parents to report behavioural intention not memory of some past event. The latter maybe influenced by a multitude of factors including the number of similar episodes experienced, the time since these episodes and the severity of symptoms experienced by children during these episodes. By specifying, *tomorrow,* the time was standardised and also encouraged parents to imagine the situation actually happening.

**Obtaining Only Parents’ Reports**

The new questionnaire was designed to collect only parents’ reports of their own behaviours in terms of managing their children’s asthma. Although emphasis has recently been placed on educating children to manage their own asthma, discussions with parents in focus groups suggested that parents take responsibility for nearly all important decisions and perform the major tasks necessary for asthma management in primary school age children. This is consistent with the results of an earlier study which showed that young children with diabetes (six to eight years of age) had very poor ability to manage their disease and only adolescent children had the cognitive skills to make appropriate adjustments in insulin doses [Johnson et al., 1982]. Acquisition of self-management skills appears to follow normal
developmental milestones [Minuchin, 1977]. Limiting the AMQ to measure parents' behaviour only rather than both parents' and children's behaviour has meant that the measure is considerably easier to administer in large studies.

PILOT TESTING THE FIRST DRAFT OF THE NEW PARENTAL ASTHMA MANAGEMENT QUESTIONNAIRE (APPENDIX I)

The next section describes how the first draft of the new questionnaire was given to 46 parents of children with asthma. The two aims of this phase were to (i) reduce the length of the questionnaire and (ii) to assess the readability of the questionnaire in terms of wording and format.

Subjects

Forty six parents of children who were inpatients at the Women's and Children's Hospital during August and September 1995 completed the first draft of the AMQ. The Women's and Children's Hospital is the major paediatric hospital in South Australia and the majority of children with acute asthma in the Adelaide metropolitan area are admitted to this hospital. Parents were approached whilst visiting their children in hospital. Eighty three percent of parents were mothers and the remainder were fathers. The Asthma Severity Index of Rosier et al. [1994] was used to rate the background severity of children's asthma in terms of frequency and intensity of symptoms experienced in the preceding 12 months (described in detail in Chapter 4 of this thesis). Using this index, 17% of children were rated as having very mild asthma, 30% mild, 40% moderate and 13% severe asthma.

Reducing the Number of Items

The first draft of the new questionnaire was found to take parents a considerable time to complete (approximately 45 minutes). A number of parents said that they
found the questionnaire repetitive. Therefore, the results of the pilot testing phase were examined in order to reduce the length of the questionnaire.

First, items with *not applicable* options were assessed. Thirty-four parents (72%) indicated their children used preventer medication and 20 parents (47%) indicated that their children used a peak flow meter. The items about preventer medications were retained because these items were applicable for a large number of parents. Items regarding peak flow meters were dropped because these items were applicable for less than half the parents.

To further reduce the number of items, frequencies of responses were examined for every item. Questions which were highly skewed were removed if they were endorsed as *very likely* or *very unlikely* (i.e., the extreme response) by approximately 75% of respondents or more (or were endorsed as *very likely* and *likely* or *very unlikely* and *unlikely* by over 95% of respondents). This was done because if the majority of parents indicated intention to carry out these behaviours, these items would detract from the questionnaire's ability to discriminate between different parental management approaches. A number of questions were retained because of their clinical importance. However, they were rewritten so as not to appear as leading. As noted previously, items with fixed option answers may encourage subjects to give a socially desirable response [Streiner & Norman, 1994]. For example, items regarding the administration of reliever medications were rewritten such that parents had to state the actual dose and frequency of medications they would use in the situation described. Frequency distributions for the 'social desirability' item relating to the use of inhaled tobramycin in the treatment of asthma were highly skewed to the left with the vast majority of parents (98%) answering *very unlikely* or writing in, "do not use". These items were therefore removed from the questionnaire.
Following the removal of 13 items relating to tobramycin and the use of peak flow meters, the total number of items was reduced from 120 to 107. Based on analyses of frequencies described above, a further 27 items were removed which had been heavily endorsed either positively or negatively by parents. Eighty items remained. The 40 items removed are listed in Table 3.4 along with the specific reasons for removing individual items.

Reducing the Number of Scenarios

A considerable number of items were not answered by parents in the longer scenarios particularly those describing infection triggered asthma symptoms. As noted previously, a number of parents said that they found the questionnaire repetitive. To reduce the length of the questionnaire further, a number of scenarios were combined. To assist this process, parental management behaviours in response to respiratory infection and exercise were conceptualised as, behaviours carried out in anticipation of asthma symptoms and behaviours carried out after the appearance of asthma symptoms. Behaviours in response to an acute attack of asthma can obviously only be carried out at the appearance of symptoms. The three exercise scenarios were thus collapsed into two (one for anticipatory and one for reactionary behaviours) and similarly, the four infection scenarios were reduced to two. The final scenario about management behaviours when children were symptom free (eg. ceasing preventer medication, taking children to be reviewed by the general practitioner etc.) was removed in total because parents of children with chronic asthma and who had never experienced symptom free periods, had difficulty answering this question. The final draft of the AMQ contained five scenarios with a total of 53 individual items and is given in Appendix IV.
Wording and Format Changes

The response format based on circling responses used in the first draft of the questionnaire confused some parents. For example, some parents left out items rather than circling the options when they did not wish to endorse the particular behaviour. The items were therefore reformatted with check boxes placed next to response options. The original Likert scale was expanded to six points and the ends were anchored, always and never. Parents felt these options should be included because some of the items would always or never be performed by these parents. The items which referred to calling the Women’s and Children’s Hospital for advice were reworded such that the hospital name was not specified. This was because other paediatric units in peripheral hospitals in South Australia may be used by parents as sources of information and advice. The use of the terms, he/she and her/his also made the description of the scenarios unnecessarily complex and these terms were replaced with they and their respectively. The description of the acute severe attack of asthma was very long and this was shortened although the main themes were retained. However, the final sentence, ‘your child’s lips were blue in colour’ was removed because the majority of parents said this had never happened to their children. Finally, the size and style of the font of the questionnaire was changed, again after asking parents which format they found the easiest to read and follow.

SUMMARY

This chapter has described the initial development of a new questionnaire to measure approaches parents use to manage children’s asthma. The semi-structured interview measure developed by Taylor et al. was used as a framework for the new questionnaire. To ensure that a parental perspective was adopted, initially a large number of parents were consulted in focus groups and individual
interviews. The asthma management behaviours that these parents reported to use were included as items in the first draft of the new questionnaire. This draft was given to 46 parents and based on their responses to the items and their verbal feedback, the questionnaire was shortened and revised. This process resulted in the development of a 53 item questionnaire, consisting of five scenarios depicting children experiencing typical asthma signs and symptoms.
CHAPTER FOUR

GENERAL METHODS

INTRODUCTION

This chapter describes the sample of children and parents involved in all subsequent analyses of this thesis including; (i) the assessment of the reliability and reliability of the AMQ, (ii) the derivation of factor-based scores for the AMQ, and (iii) the examination of the relationship between psychological factors and parental management. General statistical approaches used in subsequent chapters of this thesis and ethical considerations are also described.

SUBJECTS

The study population was parents of children aged five to 12 who had been admitted to the Women’s and Children’s Hospital (WCH) with asthma between the 1st May 1994 and the 6th May 1996. Eight hundred and fifty-two children of primary school age living in metropolitan Adelaide had been admitted to the WCH during this period with a primary diagnosis of asthma. Children who lived outside metropolitan Adelaide were excluded to keep the size of the study to manageable proportions. Children with other chronic respiratory conditions (eg. cystic fibrosis, bronchiectasis, bronchopulmonary dysplasia etc.) were excluded because treatment of these conditions could overlap with that of asthma.

The study focused on assessing parental management of children aged from five to 12 years. This was because parental management of asthma varies with the
developmental stage of the child. Younger, preschool children present different challenges to parents in terms of asthma management. During adolescence, children begin to take more control over management of symptoms and concepts of conflict and autonomy are of increasing importance. An age range of five to 12 covers the middle years of childhood where children pass through primary school. During these years children slowly develop greater independence in terms of cognitive thought and emotional development but remain dependent on parents and care-givers for provision of practical resources, nurturance and support [Minuchin, 1977]. The diagnosis of asthma and the assessment of severity of asthma is also much more difficult in younger children, where viral respiratory symptoms may mimic typical asthma symptoms [Martinez et al., 1995]. Children greater than five years of age can therefore be more confidently diagnosed with asthma. The use of hospital asthma admissions as a sampling frame ensured that every child in the sample had been diagnosed with asthma by a hospital paediatrician.

Using a sequence of random numbers generated from STATA statistical software, 146 children were randomly selected from this population base of 852 children [StataCorp, 1997]. At least one parent of 24 of these children (16%) could not be contacted by mail or telephone either because they did not have a telephone (4%) or the address and/or telephone number listed in the hospital records was incorrect (12%). Three parents (2%) could not speak English and were excluded from the study. The parent that could be contacted was asked which parent undertook most of the asthma management in the household. The parent who carried out most of the asthma management tasks for the child was asked to participate in the study. One hundred and one of 119 parents (85%) agreed to participate. A small subset of these parents (33 parents) were randomly chosen to participate in the test-retest
phase of the study which necessitated a second visit to the families home. All 33 of these parents agreed to participate in this second visit.

CONTACT PROCEDURE

A letter which included a brief introduction to the study, a detailed information sheet and a copy of the consent form were sent to the original 146 parents selected (Appendix V). Two slightly different versions of the information sheet were sent to parents depending on whether or not parents were requested to take part in the test-retest phase of the study. Parents were contacted by telephone approximately one week after mailing out the information and their informed consent to participate in the study sought. If parents could not be contacted on the first occasion, further telephone calls were made until contact was made. If parents did not wish to participate at the time they were contacted, they were asked if they would like to participate at a later date and they were recontacted at this nominated time. An appointment was made to visit the one parent whom both parents agreed took the major responsibility for managing the child’s asthma. Nine families (9%) felt that both parents had equal responsibility for the asthma management and therefore both parents completed the questionnaires. In seven of these cases, the mother’s questionnaires were used in analyses. In one family, the father was the child’s natural parent and the mother figure was a recent step-parent, therefore the father’s questionnaires were used in subsequent analyses. In the other family, only the father was present on the day of the scheduled visit. Data from the remaining father-completed questionnaires was not included in this thesis. This was because these fathers were unlikely to be representative of all fathers in the sample, the majority of whom appeared to play lesser roles in managing their children’s asthma. All parents were visited at home by N. Spurrier between June 1996 and June 1997.
SOCIODEMOGRAPHIC CHARACTERISTICS OF PARENTS AND CHILDREN WHO DID NOT PARTICIPATE IN THE STUDY

Four main reasons for not participating were given by the 18 non-participating but contactable parents. Eleven parents (61%) said they didn’t have enough time to participate in the study, five parents (28%) said their child did not have asthma or had only infrequent asthma symptoms, three parents (17%) simply said they were not interested in participating and a further three parents (17%) were unable to participate because they had significant health problems (including one mother who was undergoing intensive radiotherapy).

A number of relevant characteristics were compared between the children in the study sample, children of parents unable to be contacted and children of parents unwilling to participate in the study using a level of 0.05 to indicate statistical significance (Table 4.1). There was no significant difference in the mean age of children in the study population, those unable to be contacted and children of parents unwilling to participate.

Two markers of asthma severity were examined; the medical unit to which the child was admitted during hospitalisation and the number of asthma admissions per child to the Women’s and Children’s hospital with asthma in the 12 months preceding contact with the family. Children were categorised into whether they had been admitted under the specialist chest unit, a general medical unit or had simply stayed overnight in the short stay ward. Children admitted under the specialist chest unit generally have experienced more persistent and frequent asthma symptoms in the past, irrespective of the severity of the index attack which precipitated their admission. There were comparatively more children in the study sample admitted under the specialist chest unit compared to children not participating in the study and this difference was near significant.
The second marker of asthma severity used was the number of admissions for asthma per child in the 12 months. Although there was a trend towards more admissions in 12 months for children in the study sample, this did not reach statistical significance. Similarly, there tended to be more boys in the study population than those not participating but again the difference did not reach statistical significance. This also may reflect the fact that children in the study population had more severe asthma than those not participating because boys up until puberty generally have more significant asthma symptoms than girls [McNicol & Williams, 1973; Sennhauser & Kuhni, 1995]. These comparisons suggest that children in the study sample may have had more severe asthma than children of those parents unwilling to participate in the study although these differences were not statistically significant.

In addition, the group of parents that could not be contacted included six parents who did not have a home telephone. Overall, parents who could not be contacted may have been economically disadvantaged in comparison to parents who could be contacted and therefore who participated in the study.

**STATISTICAL ANALYSIS**

Statistical analyses were conducted using STATA statistical software (version 5.0, 1997) and SPSS statistical software (version 7.5, 1997) [StataCorp, 1997; SPSS Inc., 1997]. An alpha of 0.05 was used to indicate statistical significance. When presenting frequencies of responses, percentages have been used rather than actual numbers. This is because, with a sample size of 101, percentages are almost invariably equivalent to numbers.
In broad terms, the first task was to reduce the individual 53 items of the AMQ to factor based scores. This was done using exploratory factor analysis. The test-retest reliability of the AMQ was then assessed. To investigate the validity of the questionnaire, parents were asked to report what they had done in recent real-life asthma situations with their children. Finally, the relationships between parental management and explanatory variables were analysed using multiple regression techniques. The reasons for choosing these statistical approaches will be explained in detail in the relevant chapters of the thesis.

The number of parents enrolled in the study was based on the largest sample size required for the analyses intended and the number of home visits which could be conducted within the time available. Out of all the statistical analyses undertaken in this thesis, the factor analysis and multiple regression analyses required the largest number of subjects. The power estimations for these analyses are presented separately in the relevant chapters. A sample size of approximately 132 was calculated as ideal for the factor analysis and a size of 110 for the multiple regression analyses. The actual sample size of 101 which was used for this study is therefore close to these requirements.

ETHICS PROCEDURES

Ethical consent for all phases of the study was given by the Research and Ethics Committee of the Women's and Children's Hospital. Because a detailed information sheet was sent to all families prior to telephone contact, considerable time was allowed for parents to decide to participate and give informed consent. All parents were offered a booklet about asthma management after the interview was completed with each parent. The booklet had been designed by the Department of Pulmonary Medicine of the Women's and Children's Hospital and outlined the
medical management of asthma based on National Asthma Campaign guidelines. This was done to ensure that all parents were supplied with standard asthma management information in the event that some parents lacked knowledge in specific areas. Parents were also given the opportunity to ask questions about asthma management during home interviews. These discussions were all kept to the end of the interviews to avoid biasing results of parent interviews.

SUMMARY

This chapter has briefly outlined the sampling method, data collection methods, general statistical approach and ethics procedures used in the subsequent stages of this thesis. Parents who could not be contacted or who were unwilling to participate in the study appeared to be reasonably similar to parents participating in the study in most respects. However, children of parents not participating may have had slightly milder asthma based on the hospital unit they had been admitted to and on the number of admissions they had experienced in the preceding year, although these differences did not reach statistical significance.
CHAPTER FIVE

DESCRIPTION OF PARENTS' RESPONSES TO THE ASTHMA
MANAGEMENT QUESTIONNAIRE

INTRODUCTION

This chapter describes the frequency with which parents of children with asthma endorsed individual items of the new parental Asthma Management Questionnaire. At this stage the questionnaire consisted of 53 items. Four of these items focused on medication use, two of which required open-ended responses. In addition, the relationship between responses to the AMQ items and previous experience with the situation described by the scenario was assessed. This was done because parents who had infrequent experience or exposure to the situations may have had difficulty answering the questions and may also have responded in different ways to parents who frequently experience the situations. If this was the case, the AMQ would be of little use for assessing the asthma management behaviours of parents whose children experience infrequent asthma symptoms. Parents were grouped into categories based on the frequency with which they reported experiencing the situations described in the AMQ. Associations between parental responses to AMQ items and parental experience with the five situations were then assessed.

SUBJECTS

The characteristics of the 101 parents of children with asthma who were the subjects for this part of the study have been described in Chapter 4. For each scenario, parents were grouped into categories determined by how often they
experienced the situation described (Table 5.1). There was an uneven spread of level of experience by parents for each scenario. For example, although the majority of parents had witnessed their children undertaking physical activity (scenario 1), only half of the parents had ever witnessed their children experiencing an acute severe attack of asthma (scenario 5). The categories were therefore created for each scenario such that reasonably equal numbers of parents would fall into each category of experience. This would allow subsequent statistical testing of differences in AMQ responses between groups of parents of different levels of experience.

The majority of parents regularly witnessed their children preparing to undertake some form of physical activity (scenario 1). However, 27% of parents reported that their children had never experienced exercise induced asthma (scenario 2). In contrast, the majority of parents reported that their children frequently experienced coryzal symptoms (scenario 3) and 89% of parents reported that their children would get symptoms of asthma with a cold at least once a year (scenario 4). Scenario 5, describing a child having an acute, severe, life threatening attack of asthma had never been experienced by nearly half of the parents. The remainder of the parents said this happened infrequently, about once a year or less.

RESULTS

Scenario 1

The first scenario of the AMQ describes a child preparing to undertake physical activity. The scenario reads,
“You are about to watch your child do some physical activity (eg. playing sport or games or swimming). They are not wheezy, not coughing and not breathless.”

Parents were asked to rate on a six point Likert scale how likely they would do each of the following behaviours at that point in time.
1. Get child to inhale reliever medication.
2. Get child to warm up before starting the physical activity.
3. Warn child not to exercise too much.
4. Tell child to be careful.
5. Watch child’s breathing very closely.

**Frequency distribution.**

The frequency distribution for each item of scenario 1 is given in Table 5.2. There is considerable variation in response to these items between parents. In general, the questions which parents most commonly gave positive responses to were, ‘telling their child to be careful’ and ‘watching their child’s breathing very closely’.

The majority of parents did not report that they would, ‘warn their child not to exercise too much’. Although only 38% of parents said they would get their child to inhale reliever medication prior to the physical activity, 52% said they would get their child to ‘warm up’.

**The relationship between item responses to scenario 1 and previous experience with this situation.**

Eighty two percent of parents reported watching their child participate in physical activity at least once a week and 18% reported watching their child between once a month to once every six months. Chi square tests (or Fisher’s Exact tests for small
numbers) were used to test whether there were significant relationships between parental responses to AMQ items of scenario 1 and parental familiarity with this situation. There was no significant difference in parental response to items one to five based on how often parents experienced a situation similar to scenario 1 (Table 5.3).

However, categorising parents by the frequency with which their children simply participated in physical activity did not determine which children regularly experienced exercise induced asthma (EIA). Whether or not children consistently develop EIA would probably be a stronger predictor of parents' behaviour prior to children participating in exercise. A subsidiary analysis was therefore undertaken to assess whether a history of EIA in children predicted parental responses to scenario 1. To ascertain which children experienced EIA, the frequency of parents reporting past experience with scenario 2 was examined. This scenario describes a child actually developing symptoms of EIA. Seventy three percent of children in the sample appeared to have EIA using this criteria and parents were categorised into two groups by whether or not their child experienced EIA (coded as 0 and 1). Treating each item of scenario 1 as a continuous dependent variable and whether or not children had EIA as the explanatory variable, simple linear regression analyses were conducted for each item (Table 5.4). Parents were significantly more likely to positively endorse items 1, 3 and 5 of scenario 1 ('get child to inhale reliever medication', get child to warm up' and 'watch child's breathing very closely'), if their children had ever experienced EIA.

**Scenario 2**

The second scenario describes a child developing symptoms of asthma with exercise. The scenario reads,
“You are watching your child do some physical activity. During the physical activity your child gets slightly wheezy and breathless.”

Parents were asked how likely they would carry out the following behaviours.
1. Get child to stop the physical activity.
2. Let child resume play after a rest and symptoms have settled.
3. Get child to inhale reliever medication.
4. Get child to inhale preventer medication.
5. Take child to the family doctor.
6. Take child to a hospital to be checked.

Frequency distribution.
Percentages of parents endorsing each response option for individual items are shown in Table 5.5. The majority of parents said they would stop their child playing and give their child reliever medication and 88% of parents also said they would let their child resume play if the symptoms settled. About a third of parents reported they would take their child to the local doctor to be checked and similarly, just under a third of parents would take their child to a hospital to be checked.

The relationship between item responses to scenario 2 and previous experience with this situation.
Parents were divided into three groups on the basis of how often their children experienced EIA: at least once a month (31%), between once in three months to once in two years (43%) and never experience EIA (27%). None of the scenario items were significantly associated with parental familiarity with the situation
described, although there was a trend for parents of children who experienced EIA (first two columns of the table) to be more likely to get their child to inhale reliever medication (Table 5.6).

**Scenario 3**

The third scenario describes a child developing symptoms of an upper respiratory tract infection (URTI). The scenario reads,

"Your child wakes up that morning with a 'runny' nose but is not wheezing, not coughing and not having difficulty breathing."

Parents were asked to rate the likelihood of carrying out the following behaviours.

1. Give child vitamin tablets (such as vitamin C).
2. Check child’s temperature.
3. Give child cough or flu medication.
4. Get child to inhale reliever medication.
5. Call a hospital for advice.
6. Take child to the family doctor.
7. Take child to a hospital to be checked.
8. Use a vaporiser or air-purifying machine in child’s room.
9. Take child into a steamy bathroom.
10. Send child to school.
   
   If parents indicated they would send their child to school they were also instructed to answer the following items,

11. Check that child takes his/her reliever medication with her/him to school.
12. Speak to child’s teacher to say that child has a runny nose.
13. Write a note to child’s teacher to say that child has a runny nose.
14. Visit the school during the day to check on child.

**Frequency distribution.**

Parental responses to scenario 3 are given in Table 5.7. Again, substantial variation was found in the way parents reported they would manage this situation. About a third of parents indicated they would give their child reliever medication prior to the onset of asthma symptoms in anticipation of the URTI triggering asthma symptoms. About a third of parents also indicated they would take their child to the family doctor. Over half of parents said they would send their child to school and the majority of these parents also said they would check that their child took reliever medication to school with them that day. Parents also answered this item as *always, very likely or likely* if reliever medication was kept permanently at the school for the child. A substantial number of parents reported intending to use complementary or home remedies. Thirty one percent of parents indicated they would give vitamins, 24% said they would use a vaporiser or air purifying machine and 18% said they would take their child into a steamy bathroom. A third of parents said they would give their child some form of cough or flu medication.

**The relationship between item responses to scenario 3 and previous experience with this situation.**

Parents were divided into two groups based on how often their child experienced an URTI. One parent said that it never happened to their child and this subject was excluded from the analysis. Thirty two parents experienced this situation at least once a month and 68 parents, between once in three months and once in two years. Responses to the AMQ were compared between these two groups of parents (Table 5.8). Parents of children who experienced frequent URTIs were
found to be more likely to give their child cough/flu medication and also more likely to take their child to the family doctor. In addition there was a near significant difference for items 10 and 14. Parents of children with frequent URTIs were less likely to send their child to school and if they did send their child to school were more likely to visit the school during the day to check on the child.

Scenario 4

The fourth scenario was a continuation of scenario 3. In addition to the child having symptoms of an URTI, symptoms of asthma are described. The third scenario reads,

"Your child had been well during the day apart from a ‘runny’ nose. However in the evening they are tired and irritable and keep coughing. When you put them to bed you notice a soft wheeze and your child’s breathing seems faster than normal."

The questionnaire first asked parents to write down the names of medications they would give their child if this situation occurred the next day. They were also instructed to indicate how often they would give the medication and whether this was by metered dose inhaler, nebuliser or by mouth. Parents then responded on a six point Likert scale the likelihood that they would performing the following behaviours.

1. Give child vitamin tablets (such as vitamin C).
2. Check child’s temperature.
3. Give child cough or flu medication.
4. Use a vaporiser or air-purifying machine in child’s room.
5. Take child into a steamy bathroom.
6. Call a relative, friend or neighbour for help.
7. Call a hospital for advice.
8. Call a doctor to the home.
9. Take child to a hospital to be checked.
10. Call an ambulance.
11. Check on child’s condition regularly overnight.
12. Stay awake that night to monitor child’s condition.
13. Sleep in child’s bedroom or have child in your room that night.

*Frequency distribution.*

Ninety eight percent of parents said they would give their child some form of medication in this situation. Specifically, all of these parents said they would give their child reliever medication (salbutamol or terbutaline) (Table 5.9). Fifty two percent said they would give this every four hours whilst 10% said they would give one dose only (Figure 5.1). Parents appeared to interpret this question differently. Some parents were able to anticipate the frequency of reliever medication required by their child whilst those who said they would give a single dose were unable to make this prediction. Forty five percent of parents said they would give inhaled corticosteroids and 13%, sodium cromoglycate or nedocromil sodium. These medications would be administered routinely in the evening and the majority of parents giving these responses were simply indicating regular preventer use. In fact, 88% of children in the sample were prescribed preventer medication, suggesting a degree of under-reporting for this item. Other medications cited by parents including over-the-counter therapies are given in Table 5.9.

Parental responses to the non-medication behaviour items for scenario 4 are given in Table 5.10. The most heavily endorsed behaviour was checking on the child’s condition regularly overnight. Nearly half of the parents also indicated they would
sleep in their child’s bedroom or have their child in their own room that night. In terms of seeking outside help; 35% said they would take their child to hospital and 30% said they would call a hospital for advice. Similarly, 30% of parents indicated they would call a doctor to their home. In this scenario a number of home therapies were used. For example a third of parents said they would use a vaporiser or air purifying machine in the child’s room and a third of parents said they would take their child into a steamy bathroom.

The relationship between item responses to Scenario 4 and previous experience with the situation.

Nearly all parents had experienced the situation of asthma in the context of an URTI with their child (99%). Thirteen parents said this happened on average at least once a month, forty nine parents said this happened between once in three months to once in six months and 32 parents said it happened between once a year to once in two years. There was no significant difference in the way parents with more or less familiarity with the situation answered the behaviour items of scenario 4 (Table 5.11).

Scenario 5

Scenario 5 describes a child experiencing an acute severe attack of asthma in the absence of any obvious precipitating factor. Scenario 5 reads,

“Your child was well yesterday. This morning they wake up early with a dry cough and an obvious wheeze. Your child begins to get dressed for school, however they become increasingly breathless. They don’t want to eat breakfast and instead go back to bed. Fifteen minutes later your child’s wheezing is louder, they are
breathing very fast and look pale and frightened. Your child has trouble talking because they seem to be fighting for breath."

Parents were first asked to write down the names of any medications they would give their child in this situation and the anticipated frequency and route of administration of these medications. Parents then indicated the likelihood of carrying out the following behaviours.

1. Check child’s temperature.
2. Give child panadol if they have a temperature.
3. Give child cough or flu medication.
4. Use a vaporiser or air-purifying machine in child’s room.
5. Take child into a steamy bathroom.
6. Call a relative, friend or neighbour for help.
7. Call a hospital for advice.
8. Call a doctor to the home.
9. Take child to a hospital to be checked.
10. Call an ambulance.
11. Take child to the family doctor.

**Frequency distribution.**

Medications reported by parents for scenario 5 are given in Table 5.12. Five parents said they would not give their child any medication in this situation. This was unexpected because the scenario describes a very severe episode of asthma. These parents verbally reported that they could only envisage seeking immediate medical help because the situation described was so serious. Ninety four percent of parents said they would give reliever medication. However only 7% suggested giving this continuously through a nebuliser and another 7% said they would
administer ventolin every half an hour (Figure 5.2). The majority of parents said they would give reliever between every two hours and every four hours (57%). Nineteen percent of parents said they would give only one dose of reliever. As discussed previously, these latter parents were unable to predict the frequency of medication required by their children in this situation. Compared to scenario 4, there was a reduction in the reported use of nonspecific cough and flu medications (2% compared to 14%). The other medications that parents reported for this severe asthma situation were salmeterol (14%) and ipratropium bromide (6%).

The remaining behaviour items for scenario 5 are given in Table 5.13. As noted in the other scenarios, there were considerable differences in reported management strategies between parents. Although the majority of parents indicated that they would take their child to hospital (85%), only 35% said they would call an ambulance. Seventy three percent reported that it was likely they would call a doctor out to their home, reflecting the perceived severity of the situation. Apart from the very leading item, 'give child panadol if they have a temperature' which was positively endorsed by the majority of parents, most parents answered, unlikely, very unlikely or never for home therapies (giving cough/flu medication, using a vaporiser or air-purifying machine, taking child into a steamy bathroom).

The relationship between item responses to scenario 5 and previous experience with the situation.

Half of the parents had witnessed their child developing acute asthma symptoms as described in scenario 5 in the past two years (51%). Specifically, 26% had experienced this at least once a year and 26%, about once in two years. There were no significant differences in responses to AMQ items between parents with different degrees of experience with this situation. This suggested that experience
with the situation did not significantly predict parental responses to questionnaire items (Table 5.14).

DISCUSSION

The most important finding when the AMQ was simply analysed in terms of frequency of responses to individual items was that parents showed substantial variation in asthma management approaches. Some parents tended to positively endorse many items suggesting that they intended to be particularly active in managing their children's symptoms. On the other hand, other parents appeared to be less active when confronted with asthma symptoms in their children. Generally speaking, parents in this study appeared to be more active in asthma management than expected from the severity of the asthma symptoms described. For example, even when the scenario described symptoms of a simple URTI (scenario 3), a substantial number of parents indicated they would take their children to the family doctor for review. In terms of medication taking behaviour, the vast majority of parents indicated they would get their children to take specific asthma therapy with symptoms. These questions were open-ended and thus less likely to be contaminated by social desirability bias compared to the original fixed response items in the first draft of the questionnaire [Streiner & Norman, 1994]. It was particularly reassuring to note that 94% of parents said they would give their children reliever medication with an acute severe attack of asthma (scenario 5), and those that did not, indicated they would take their children straight to hospital or call an ambulance.

One possible reason for the variation in parental response to items of the AMQ was that parents differed in their past experience with the situations described. For example, children with a known tendency to develop asthma symptoms with
exercise may be treated differently to children without this tendency. Parents who have never seen their children experience an acute life threatening attack of asthma may be unable to predict their own behavioural responses to this situation. If responses are dependent on whether parents have previous experience with the situations, the questionnaire may not be applicable for all parents of children with asthma, thus limiting the usefulness of the questionnaire. However, the analyses conducted suggested that parental responses to the majority of AMQ items showed no clear relationship with parental familiarity with the situations described. In particular, all items of scenarios 2, 4 and 5 appeared independent of past parental experience with the situations described.

There were two exceptions to this general finding. First, when children were categorised as having exercise induced asthma or not, parental responses to three of the five items for scenario 1 describing a child preparing to undertake physical activity showed significant differences. Parents of children with a known tendency to develop asthma with exercise were significantly more likely to premedicate their children with reliever, more likely to warn their children not to exercise too much and watch their children’s breathing very closely. Assuming these were true associations, this finding would need to be borne in mind in subsequent analyses of the questionnaire. Second, parents of children experiencing more frequent URTIs (upper respiratory tract infections) were significantly more likely in this particular situation (scenario 3) to give their children cough or flu medication and take their children to the family doctor. They were also more likely to keep their children home from school, and if they did send them to school, to visit the school to check on their children. As will be shown in Chapter 8 of this thesis, these findings probably represent an age effect. Younger children are more likely to both experience more URTIs than older children and be managed in a more protective fashion by their parents compared to older children [Denny, 1995]. Although,
parental responses to the AMQ items just described were found to differ with level of parental experience and these were suspected to be true findings, these associations may also have occurred by chance. Undertaking a large number of hypothesis tests can lead to spuriously significant associations being found [Field & Armenakis, 1974].

Scenarios 4 and 5 required parents to state names and frequencies of medications they intended giving their children. These questions were formatted in an open-ended way to reduce the extent of social desirability bias. Although this method was useful to describe what medications parents generally use to treat asthma, responses were difficult to code and score. Also of concern, a considerable number of parents had difficulty predicting how frequently they would give medications making these items somewhat invalid. For example, some parents ticked, one dose only, at the same time verbalising that they would subsequently review the child and decide if further doses were necessary. Other parents felt confident to suggest how frequently repeat doses maybe required and answered accordingly. The vast majority of parents indicated they would give their child reliever medication which reduced the discriminatory capacity of this question. Consequently the two open-ended items about medication use in scenarios 4 and 5 were not included in the subsequent factor analysis of the questionnaire (Chapter 6).

**SUMMARY**

This chapter has described the frequency with which parents endorsed each item of the new questionnaire. The two major findings of this chapter were that responses to the new parental Asthma Management Questionnaire showed considerable
variation between parents and that parental responses generally did not vary by 
previous experience or familiarity with the situations described.
CHAPTER SIX

THE ASTHMA MANAGEMENT QUESTIONNAIRE AS A MEASURE OF PARENTAL INTERVENTION: DERIVATION OF FACTOR BASED SCORES FOR THE AMQ

INTRODUCTION

This chapter describes how summary scores were derived for the AMQ. A broad picture of parental behaviour can be obtained by examining the frequency distributions of the 53 items which comprise the questionnaire. In contrast, total scores derived by combining items is an alternative way of presenting information about parental behaviours. The derivation of summary scores is an important process in questionnaire development because it implies that responses to individual items are considered to reflect underlying traits or constructs. In addition, from a purely practical viewpoint, summary scores make the analysis of relationships between the underlying construct and potential explanatory factors considerably easier. An exploratory factor analysis was therefore undertaken to delineate underlying traits or constructs represented by parental responses to AMQ items. This process resulted in the identification of three distinct subscales which appeared to represent the degree of parental intention to perform behaviours in three areas of asthma management; taking children for medical assessment, seeking external advice from knowledgeable others and monitoring and treating children at home.
RATIONALE

There are two possible approaches that could be used to assess asthma management approaches used by parents. The first is to pay particular attention to behaviours which clinicians consider to be effective for the management of children's asthma. The second is to include in the assessment all asthma management behaviours used by parents whether or not they are generally considered by clinicians to be effective management behaviours.

An example of the first approach is the questionnaire by Taylor et al. [1991]. In the development of this semi-structured interview, the opinions of a group of clinicians with expertise in the treatment of childhood asthma were used to determine which parental behaviours would receive positive scores. Similarly, Kolbe, Vamos, James, Elkind and Garrett [1996] used current recommended guidelines to derive a scoring schedule for their adult asthma management questionnaire. Such methods of questionnaire scoring have the potential advantage of obtaining resultant parental management scores which make intuitive sense to medical professionals; i.e., parents can be categorised as managing their children's asthma appropriately or inappropriately. The major limitation however of this approach is that it assumes that there is strong consensus amongst clinicians about which behaviours are and are not universally effective for the management of childhood asthma. In reality, one set of behaviours may be appropriate for an individual child under certain circumstances but not for another child.

The alternate approach is to identify all the behaviours that parents report using when managing children's asthma. This overcomes the problem of trying to determine which parental behaviours are more or less appropriate according to clinicians. Using this approach, parents reporting many behaviours are conceived as being very active in their management of children's asthma, and parents
reporting fewer behaviours as less active in their asthma management. The descriptive data presented in Chapter 5 showed that considerable variation existed amongst parents in their approaches to manage children’s asthma. Some parents appeared very active in managing symptoms whereas other parents adopted a more “wait and see” approach. Deriving total scores by simply adding up Likert scores for items without considering the doctor-judged appropriateness of individual behaviours therefore seemed to best reflect actual asthma management behaviour of parents. This approach has the advantage of not relying on health professionals to agree about the appropriateness of individual behaviours and is instead an attempt to simply summarise what parents do and do not do. The resultant scores on the AMQ would not reflect good and poor parental management but rather the level of intervention or action intended by parents. Subsequent longitudinal studies would then be required to assess whether greater or lesser levels of parental intervention result in better or worse outcomes for children with asthma. This would allow a much stronger scientific basis on which to determine the appropriateness of parental behaviour.

The non-judgemental additive approach described above was used to delineate summary scores for this thesis. To most easily collapse the full 53 items into summary scores, a factor analysis was undertaken. Rather than simply sum all 53 items, Exploratory factor analysis (EFA) allows those items which most reliably measure the underlying construct (in this case, the degree of parental action) to be identified. EFA groups together items which are highly correlated with each other but not with other items. If consistent with theoretical considerations, these distinct groups or clusters of items are considered to reflect underlying constructs or factors. In this study, “degree of parental intervention or action” was hypothesised to be the underlying or latent construct hypothesised to be reflected by responses
to the AMQ. That is, the degree of intervention parents intend to make when their children experience asthma symptoms.

Confirmatory factor analysis (CFA) is the alternative statistical approach to reducing a large number of items to factor based scores. CFA pre-specifies a model and tests the ‘goodness of fit’ of the data to this model. There is controversy about the appropriate application of exploratory and confirmatory factor analysis. Merenda [1997] suggests that when little is known about a particular area or construct, an exploratory factor analysis using principal components analysis is the preferred method. In contrast, when assessing the fit of empirical data to hypothesised theoretical models, confirmatory factor analysis is more appropriate. Despite having a strong a priori hypothesis that parental responses to the AMQ reflected their degree of intervention, very little is currently known about parental management behaviour. A thorough exploration of the meaning of the questionnaire was therefore considered the most appropriate step during the developmental phase of the new measure and consequently exploratory rather than confirmatory factor analysis was undertaken.

Reliability analysis explores the consistency of responses to items assuming that all items contribute to a total score of a scale. The internal consistency is reassessed as each item is systematically removed from the scale. The rationale for removing items is that items which are poorly correlated with the other items are probably not assessing the underlying construct. EFA was used initially to explore the potential factor structure of the AMQ and reliability analysis was used to help determine which items should be deleted from each scenario. EFA was repeated iteratively after removal of these items.
SUBJECTS

The subjects for this phase of the study were the 101 parents of children with asthma previously described in Chapter Four. Adequate sample size for undertaking factor analysis has been the subject of some debate, with recommended ratios of subjects to item numbers ranging from 3:1 to 20:1 [Merenda, 1997]. Because EFA is the initial step in attempting to reduce a large number of items to total scores, a ratio of 3:1 is just adequate. As will be described below, 44 of the 53 items of the new AMQ were used for the factor analysis. Factor analysis of 44 items would require 132 subjects. The sample size available in this study is therefore less than desirable. The result of this, as in any linear modelling, is that the correlation coefficients between variables (in this case the items of the AMQ) tend to be less reliable. However, if there are only a few distinct factors and the correlations between items are high, a smaller sample size can be adequate [Tabachnick & Fidell, 1996].

STATISTICAL APPROACH

Before the factor analysis was undertaken, a number of items from the original questionnaire were removed. These included the open-ended items in scenarios 4 and 5 asking about medication use. This was done because the vast majority of parents indicated they would give their children reliever medication which limited the discriminatory capacity of this question. In addition, parents interpreted the question about the frequency of administration of medications in different ways. Item 4 of scenario 2 ('get child to inhale preventer medication') was not included because this could be answered 'not applicable' by parents, thereby reducing the number of subjects available for the EFA. Items 11 to 14 of scenario 3 were also not included because parents responding negatively to item 10 ('send child to school'), were unable to answer these following four questions. The EFA was
conducted using the remaining 44 items. Two items were reverse scored; item 2 of scenario 2 ('let child resume play after a rest and symptoms have settled') and item 10 of scenario 3 ('send child to school'). This was done because conceptually these items would then reflect positive parental action.

Principal components extraction was performed using SPSS statistical software [SPSS version 7.5, 1997]. This approach is recommended over other forms of EFA (e.g., principal factor extraction, image factor extraction etc.) when the aim is to reduce a large number of items down to a smaller number of components [Tabachnick & Fidell, 1996]. The terms factor and component tend to be used interchangeably but the term factor is used in this thesis. Both orthogonal (varimax) and oblique (direct oblimin) rotations were performed because it was difficult to determine prior to analysis whether resultant factors would be uncorrelated (orthogonal rotation required) or correlated (oblique rotation required).

To determine the adequacy of extraction and the number of factors present, the amount of total variance explained by one or more factors was first assessed. Some authors recommend that at least 50% of the variance should be accounted for by the first unrotated factor [Merenda, 1997]. To help determine the number of factors present in the solution, eigenvalues for each factor were examined. Eigenvalues reflect the amount of variance explained by each factor. One rule commonly used is to retain factors with eigenvalues greater than unity [Tabachnick & Fidell, 1996]. The Scree method of determining the number of factors however, is preferred by other authors [Merenda, 1997; Streiner, 1994]. Scree plots for each scenario were derived with eigenvalues plotted against the number of factors. Ideally, the slope of the resultant plot should change dramatically at a single point, reflecting the presence of one or more distinct components or factors.
To interpret the meaning of the factor structure, the size and direction of loadings for each item on each component or factor were examined after performing orthogonal and oblique rotations. Some psychometricians use a squared loading of 0.09 (i.e., $\pm 0.3$) or above to indicate that an item belongs to a particular factor. However, inclusion of items with such comparatively low loadings can lead to complicated and sometimes uninterpretable factor structures [Merenda, 1997]. Comrey and Lee [1992] graded loadings as excellent ($> 0.71$), very good ($> \pm 0.63$), good ($> 0.55$), fair ($> 0.45$), and poor ($< 0.32$). A cut off point of approximately 0.50 for item loadings was therefore used in this study.

Following each iteration of the EFA, a reliability analysis was undertaken. The term reliability here refers to the internal consistency or homogeneity of the items assuming that together items contribute to a total score. Again, SPSS statistical software was used to perform these analyses. Kaiser-Meyer-Olkin (KMO) statistics for each item were used to assess which items should be removed from the questionnaire prior to the next iteration of the FA. This statistic ranges from 0 to 1 and reflects how much each individual item contributes to the underlying latent factor. KMO values over about 0.60 to 0.70 suggest that items have a reasonable association with the underlying factor structure. Corrected item-total correlations were also assessed. Low correlations suggest that items again have little in common with the underlying construct. Finally, Coefficient $\alpha$ (or Cronbach's alpha) were calculated with all items of the scenario included and recalculated with removal of each item. Coefficient $\alpha$ refers to the average of all of the possible split-half reliabilities of a scale, where split-half reliabilities are the correlations of items randomly divided into two subscales [Streiner & Norman, 1994]. If $\alpha$ increases
significantly when an item is removed from the scale, then its exclusion would increase the homogeneity of a scale.

RESULTS

Exploratory Factor Analysis of the AMQ

Iteration One:
The first iteration of the EFA, using 44 items of the new parental Asthma Management Questionnaire, resulted in extraction of 12 factors with eigenvalues greater than unity (Table 6.1). However, the corresponding scree plot suggested that two factors dominated (Figure 6.1a). These two factors accounted for only 36.8% of the total variance (Table 6.1). The first three factors after varimax rotation are given in Table 6.2. Seven of the nine items loading above 0.5 on the first factor were common items across scenarios 2, 3 and 4 ('take child to hospital to be checked', 'take child to the family doctor' and 'call a hospital for advice'). Only item 10 of scenario 3 ('send child to school') and item 8 of scenario 4 ('call a doctor to the home') were unique. Items corresponding to the second factor of the first iteration appeared to all focus on calling someone (a friend, relative or neighbour, a hospital or an ambulance) for help or advice. The third factor contained only three items which were common items across scenarios 3, 4 and 5. The factor solution after direct oblimin rotation is given in Table 6.3. A very similar group of items loaded on the first factor but now the second factor appeared to be made up of items from scenarios 1 and 2 (focusing on exercise induced asthma). A summary of the results of the reliability analysis is given in Table 6.4. The alpha coefficient was little changed by item deletion so these changes are not shown in the table. The criteria, KMO statistic ≤ 0.60 and/or a corrected item-total correlation ≤ 0.30 were used to determine which items showed little relationship with the other items.
Using these criteria, 13 items were removed prior to the next EFA iteration. The coefficient $\alpha$ was 0.93 with 44 items and 0.94 with the remaining 31 items.

**Iteration Two:**

The second iteration, using 31 items, extracted seven factors with eigenvalues greater than unity (Table 6.5). As in the first iteration, the scree plot suggested the presence of two dominant factors (Figure 6.1b). These two factors together now accounted for 45% of the variance (Table 6.5). The item structures for the first three factors after varimax rotation are given in Table 6.6. The items loading on the first factor were nearly identical to those noted after the first iteration. However, now the second factor appeared to be more clearly separated from the first factor with items loading on the second factor again chiefly focusing on calling or telephoning for outside help (e.g., calling an ambulance, a doctor, a hospital or a relative, friend or neighbour). After direct oblimin rotation, items loading on the first factor were identical to those loading on the first factor after varimax rotation (Table 6.7). The third factor of the direct oblimin rotation was a negative reflection of the second factor of the varimax rotation. Reliability analyses are summarised in Table 6.8. For this iteration the criteria, KMO statistic $\leq 0.75$ and/or a corrected item-total correlation $\leq 0.40$ was used to determine which items should be removed. Seven items were removed and these are marked in Table 6.8. Overall, comparatively more items were removed from scenarios 1 and 2 than from the other scenarios. Following removal of these items, the coefficient $\alpha$ remained unchanged at 0.94.

**Iteration Three:**

The third iteration was conducted on the 24 items remaining from iteration two. Now only five factors had eigenvalues greater than unity and a two factor solution
explained 51% of the variance, whilst a three factor solution explained 58% of the variance (Table 6.9). Although the scree plot again suggested the presence of, at the most, a two factor structure, examination of the item loadings after varimax rotation revealed three clearly separate factors (Table 6.10). Even more importantly, these three factors were conceptually interpretable. The first factor, as noted in the previous iteration, contained items from scenarios 3 to 5 about taking the child either to the hospital or to the local doctor. Two other items, ‘sending the child to school’ (reverse scored) and ‘calling the hospital for advice’ (scenario 3) also loaded on this factor. Apart from these two latter items, the first factor appeared to reflect the likelihood of children being taken by their parents to be assessed by a health care professional. All but one of the eight items loading on the second factor were about calling or telephoning for outside advice or assistance (calling a relative, friend or neighbour, calling a doctor to visit the home or calling an ambulance). The item ‘sleep in child’s room or have child in parent’s room that night’ (scenario 4) loaded both on factor two and factor three, although this item was more closely related conceptually with factor three. This final factor contained items focusing on assessing and monitoring the child closely by parents at home. The direct oblimin rotation did nothing to improve the factor structure of the third iteration (Table 6.11).

**Summary of the Factor Based Scores**

The three factors and the items loading on these factors derived from the exploratory factor analysis of the parental Asthma Management Questionnaire are summarised in Table 6.12. The factors were labelled; *medical assessment*, *external advice*, and *home management*. Loadings ranged from 0.46 to 0.79 with only one item needing to be reverse scored.
As suggested by a number of authors, total scores for subscales can be derived without using weightings because scores derived with and without weights are highly correlated [Lei & Skinner, 1980; Streiner & Miller, 1989]. The advantage of using unweighted items to derive scores is that the computation of scores is easier and there is less risk of computational errors. Subscale scores were thus computed by simply adding up unweighted Likert scores for individual items. The frequency distributions of the scores for the three scales are given in Figure 6.2. The medical assessment and external advice subscales are skewed to the right indicating that parents in the sample tended to score towards the lower end of these scales (lesser degrees of intervention) (Figure 6.2a and 6.2b respectively). In contrast, the distribution for the home management scale was skewed to the left, indicating that parents tended to score towards the higher end of this scale (higher degrees of intervention) (Figure 6.2c). The ranges, means, standard deviations and coefficient α’s for the three subscales of the AMQ are given in Table 6.13. The coefficient α’s were all greater than 0.80, indicating a high degree of internal consistency or reliability within subscales. Finally the relationships between the three subscales were assessed with Pearson’s correlation coefficients and moderate to high correlations were found between the three subscales (Table 6.14).

**DISCUSSION**

This chapter described the process of deriving factor based scores for the Asthma Management Questionnaire. Exploratory factor analysis of the new questionnaire using principal component extraction with varimax rotation resulted in delineation of three clearly interpretable factors. After three iterations, reliability analyses showed consistently high KMO statistics and item-total correlations, and stable alpha coefficients. Out of 44 items, only 20 items were needed to delineate the three factors but these items were distributed across all five scenarios. A summary of the
items, grouped by factor is given in Table 6.12. The three factors were interpreted as follows.

1. Factor One (taking child for medical assessment): Parents scoring high on this factor demonstrate greater intention to take their child to hospital or to their family doctor to be examined both when their child has symptoms of a cold or specific asthma symptoms. These parents are also more likely to keep their child home from school when the child has a cold.

2. Factor Two (calling for external advice): Parents scoring high on this factor demonstrate greater intention to call for outside assistance, advice or help when their child has symptoms of moderate to severe asthma. These parents are likely to call a neighbour, friend or relative for help, call a locum doctor to the home, call a hospital for advice and call for an ambulance in this situation.

3. Factor Three (home management; monitoring and intervention): Parents scoring high on this factor demonstrate greater intention to be hypervigilant when their child has a cold or moderate asthma symptoms. These parents are more likely to sleep in their child’s room (or have the child in their room), keep awake during the night to monitor their child and check their child’s temperature. They are also more likely to give cough or flu medication when their child has a cold and more likely to tell their child to be careful even when the child is well.

As described, a number of the items, particularly in the medical assessment and the external advice subscales, were the same item in terms of wording but were derived from different scenarios. Thus, one possible reason that these items clustered together was that they were fundamentally the same question and not that they were reflecting a specific underlying construct. However, there are two findings which argue against this possibility. The first is that items other than those that were worded the same also clustered together into the subscales. This was particularly so with the home management subscale, where only two of the six
items were the same. Second, although some of the items were identical in words, they were answered in the context of different scenarios.

Chapter 5 examined the relationship between parents' experience with the scenarios described in the AMQ and responses to individual items of the AMQ. The most relevant finding of these analyses was that parental behaviours when children were about to participate in physical activity were significantly associated with whether children regularly experienced exercise induced asthma. As discussed previously, if this was a true and not a chance finding, it may limit the future applicability of the questionnaire. However, the three items in scenario 1 which showed this significant relationship were not included in any of the subscales generated by the factor analysis described in the current chapter. Thus, although these findings were interesting, they had no impact on the final scoring or interpretation of the new questionnaire. The other items of the AMQ which were significantly associated with parents' past experience with the scenarios described in the AMQ were three items of scenario 3 (symptoms of an URTI). Unlike the items of scenario 1 however, these items were included in the subscales generated by the factor analysis. As will be shown in Chapter 8, the significant association found between responses to these items and parents' past experience with the scenario was likely an age effect. That is, younger children experience more frequent URTI's compared to older children [Denny, 1995]. In addition, parents may be more interventionist in managing symptoms experienced by younger children.

Not unexpectedly, scores on the three subscales of the AMQ were moderately correlated with each other, indicating that parents who tended to be more interventionist in one area, responded similarly to the questionnaire in the other
areas of management. Each scale had a moderate to high coefficient $\alpha$ indicating excellent internal consistency.

**SUMMARY**

The exploratory factor analysis of the AMQ showed that the questionnaire could be summarised by three easily interpretable subscale scores. The scores derived do not allow judgements to be made about the appropriateness of parental asthma management but instead reflect the level of activity that parents intend to adopt when their children develop symptoms of asthma. These subscale scores could be used to explore relationships between parental asthma management and other constructs, such as the level of asthma severity or psychological factors, thereby resulting in a better understanding of the behaviour of parents when managing their children's asthma.
CHAPTER SEVEN

THE RELIABILITY AND VALIDITY OF THE ASTHMA MANAGEMENT QUESTIONNAIRE

INTRODUCTION

This chapter describes the reliability and validity of the new parent Asthma Management Questionnaire. The assessment of reliability focused on the stability of the questionnaire over time and was assessed in a subset of parents who completed the questionnaire twice, four weeks apart. The validity of the questionnaire was determined using two methods. First, responses to individual AMQ items were compared with parents' reports of behaviours they had performed in response to recent real-life asthma situations experienced by their children. Second, scores on the three subscales of the AMQ were compared to the recent use of health care services by children and the number of school days missed by children because of asthma.

RATIONALE

Reliability

Reliability is defined as "the degree of stability exhibited when a measurement is repeated under identical conditions" [Last, 1988, p.114]. The most important aspect of reliability for a self-completed questionnaire is the stability of responses over time (i.e., test-retest reliability). The AMQ appeared to reflect the degree of intervention parents intended to make when their children had symptoms of asthma. We hypothesised that the level of parental intervention would be an
enduring characteristic and unresponsive to minor alterations in the medical management of children's asthma or fluctuations in children's asthma symptoms. Therefore we expected that parents would respond to the questionnaire in a similar manner when completing it on two separate occasions. To assess the test-retest reliability of the AMQ, the questionnaire was administered on two occasions. The intervening period was four weeks which was considered long enough to minimise the possibility that parents would remember their previous answers to the questionnaire [Streiner & Norman, 1994]. Responses to questions may also vary depending on where the questionnaire is completed (e.g., a busy casualty department versus a private home). The AMQ was therefore administered on both occasions in parents' homes.

Validity

Validity describes the ability of a questionnaire to assess an underlying construct. Although various classification systems highlight different types of validity (content, criterion, construct etc.), in practice validity describes how the questionnaire performs when used in subsequent studies [Streiner & Norman, 1994]. In this chapter the criterion validity of the AMQ was assessed by comparing the relationship between AMQ responses and what parents reported doing in real-life asthma situations.

The criterion validity at an individual item level.

To test the relationship between responses to the AMQ and actual behaviour the following procedure was followed. First, parents who had experienced the situations described in the AMQ in the last month were identified. After these parents had completed the AMQ, they were then asked to describe behaviours they
had actually performed in response to their children's symptoms in situations occurring in the last month. Next, parents were directly prompted to recall whether they had carried out the individual behaviours described in the AMQ, if these behaviours had not been mentioned by parents initially with open-ended questioning. For all 33 parents participating in the test-retest phase of the study, these steps were conducted at the first not the second administration of the AMQ. The proforma used for this section of the study is given in Appendix VI.

Two different but complimentary ways of comparing parental reports of past actual behaviour and AMQ responses were used. First, parental reports of past real-life behaviours and behavioural intention measured by the AMQ, were compared for each behaviour (item) individually. Second, it was also possible to derive subscale scores based on real-life behaviours which corresponded to the subscale scores derived from responses to the AMQ. The relationship between these scores and the corresponding AMQ subscale scores was also examined. A similar approach was used by Kolbe, Vamos, Fergusson, Elkind and Garrett [1996] to determine the relationship between responses to hypothetical asthma situations and interviews of actual acute asthma episodes in adult patients admitted to hospital.

**The criterion validity of the AMQ at a subscale level.**

To further assess the validity of the AMQ, the following procedure was adopted. Parental subscale scores on the AMQ were hypothesised to reflect recent use of health care services by parents and the number of days kept home from school. This was because these specific behaviours were included as AMQ items. Parents may have found it difficult to recall in the section described above, whether or not they had actually carried out individual behaviours in the past month if these behaviours were frequently performed (e.g., telling the child to be careful, or
watching the child's breathing very closely). Less commonly performed activities such as taking the child to the family doctor may be less affected by this reporting bias because these behaviours may have greater impact on the family. Thus, parents were asked how many visits to the family doctor they had made for their children's asthma in the past 2 months, the number of visits to the emergency room (ER) room for asthma in the past 2 months and the number of school absences because of asthma in the past 2 months. Parents reporting more of these activities were expected to score higher on the subscales of the AMQ, particularly on the medical assessment subscale.

SUBJECTS

The group of 101 parents who were the subjects for this part of the study have been described in Chapter 4. Thirty three parents in the group were randomly selected to participate in the test-retest phase of the study. None of these parents refused to participate in this phase of the study which required a second visit to their home. Twenty five parents (76%) completed the questionnaire a second time between 24 and 31 days after the first administration (i.e., approximately four weeks later). The remaining eight parents (25%) completed the questionnaire a second time between 32 and 46 days later (i.e., between five and six weeks later). On both occasions parents completed the questionnaire in their own home.

RESULTS

Test-Retest Reliability of the AMQ

Thirty three parents completed the questionnaire twice. Subscale scores were calculated for the 33 parents by adding up the individual unweighted items (scored one to six) corresponding to the medical assessment, external advice and home
management subscales of the AMQ. The means and standard deviations for these scales at first and second administration in this subgroup of parents are given in Table 7.1. Pearson correlation coefficients were calculated to test the strength of the linear relationship between the two scores. Correlations were all high suggesting that parental responses to the AMQ were stable over time.

The relationship between scores obtained at time one and two may theoretically be affected by changes in the frequency of children's symptoms or changes to the medical management of children's asthma during the intervening period. To assess the effect of these factors, parents were asked whether their children had experienced asthma symptoms in the intervening four weeks between administrations of the questionnaire. Twenty two of the 33 children (67%) had experienced one or more exacerbations of asthma during this time and half of these children had visited a general practitioner (GP) for treatment. Three children (9%) had visited the emergency room (ER) and two children (6%) had required admission to hospital. Ten parents (43%) reported minor changes to their children's asthma management regimen. These changes included small increases or decreases in doses of preventer medications in response to changes in asthma symptoms (eight parents), starting the child on vitamin supplements on the advice of a naturopath (one parent) and introducing peak flow monitoring on the advice of the general practitioner (one parent).

The 33 parents were divided into two groups twice, based on two dichotomous variables. The first division was based on whether children had or had not experienced one or more exacerbations of asthma in the preceding four weeks. The second division was based on whether or not there had been any change in children's asthma management regimen. Differences in AMQ subscale scores at times one and two were calculated, producing a new variable which was labelled,
"change in subscale score". Unpaired t tests were used to assess whether there were significant differences between 'change in subscale score' for the groups of parents, divided in terms of significant symptoms experienced by children in the intervening period and changes to asthma regimens (Table 7.2). There were no significant differences in the variable, 'change in subscale score' between groups of parents for each subscale of the AMQ. This suggested that fluctuations in asthma symptoms and minor changes to the medical regimen did not significantly influence parents' responses to the AMQ.

The Validity of the AMQ

1. *The criterion validity of the AMQ at an individual item level.*

The relationships between parental responses to individual items of the AMQ and parental reports of actual behaviours performed in the preceding four weeks were determined. AMQ items were scored on the standard Likert scale from one to six whilst parental reports of past behaviour were dichotomised into *did perform the behaviour* or *did not perform the behaviour* for each behaviour in turn. Initially, analyses were done for each individual item in turn. The strength of the linear relationship between reported actual behaviour and behavioural intention was assessed using a series of logistic regression analyses with actual behaviours the dependent variables and individual AMQ item responses the explanatory variables.

Eighty six parents had watched their children participate in some form of physical activity approximating the description of scenario 1 in the four weeks prior to interview. These parents were asked what they did in this real-life situation. Parental responses to this question and AMQ answers are given in Table 7.3. Statistically significant associations were found between answers to the AMQ and
actual behaviours for all items of scenario 1. This suggested that there was a close relationship between what parents reported doing in the past and what they intended to do when watching their children prepare to undertake physical activity.

Twenty five parents reported they had witnessed their children developing symptoms of asthma with exercise, approximating scenario 2, in the past four weeks. Behaviours performed by these parents were compared to responses to scenario 2 (Table 7.4). Item 2, 'let child resume play once symptoms have settled' and item 4, 'get child to inhale preventer medication' showed a significant or near significant linear relationship between past behaviour and response to AMQ item. Analysis of other items for this scenario were not significant. However the number of subjects available for the analysis was small and a type II error was possible. Bearing this in mind, the direction of the relationship suggested that what parents reported doing in real-life situations even for these questions was probably close to their responses on the AMQ. However, 11 of 26 parents (42%) indicated on the AMQ that they would take their child to the GP in this situation and eight of 26 parents (31%) said they would take their child to a hospital but no parent in reality did this in the past four weeks when their children experienced EIA.

Fifty one children had experienced an URTI similar to that described in scenario 3 in the preceding four weeks. The majority of items showed statistically significant or near significant relationship between past and intended behaviour (Table 7.5). However a number of behaviours concerning seeking outside help (i.e., calling a hospital for advice and taking child to hospital) were not performed by any parent in the past four weeks, despite seven parents (14%) responding positively to these items in the AMQ hypothetical scenarios.
Twenty four parents reported that their children had developed significant asthma symptoms with an URTI approximating scenario 4 in the four weeks prior to interview. Past and intended behaviours were compared for these parents (Table 7.6). Because of the small number of subjects, some items could not be analysed statistically. In general, behaviour items which showed significant or near significant relationships between past behaviour and behavioural intention were those concerning home management (e.g., giving vitamin tablets, checking the child's temperature, giving child cough or flu medication and sleeping in child’s room). Items about seeking outside help (e.g., calling a hospital for advice, calling a doctor to home, taking child to hospital and calling an ambulance) were performed less in real-life situations than expected by parental responses to hypothetical scenarios.

Although 51 parents had experienced the acute severe asthma situation described in scenario 5 in the past two years, only two parents had experienced this in the four weeks preceding interview. It was therefore impossible to draw conclusions about the relationship between behavioural intention and behaviour for this scenario.

2. The criterion validity of the AMQ at a subscale level.

In addition to the above analyses, scores equivalent to AMQ subscale scores (medical assessment, external advice and home management) were derived using reports of the relevant actual behaviours performed by parents in the preceding four weeks. A score of 1 was assigned for each behaviour parents reported not performing and a score of 2 was assigned for each behaviour they did perform for all items corresponding to the three AMQ subscales. However, because of the small number of parents experiencing all five scenario situations in the past four
weeks, only a total score equivalent to the *home management* subscale could be calculated from reports of real-life behaviours. This score could be calculated for 16 parents. A moderate Pearson correlation of 0.60 ($p = 0.01$) was obtained between the *home management* subscale of the AMQ and the equivalent real-life *home management* score.

3. **The relationships between scores on AMQ subscales and health care service use for asthma and school absences because of asthma.**

The number of times children had been taken to the emergency room (ER) and to the general practitioner (GP) with asthma symptoms and had been kept home from school by their parents in the two months prior to data collection, are summarised in Table 7.7. Although only a small number of children had been taken to the ER, 40% of children had been taken to the GP at least once in the preceding two months. Similarly about 40% of children had been kept home from school at least one day in the past 2 months because of asthma.

A series of simple bivariable regression analyses were conducted to test whether there was a significant relationship between subscale scores on the AMQ and these three variables (Table 7.8). As predicted, whether the child had been taken to the ER in the past two months was significantly associated with parental responses on the *medical assessment* subscale of the AMQ but was not associated with the *external advice* nor the *home management* subscales. All three subscales were significantly positively associated with the number of visits to the GP with asthma. Higher scores on both the *medical assessment* subscale and the *home management* subscale were significantly associated with more days of school missed because of asthma in the preceding two months.
DISCUSSION

This chapter described a number of important psychometric properties of the AMQ questionnaire. The reliability or reproducibility of the questionnaire was tested by giving the questionnaire twice to a randomly selected subgroup of parents. The questionnaire aimed to measure the tendency of parents to manage children’s asthma more or less actively. This tendency towards being more or less interventionist was hypothesised to be an enduring characteristic of parents. Thus, scores on the questionnaire were not expected to change with minor alterations in children’s medical regimens nor to change when children experienced exacerbations of asthma symptoms. This was supported by finding that responses to the AMQ did not change significantly over time. There were also no statistical differences found in the stability of parental responses over time when minor changes in children’s asthma symptoms or asthma treatment were accounted for. Parents whose children had experienced asthma symptoms during the intervening period demonstrated AMQ responses as stable as parents whose children had been well. Similarly, parents whose children’s asthma treatment had been modified in the intervening period demonstrated AMQ responses as stable as parents whose children’s treatment had remained unchanged.

The criterion validity of the questionnaire was first tested by comparing questionnaire responses and parents’ descriptions of their behaviour in a recent situation which resembled the hypothetical scenario described in the AMQ. Generally, a close relationship was found between past behaviour and responses to items of the AMQ. However, some items performed better in this regard than others. All items in scenario 1 showed a strong relationship between past behaviour and intention. About half the items in scenario 2, showed close association between past behaviour and intention. Scenarios 3 and 4, describing the progression of an URTI and the development of asthma symptoms, showed
close relationships for items pertaining to home management of children but weaker relationships for items asking about seeking outside help or taking the child out of the home for medical assessment. In general on the AMQ, parents reported a stronger intention to carry out these behaviours compared to their reports of actual past behaviour.

The validity of the 20 items comprising the three subscales of the AMQ is of most importance however, if subscales rather than individual items are used in subsequent analyses. Only 17 of these 20 items could be analysed in this study because three items were derived from scenario 5 and only two parents had recently experienced this situation. Eight of the remaining 17 items showed a close relationship with actual past behaviours whereas responses to nine of 17 items were clearly different to what parents had actually done in the past. These latter items were predominantly about taking children for medical assessment. An attempt was made to assess AMQ responses and parental reports of actual behaviours at a subscale level as well as at an individual item level. However, because of the small number of subjects available for these analyses, only the home management subscale could be compared in this way. Not unexpectedly, a moderate correlation was found between the AMQ subscale, home management and equivalent scores based on real-life behaviours.

There are a number of plausible explanations why the relationship between past behaviour and behavioural intention varied depending on whether the behaviours assessed asked about home or outside management. First, the outcome of a recent past asthma situation managed by a parent could change the way in which this parent intended to manage future situations. For example, a past asthma situation treated at home may have resulted in the child failing to respond to treatment and these parents may therefore intend to have their child checked by a
doctor in future similar situations. The only way of assessing this possibility would be to prospectively collect information about real-life situations. Second, during the time spent with parents, subtle and sometimes more obvious differences between past situations and the hypothetical scenarios were noted. For example, the severity of symptoms and the speed of progression of symptoms sometimes differed between past real-life situations and hypothetical situations described in the questionnaire. Generally speaking, the past real-life situations were less severe than the hypothetical scenarios. This may help to explain why parents took their children for medical assessment less in recent real-life situations than was indicated by their responses to the AMQ.

Third, parents may simply have answered the questionnaire in a socially desirable manner and have over-reported their intention to undertake management behaviours listed in the AMQ. The extent of social desirability bias may have been more pronounced in this study because the thesis candidate conducting the interviews was a medical doctor. The results of such a bias may be more evident for behaviours which require greater parental effort such as taking children for medical assessment. Although it is easy for parents to tick these options on a pencil and paper questionnaire, considerably more effort is required to actually take children to hospital or to the GP’s surgery in real-life.

Another problem encountered in this study was that some parents had difficulty remembering exactly what they had done in past situations even though only situations in the preceding four weeks were considered. This was particularly the case with behaviours which were routinely performed by parents such as telling their children to be careful or watching their child’s breathing. Finally, analysis and interpretation of the data was difficult because of the small numbers of parents recently experiencing situations similar to AMQ scenarios. Relationships between
AMQ responses and recent past parental behaviours may have been more consistent if the number of parents available for these analyses had been larger.

A second, complimentary approach to assess the criterion validity of the questionnaire was also used. Subscale scores were compared to recent visits to the GP, the ER, and to days absent from school because of asthma. These analyses helped to overcome the problem of a small sample size as described above. Because all parents could respond to questions about recent health service visits and school absences, a sample of 101 parents was available for these analyses. Overall, significant positive relationships were found between AMQ scores and recent health service use and school absences, supporting the validity of subscale scores in terms of reflecting parental behaviour. As initially hypothesised, the medical assessment subscale showed the strongest relationship with past reported visits to both the ER and the general practitioner (GP). Items in this subscale specifically asked parents about their intention to perform these behaviours (e.g., ‘take child to a hospital to be checked’ and ‘take child to the family doctor’). In addition, high scores on this subscale were also associated with a greater number of recent school absences for children. This is most likely because the medical assessment subscale contains the relevant item from scenario 3, ‘send child to school that day’. Therefore, although the criterion validity of individual items focusing on taking children for medical assessment appeared weak, when the items were combined into subscale scores, much stronger relationships were found between actual past behaviour and behavioural intention. This may have been because of the larger sample size available for analysis. In addition, combining items into subscales generally results in greater stability of scores. Subscale scores rather than responses to individual items may be a much better general reflection of parental approaches to asthma management.
Higher scores on the external advice subscale were significantly associated with more visits to the GP but not with ER visits and school absences. Higher scores on the home management subscale were significantly associated with more visits to the GP and more school absences but not with ER visits. The three subscales of the AMQ showed moderate correlations with each other as described in Chapter 6, implying that parents tended to be more or less active in all areas of asthma management. This probably explains why these subscales were significantly associated with GP visits and number of school absences even though the items specifically inquiring about these behaviours were not included in these subscales.

**SUMMARY**

This chapter has shown that parental scores on the AMQ remained stable over a relatively short period of time despite minor alterations in children's asthma symptoms and medical management. This supports the notion that parental approaches to the management of asthma represents a pervasive and enduring characteristic of parents. In addition, by assessing the relationship between behaviours that parents reported undertaking in recent real-life asthma situations and AMQ responses, this study has provided preliminary data supporting the criterion validity of the new questionnaire.
CHAPTER EIGHT

ASSESSMENT OF THE RELATIONSHIP BETWEEN
PSYCHOSOCIAL FACTORS AND PARENTAL ASTHMA
MANAGEMENT

INTRODUCTION
This chapter explores the relationships between a number of psychological
variables and parental asthma management. Parental asthma management was
measured using the new Asthma Management Questionnaire. The psychological
factors chosen for this study were, (i) parental perceptions of child vulnerability, (ii)
parents’ protectiveness towards their children and (iii) family functioning. The
analyses undertaken adjusted for important disease-specific and demographic
variables. The two disease-specific variables included were (i) asthma severity and
(ii) parent’s past familiarity with asthma, and the three demographic variables were,
(i) children’s age, (ii) children’s gender and (iii) socioeconomic status of the family.

RATIONALE
This section of the thesis assesses the role of psychological and other factors in
explaining differences in parental asthma management. This is important for a
number of reasons. The first is that the AMQ is a new questionnaire and assessing
the relationship between parental responses to the AMQ and other variables
provides a better understanding of the meaning of the questionnaire. This quality of
the questionnaire is known as its construct validity. Streiner and Norman [1994]
described this form of questionnaire validation as, “an ongoing process, of learning
more about the construct, making new predictions, and then testing them" [p. 115].
Second, a better understanding of factors which influence parental behaviours may
assist in designing more effective interventions to help parents manage their
children’s asthma.

Psychological Variables
Previous studies assessing morbidity and mortality due to asthma suggested that
various psychological factors may play an important role in determining outcomes
for these children [Campbell et al., 1995; Martin et al., 1995; Strunk, Mrazek,
Wolfson Fuhrmann and LaBrecque, 1985]. For example, Martin et al. found that
73% of families of children experiencing a near fatal attack of asthma demonstrated
significant general psychosocial problems such as denial of asthma and the
severity of asthma, failure of parental responsibility, parental conflict or a past
history of psychiatric consultation. As described in Chapter 2, a multitude of
psychological factors have been associated with compliance to medical regimens.
In addition, a number of psychological models exist which help explain and predict
health behaviours such as the Health Belief Model, the Triandis Model, Fishbein’s
Ajzen & Fishbein, 1980; Triandis, 1979; Rotter, Chance and Phares, 1972,
respectively]. All such models include psychological factors as important
determinants of health behaviour. For example, constructs such as attitude
towards illness, self-efficacy, emotional adjustment and personality have been
shown to predict future health behaviour in a wide variety of areas. Two sources of
information were used to determine which specific psychological factors would be
addressed in this study. These were the results of previous research and
discussions with parents in both focus groups and individually.
Parental perceptions of vulnerability and parental overprotectiveness.

Green and Solnit coined the term, the ‘vulnerable child syndrome’ over thirty years ago when they described a group of children who had been expected to die because of a serious illness but who survived and subsequently remained healthy [Green & Solnit, 1964]. They reported that excessive parental concerns of vulnerability could disrupt the child-parent relationship leading to behavioural and emotional problems in the child. Since this time, studies of parental reactions to acute childhood illness such as gastroenteritis and premature birth have suggested that potentially life-threatening events can alter the way parents view their children [Perrin, West and Culley, 1989; Sigal & Gagnon, 1975]. Chronic as well as acute childhood illness may also enhance dependency between children and parents. For example, Hoare [1984] showed that levels of dependency were higher in children with epilepsy compared to normal children.

Heightened perceptions of child vulnerability may result in a number of important sequelae for children. For example, Casey, Ludwig, McCormick [1986] showed that children experiencing minor head trauma have greater impairment of functional morbidity and more behavioural problems despite having very low rates of physical problems, compared to children from the normal childhood population. The authors interpreted these findings as evidence that parents frequently overreact to minor head trauma and place limitations on their children’s activities. Similarly, Sigal and Gagnon [1975] showed that children hospitalised for severe gastroenteritis between 2 and 5 years of age had a greater prevalence of conduct disorders and a tendency to greater dependence at 8 to 12 years of age if they had been severely ill during the original hospitalisation or if their parents had been worried that their child might die during the illness compared to children with gastroenteritis without these characteristics. Forsyth and Canny [1991] reported that children who had had feeding difficulties and irritability as infants, were later perceived by their parents as
more vulnerable and also had more behavioural problems compared to other children who had not had these problems.

Parental perceptions of children’s medical vulnerability may also influence parents’ use of paediatric health care services. For example, Wakefield et al. [1997] found that parental concern about their child even when the child was well, predicted repeat attendance with asthma to the paediatric emergency department. Kemper, Forsyth and McCarthy [1990] showed that infants with a history of uncomplicated neonatal jaundice were more likely than controls to have had more than four well-child visits, more than two sick visits to a doctor and were more likely to have visited an emergency department by the age of six months. Levy [1980] found that parents of children who perceived their children as more vulnerable in the absence of a medical reason for this, made more visits to the emergency room per year and were generally dissatisfied with the care their children received.

The relationship between parental attitudes towards their children’s health and how parents manage childhood illness has not been thoroughly addressed although it is of potential importance. For example, heightened perceptions of child vulnerability may have positive outcomes for children if this leads to greater adherence to medical regimens. On the other hand, excessive use of medications, frequent decisions by parents to keep their children home from school and restrictions placed on children’s physical and social activities by parents may be detrimental for the psychological and social development of children. One study has shown that parental perceptions of their children’s vulnerability to develop common acute childhood illnesses was positively associated with greater use of over-the-counter medications by parents [Maiman, Becker and Kattic, 1985]. It therefore seemed plausible that parental perceptions of child vulnerability may be associated with how parents manage children’s asthma.
Parental perceptions of child vulnerability have been assumed to be reflected in an overprotective parenting style, where parents exhibit excessive and developmentally inappropriate protectiveness towards their children. The concept of maternal overprotection was first described by Levy [1931] and included four general features of parenting; (i) excessive physical or social contact (e.g., extended co-sleeping), (ii) prolonged infantalisation (e.g., persistent breast or bottle feeding), (iii) active prevention of independent behaviour and social maturity (e.g., delaying school entry and, restricting contact with other children) and (iv) either an absence or excess of parental control over the child (e.g., absence of limit setting or rigid overregulation). Although it has been generally accepted that children perceived as more medically vulnerable will have overprotective parents and the terms, parental overprotectiveness and the vulnerable child syndrome tend to be used synonymously, Thomasgard and Metz [1997] have suggested that they may represent two distinct clinical syndromes. Parental overprotectiveness they suggest, may arise de novo or when parents themselves have experienced overprotective parenting, whilst the vulnerable child syndrome usually occurs following a significant medical illness in the child. Their studies showed that parental overprotectiveness was associated with younger age of the child, single parenthood and lower socioeconomic status, whereas heightened perception of children’s vulnerability was associated with health related variables (e.g., a previous life-threatening medical condition or a concurrent medical condition) [Thomasgard & Metz, 1997; Thomasgard, Shonkoff, Metz and Edelbrock, 1995].

Few studies have investigated the short and long term consequences of overprotective parenting on children. Thomasgard, Metz, Edelbrock and Shonkoff [1993] investigated the influence of overprotective parenting and parental perceptions of child vulnerability on the use of health care utilisation. They found
that parental overprotection was not related to excessive use of paediatric outpatient services although greater levels of perceived child vulnerability was. Because little is known about the relationship between overprotective parenting and parental management of children’s health problems, and because a positive relationship between these variables has been assumed to exist by health care providers, a measure of parental protectiveness was included in this study along with a measure of parental perception of children’s medical vulnerability.

In the present study, themes of parental anxiety and fear for children’s safety were dominant in all three focus groups conducted during the developmental phase of the new Asthma Management Questionnaire. Parents expressed concerns about the well-being of their children in terms of ability to participate in normal childhood activities and fear of their children suddenly dying from asthma. Even during periods of hospitalisation, parents remained highly vigilant and wanted to remain close to their children at all times. The following quotations from parents reflect these feelings.

‘when J is not feeling well and I know something’s happening, but its, a doctor couldn’t diagnose it, and I can’t, not sure if its exactly going to happen, and I tend to say well look go to bed early, or no running around, or you know, its that constant keeping an eye on him all the time’

‘We, we go with our children to practice and to the games, and we’re there the whole time they play, just in case something....’

’I’m a bit frightened to leave him (at child care), I sort of, see him look, and they kept saying to me go, go, but they don’t know his ways and if they can’t understand what he’s saying they won’t know.’

‘I think if he had, if he had sort of wheezy asthma, that might, I’d probably do that I think, and then just give him some Ventolin and what have you, but because he gets sick for three weeks, four weeks, five weeks at a time, I tend to baby him.’

‘To be on the safe side though, if I had any doubts about sending her to school or something, I keep her home, you know. I would rather not take the risk’
Discussions with these parents were also consistent with research which suggested that discrepancies exist between parents' and health care professionals' perceptions of asthma severity. Perrin, MacLean and Perrin [1989] showed that although parental estimates of asthma severity were significantly correlated with a composite, physician derived measure based on history of asthma symptoms ($r = 0.39$), the concordance value was only 54%. Parents tended to rate their children's asthma as more severe than an objective measure. In general, parents participating in focus groups described perceiving their children's symptoms more severe than that of attending medical professionals. This had caused considerable concern for some of these parents. For example,

'it sounds like a piano accordion, and you hear those things as a parent over the years, and we're probably better at it than most doctors in many ways, and this doctor said oh well, he can probably go home tonight, and his oximetry was 90. Now that is frightening'

'we've found that we have been classed as paranoid parents and everything else, umm, again this particular person had written in my son's notes, err, over dramatic, over dramatises the situation but 3 hours after he says you know, go home you're a paranoid you silly woman'

'I sometimes have a problem in umm, in emergency, because I'm dealing with doctors who obviously know more about medicine than I do, but they do not sometimes know as much about asthma as I do, or they don't pick up the individual child's problem'

Because previous research suggested that parental perceptions of how sick children are (or can be) could potentially influence future parental management strategies, and these findings were supported by information obtained directly from parents, parental perceptions of child vulnerability and parental overprotectiveness were included in this study as independent variables to explain differences in parental asthma management. Specifically, higher parental perceptions of child medical vulnerability and an overprotective parenting style were hypothesised to be associated with higher scores on the Asthma Management Questionnaire (AMQ).
Family functioning.

Family functioning refers to the way family members interact together and find solutions to practical and emotional everyday problems. Family functioning has long been considered a major determinant of health outcomes for children with asthma. In the past, asthma was considered a psychosomatic disorder and family psychotherapy was used to improve control of children’s symptoms [Lask & Matthew, 1979]. As described in Chapter 2, treatment of children with severe asthma also included removing children from the family environment and placing children in long term institutional care [Munro Ford, 1968; Peshkin, 1930; Purcell et al., 1969]. More recent research has supported the hypothesis that a supportive family environment can protect children against the negative psychological effects of having a chronic illness. For example, Lewis and Khaw [1982], compared three groups of children with asthma, cystic fibrosis and healthy controls and found that family functioning was a better predictor of child psychological adjustment than the presence of the illness. Families which have the capacity to deal with illness situations are better able to protect children against emotional stresses of having a chronic medical condition.

There is some evidence that family factors impact on physiological outcomes for children [Campbell, 1993]. A large prospective study by Patterson, Budd, Goetz and Warwick [1993] followed children with cystic fibrosis over a 10 year period. They found that lung function declined more rapidly in children whose families emphasised personal growth. On the other hand, children who lived in families displaying balanced coping mechanisms, so that family system needs, individual needs and medical issues all received attention, experienced a less rapid decline in lung function. The authors also showed that some facets of therapy compliance
were related to these family attributes. Recent intervention studies have also supported a positive relationship between family functioning, compliance with treatment and outcome. Weinstein, Faust, McKee and Padman [1992] provided a family centred, short-term residential program for 44 children with severe and unstable asthma, unable to be managed with outpatient care. Although the study was uncontrolled, the intervention reduced subsequent hospitalisation by 91% and emergency care by 81% in a follow-up of 20 months. They also found that 70% of families had difficulty disciplining their children because responses to parental discipline (crying, coughing or hyperventilation) precipitated asthma symptoms. The association between family functioning, parental health behaviours and subsequent health outcomes for children, is not surprising. Managing a chronic disease such as asthma involves complicated decision making. Families have to anticipate the onset of symptoms and try to avoid situations which may exacerbate asthma. Once symptoms develop, decisions need to be made about treatment, whether to seek medical help and how frequently children need to be assessed. It seems plausible that family characteristics such as problem solving abilities and communication are important for the successful management of children's asthma.

Information from focus group discussions conducted with parents in the preliminary phase of this study, suggested that family factors were important when managing children's asthma. Management of the child with asthma appeared easier for parents if other family members shared responsibility for asthma management. For example,

'my wife tends to panic more than I, I'm calmer about it. I do most of the admission stuff, umm, if he needs to go in it's me that does it, and err, then we tend to share it as much as possible. My wife works nearly full time, umm and I work full time'

'if you don't have support from your husband, every time M's come here for an operation or anything, I've come all by myself......Oh he (my husband) knows and like, now he'll give him his, if I was going out and, he had to go on his nebuliser, oh I'd have to put the stuff in the nebuliser before I went
out, he’d put the mask on and give it to him, but I had to put it into the nebuliser before I went out’

Sometimes giving medications and trying to organise other family activities caused conflict for parents.

‘and she’s got to have it 15 minutes before she eats, and with everything else going on in our house, it’s just impossible to remember to give the bloody medicine, 15 minutes before she eats, you know, and it’s like, it’s a waste of time’

Because previous research supported a positive relationship between better family functioning and management of chronic childhood illness and this was supported by information obtained directly from parents, family functioning was included as an explanatory factor in the current study.

Potential Confounding Variables

Two disease-specific variables were included in the study. These were the background severity of children’s asthma and parents’ past familiarity with asthma. Parents of children with more frequent and severe asthma symptoms were hypothesised to intervene with treatment more actively because these parents may expect their children’s symptoms to progress rapidly. In contrast, parents of children with mild and infrequent symptoms may be less likely to carry out certain management behaviours in anticipation that their children’s clinical condition will not progress. Thus asthma severity was considered the major confounding variable in the relationship between psychological factors and parental management.

Parents’ familiarity or past experience with asthma symptoms and treatment regimens was expected to influence how parents manage children’s asthma. For example, parents of children diagnosed with asthma for many years, may show
differences in asthma management approaches compared to parents whose children have only been recently diagnosed. To better characterise this construct, parents’ familiarity with asthma was conceptualised to be reflected by three factors; (i) the length of time children had been diagnosed with asthma, (ii) previous participation by parents in an asthma education program and (iii) whether or not other members of the immediate family (parents or siblings) have/had asthma. A composite variable reflecting parental familiarity or exposure to asthma was included as the other potential disease-specific covariate in this study. A composite variable was used rather than the three individual variables to help reduce the total number of variables required to be entered in subsequent regression analyses. This strategy is suggested by Tabachnick and Fidell [1996] as one way of improving the power of multiple regression analyses. Parents reporting greater familiarity with asthma were specifically hypothesised to be less likely to take their children for medical assessment and seek outside advice when their children experienced symptoms of asthma.

Children’s age and gender were also included in the analyses. Parents participating in focus groups suggested that younger children were more difficult to manage for a number of reasons. Younger children cannot reliably describe to parents how they feel, they are much more likely to require assistance taking medication, they do not fully understand the need for medication and they are also more likely to fret or refuse to cooperate when they are required to take asthma medication. There is some research evidence that girls and boys are treated differently by parents during periods of illness. For example, Walker and Zeman [1992] found that girls perceived their parents to encourage illness behaviour with positive reinforcements more than boys. Therefore, parents of younger children were expected to have higher scores on the AMQ and similarly, parents of girls were expected to have higher scores than parents of boys.
Finally, socioeconomic status was included as a potential confounding variable. Several authors have suggested that the differences noted in asthma morbidity and mortality between children and adults of different racial and social groups can be explained by differences in asthma management behaviour [Anderson, Cooper, Bailey and Palmer, 1981; Bauman, Young, Peat, Hunt and Larkin, 1992; Evans, 1992; Heard et al., 1997; Mitchell, 1991]. For example, Evans suggested of families living in inner-city slum areas of the United States that, "in such an environment, many already unskilled parents become punitive or disengaged. Pressures of daily living may leave them with little time or inclination to see that children comply with medical treatment" [Evans, 1992, p. 369S].

There is some research evidence directly linking lower socioeconomic status with less active parental asthma management. For example, Clark et al. [1990], showed that mothers with a higher education and mothers who received public health benefits, were generally more involved in their children's asthma care compared to other mothers. Similar relationships have been found with other childhood illnesses. Ames, Hayden, Campbell and Lohr [1982] found that younger, less educated parents in lower-status occupations were least well informed about over-the-counter medications for treating fever and nasal congestion. Maiman, Becker and Katlic [1985] reported that mothers of higher socioeconomic status were more likely to keep over-the-counter medications available and also more likely to administer such medications to their children. This particular study used a judging panel of paediatricians to assess the appropriateness of mothers' pharmaceutical choices. Overall, the judges considered that mothers from all socioeconomic groups had poor understanding of the treatment of minor childhood ailments. However, the mothers from higher socioeconomic groups were considered to choose the best management options. Based on these previous research findings,
parents in the study sample from lower socioeconomic groups were hypothesised to be less active in managing their children's asthma (lower AMQ scores) compared to parents in higher socioeconomic groups.

MEASURES (APPENDIX VII)

The following section describes the questionnaire measures used to assess the constructs of interest in this study. All questionnaires described below are given in Appendix VII.

Parental Perceived Child Vulnerability

The Child Vulnerability Scale (CVS) is a measure of parents' perception of their children's vulnerability to medical illness [Forsyth, Horwitz, Leventhal, Burger and Leaf, 1996]. The scale is based on the theory that two situations may lead to parental perceptions of child vulnerability. The first situation is when a child is truly medically vulnerable because of illness and the second is when the parent has previously feared that the child might die. Twelve potential items were devised and piloted with groups of parents experiencing both these situations and a group of parents of children with no past or current medical condition. Eight of the 12 items were found to have maximal predictive ability. The scale has a reported internal consistency of 0.74 (Cronbach's $\alpha$). The authors have compared the CVS to scores on the Child Behaviour Checklist (CBCL) and the number of visits to physicians for acute medical problems. Statistically significant differences in these variables were found between parents scoring high and low on the CVS. These results tend to support the validity of the scale.

The CVS consists of items focusing on physical or medical vulnerability. For example, "my child gets more colds than other children I know" (item 1), "I often
have to keep my child indoors because of health reasons" (item 5) and “I get concerned about circles under my child’s eyes” (item 7). Parents respond to each item using a four point Likert scale, strongly agree to strongly disagree, scored as 0 to 3, resulting in a total score ranging from 0 to 24.

**Parental Protectiveness**

Parental protectiveness towards their children, was measured using the Vulnerable Child Overprotectiveness Scale (VCOP) [Wright, Mullen, West and Wyatt, 1993]. This questionnaire focuses on parenting constructs such as discipline, teaching skills, freedom, autonomy and communication. In contrast to the Child Vulnerability Scale, the VCOP assesses general parenting principles rather than parental perceptions of medical vulnerability. The authors generated a large pool of items and administered these to a group of parents, half of whom had a child with a physical disability and half whom did not. Parents were also rated by the child’s referring physician or day-care worker as having an overprotective or optimal parenting style. A stepwise multiple regression procedure was used to determine 28 items which had maximum predictive ability. These 28 items explained 94% of the variance in health professionals or day care worker ratings of overprotective versus optimal developmental stimulation. The coefficient $\alpha$ of the resulting scale was 0.84. Because the VCOP has only been recently developed there is a paucity of information available on the validity of the scale.

The VCOP is suitable to administer to parents of children aged from 2 to 18 years. The VCOP consists of items such as, “I think it is important for my child to learn and think for him/herself” (item 5), “If my child is unhappy, I will also be unhappy” (item 22), and “I worry about my child participating in activities which may be too exhausting” (item 24). Parents are asked to respond on a six point Likert scale how
true or false the statement is for them. The scale is anchored, extremely true to extremely untrue. Using the weightings provided by the authors, total scores range from -12 to 12. Higher scores reflect greater parental tendency to be overprotective towards their children.

**Family Functioning**

The final psychological construct hypothesised to be associated with differences in parents' management of asthma was family functioning. The Family Assessment Device (FAD) which is based on the McMaster model of family functioning was chosen to measure this variable [Epstein, Baldwin and Bishop, 1983; Miller, Bishop, Epstein and Keitner, 1985]. This questionnaire was chosen for this study because it is based on a well developed theoretical model of family functioning. This model has been used extensively in clinical settings and views families on a continuum of healthy to unhealthy functioning in six different areas; roles, problem solving, affective involvement, behaviour control, communication and affective responsiveness [Epstein, Bishop and Baldwin, 1982]. The FAD consists of six corresponding subscales and an additional, general functioning subscale.

Four of the subscales were chosen for use in this study because these areas were most closely associated theoretically with management of chronic childhood illness. The areas chosen were roles, problem solving, affective involvement and behaviour control. The dimension, roles considers the set patterns of behaviour through which family members fulfil family functions and is assessed by considering how the family allocates responsibilities and handles accountability for them. A more effective family will have clear and equitable allocation of roles and some way of assessing accountability of family members in these roles. Problem solving assesses the ability of families to solve problems, both practical and emotional.
Epstein et al. [1982] suggest there are seven stages to this process; identification of the problem, communication of the problem, development of action alternatives, decision on one alternative, action, monitoring and evaluation. Better functioning families carry out all seven stages whereas the least effective will fail to even clearly identify the problem. *Affective involvement* refers to the amount of interest family members have in each others' activities and concerns. The most effective families are characterised by empathetic involvement whereas unhealthy functioning is characterised either by a lack of involvement or enmeshed, symbiotic relationships. *Behaviour control* considers what standards the family holds and how they maintain these standards in terms of dangerous, psychological and social situations. Flexible behaviour control is considered the most effective style for families whilst chaotic behaviour control is considered the least effective. Items on each scale are answered using a four point Likert scale labelled *strongly agree, agree, disagree* and *strongly disagree*, scored 1 to 4. The subscale scores are derived by averaging the items after reversing appropriate items. Total scores for each subscale therefore range from 1 to 4, a lower score indicating more healthy functioning in that area.

The FAD has been used extensively in previous research and has well documented psychometric properties. Internal reliability coefficients were reported on a large number of families from nonclinical, psychiatric and medical samples as part of the FAD research files of the Brown University Family Research Program [Kabacoff, Miller, Bishop, Epstein and Keitner, 1990]. Alpha coefficients were, *roles* (0.57-0.69), *problem solving* (0.74-0.80), *affective involvement* (0.70-0.78) and *behaviour control* (0.70-0.73). Families attending psychiatric clinics had lower scores on the FAD for all subscales compared to medical or nonclinical families. Test-retest reliability was assessed by administering the FAD to 45 families and repeating this one week later [Miller et al., 1985]. Test-retest estimates ranged from 0.66
(problem solving) to 0.75 (roles). Miller et al. also compared scores on the FAD with scores on two other self-report family assessment measures, the FACESII and the Family Unit Inventory. Correlations between scores were very close to predictions and suggested good concurrent validity of the FAD. Finally, Sawyer, Sarris, Baghurst, Cross and Kalucy [1988] administered the FAD to 188 families in South Australia and demonstrated that the FAD could discriminate between families attending mental health clinics and families randomly selected from the community.

Asthma Severity

The severity of children’s asthma was measured using the Asthma Severity Index (ASI) [Rosier et al., 1994]. This is one of the few validated and published measures of background asthma severity available as a self-report measure. It consists of six items which ask about the frequency and intensity of asthma symptoms in the past 12 months. The six items are scored from 0 to 4 and total scores are derived by summing all items. The validity of the questionnaire was assessed by Rosier et al. [1994] by comparing scores on the ASI with markers of functional disability and burden of care. For example, scores were significantly correlated with days off school and number of visits for medical care in the past year although it should be noted that Spearman r’s were only 0.35 and 0.22 respectively. Scores were also compared to scores on a complementary measure, the Functional Status II-R of Stein and Jessop [1990]. This measures the functional status of children in the preceding two weeks and is a generic measure of health status. The correlation between the Asthma Severity Index scores and FSII-R scores was 0.30.

The major limitation of the Asthma Severity Index is that it fails to account for medications used by children. For example, children on high doses of inhaled corticosteroids may experience few symptoms, and therefore would rate as having
less severe asthma on the index. Clinically, these children would be considered to have severe asthma. This is an important point because significant true relationships between asthma severity and other variables may be obscured due to this characteristic of the Asthma Severity Index questionnaire. This methodological problem will be highlighted later in this chapter. Klinnert, McQuaid and Gavin [1997] refer to another measure or index of severity which does account for medication usage, but the items and scoring for this scale have not been published.

Parents' Familiarity with Asthma

For the purpose of this study, a composite score reflecting three facets of parental experience or familiarity with asthma was calculated for each parent using the following algorithm. Parents of children diagnosed with asthma for two years or less scored 1. Parents of children diagnosed between two years and five years ago scored 2 and parents of children diagnosed with asthma for greater than five years scored 3. Parents in focus groups said that after about two years from diagnosis they had built up considerable confidence about managing their children's symptoms. Parents who participated in an asthma education program scored 1 whilst parents who did not scored 0. Similarly, if parents or other siblings had asthma they scored 1 whilst those who did not scored 0. These three numbers were totalled to give a score from 1 to 5. This method of calculating a total score for parents' familiarity or experience with asthma was used rather than calculating a standardised z score because two of the three factors were dichotomous. An alternate approach to defining parent's familiarity with asthma would have been to undertake a factor analysis of these three variables. This approach would allow the three variables to be combined using statistically derived weights. However, as shown by Streiner and Miller [1989], the use of weighted items does not substantially change the statistical properties of the resultant new variable.
Socioeconomic Status of the Family

There are a large number of definitions of socioeconomic status, and different authors use a variety of approaches to combine separate indicators into composite scores [Spencer, 1996]. This is because simply considering one indicator such as income or education in isolation may not adequately reflect the degree of economic advantage or disadvantage experienced by a particular individual. In this study, the highest education level of both parents, the highest occupation level of either the mother or the father and the family income were recorded for each family.

Occupation was scored using the Daniel's scale of Occupational Prestige [Daniel, 1983]. This scale was developed some years ago to reflect the relative prestige of various occupations in Australia. The more prestigious occupations score lower on the scale. For example, an electrical engineer would be scored as 2.4, whilst a forklift driver would be scored as 5.9. As will be shown in the results section to follow, the three markers of socioeconomic status collected in this study were moderately correlated. Therefore, a standardised index representing parents' education, occupation and income was calculated by adding together standardised z scores for each of these variables. Analyses were undertaken using both the combined socioeconomic index and the individual variables (education, occupation and income). Because the socioeconomic status of the child and family was the critical factor under study as a marker of advantage or disadvantage, the highest scores of either the mother or father for both education and occupation were used to calculate the socioeconomic index. However, when the effect of parental education was assessed as a separate variable, the educational level of the parent responding to the questionnaire was used.
STATISTICAL APPROACH

The analyses were conducted using STATA statistical software (StataCorp, 1997). For the purpose of presenting the results, statistical significance was defined as \( p \leq 0.05 \).

1. Distributions for all variables were examined and means and standard deviations were calculated. Comparisons with Australian norms (where available) were made for variables such as family functioning and asthma severity.

2. Second, relationships between the independent variables were examined. The results of these analyses are important for two reasons. First, they may point to the presence of more complicated relationships existing between psychological, disease-related and sociodemographic variables, and parental asthma management. In addition, the presence and degree of multicollinearity in subsequent multiple regression analyses can be assessed. Normally distributed variables were analysed using Pearson’s coefficient, skewed variables were analysed using Spearman’s coefficient. Child’s gender was the only dichotomous variable and t tests were used compare differences in means of all the other variables between boys and girls.

3. The relationships between the degree of parents’ intended actions in response to their children’s asthma symptoms (AMQ subscale scores) and the nine proposed independent variables were first assessed using simple (bivariable) linear regression analyses. Next a series of multiple (multivariable) linear regression analyses were conducted. Each of the three subscales of the AMQ was treated in turn as the dependent variable. The psychological variables, parental perception of child vulnerability, parental overprotectiveness and the four family functioning subscales were entered as the first independent variable. The two disease-specific variables and the three sociodemographic variables were then
entered to each of these models to assess the contribution of each variable whilst controlling for the effect all other variables. The models assessed are shown schematically in Figure 8.1. The psychological factors were not theoretically considered to be confounders of each other, whereas the other independent factors were all potential confounders in the relationship between the level of parental intervention (AMQ scores) and the psychological factors. For each model assessed, the statistical significance of the regression coefficient was examined to determine whether an important independent association existed between dependent and independent variables. Not only were simple bivariable analyses and full rank analyses undertaken for each independent variable, but all possible combinations of independent variables were also examined. This was done to generate a range for change in adjusted $R^2$ for each independent variable. The term adjusted $R^2$ is used here to describe the variance explained by the model, adjusted for the number of variables entered in the model. This value allows for more equivalent comparisons between models with varying numbers of independent variables. The change in adjusted $R^2$ describes the incremental change in the variance explained by the model attributed to specific independent variables rather than the adjusted $R^2$ of the model as a whole. To aid interpretation of the results of this thesis, a small effect size was considered to be reflected by a correlation coefficient of about 0.1, a medium effect size by $r$ of about 0.3 and a large effect size by $r$ of about 0.5 [Cohen, 1988]. These figures translate into $R^2$ of 1%, 9% and 25% respectively. In terms of the significance of the coefficients, the conventional level of 0.05 was used to indicate statistical significance. Although the interpretation of the significance of any statistical test is somewhat subjective, these figures allowed relative interpretation of the importance of the various independent variables. In this study, variables showing both a moderate to large change in adjusted $R^2$ (i.e., over 9%) and a significant regression coefficient,
were considered to be of probable clinical or practical significance. Variables which had a significant coefficient but were only associated with a small change in adjusted $R^2$ (less than 9%) were considered to be statistically significant but were possibly not of clinical or practical relevance.

SUBJECTS
The subjects for this phase of the study were the 101 parents previously described in Chapter 4. There are no straightforward methods to determine the appropriate sample size for multiple regression analyses [Green, 1991]. The simplest rule of thumb suggested by Tabachnick and Fidell [1996] is $N \geq 50 + 8m$ (where $m$ is the number of independent variables) for testing the multiple correlation and $N \geq 104 + m$, for testing the significance of individual independent variables. These rules assume a medium size relationship existing between the independent variables and the dependent variable, an $\alpha$ of 0.05 and a $\beta$ of 0.20 (i.e., 80% power). Thus for the models proposed above, where $6$ is the maximum value of $m$, a sample size of $98$ would be appropriate to test the significance of the correlation of the full model, and $110$ to test the significance of individual coefficients. The sample size of 101 is thus adequate for the proposed analyses.

RESULTS
The first part of this section presents summary statistics for the nine independent variables. Means and standard deviations for the three subscales of the AMQ were described in Chapter 6. Bivariable relationships between the independent variables are examined. Multivariable analyses exploring the relationship between AMQ scores and the nine proposed independent variables are then presented.
Descriptive Statistics

1. *Parental perceptions of child vulnerability.*

Total scores on the CVS were derived by summing the eight items. High scores indicate that parents perceive their children as being more medically vulnerable. The frequency distribution of scores on the CVS approximated a normal distribution (Figure 8.2). The mean score for the study sample was 10.3 (S.D. = 5.32, range = 0 to 23) and there were no missing values. Forsyth et al. [1996] suggested employing a cut off point of 10 for this scale. They described a sample of 288 parents of children with no medical condition and 46 children with a chronic medical condition such as severe asthma. Only 3% of parents of healthy children had a score on the CVS of 10 or above compared to 41% of parents whose children had a medical condition. Using a cut off point of 10, 53 (53.5%) parents in the current study sample could be categorised as perceiving their child to be medically vulnerable. Although no Australian norms for this scale have been published, parents participating in the current study demonstrated a relatively high level of perceived child vulnerability.

2. *Parental protectiveness.*

Parental protectiveness was measured using the Vulnerable Child Overprotectiveness Scale (VCOP) [Wright et al., 1993]. The frequency distribution of total scores for the study sample approximated a normal distribution (Figure 8.3). Parents with high scores have a more protective parenting style. Parents with low scores have a less protective style. The mean score for the study sample was -0.43 (S.D. = 0.79, range = -2.83 to 2.17). There were no missing values for this scale.
3. Family functioning.

The Family Assessment Device (FAD) was used to measure the four relevant dimensions of family functioning, namely, roles, problem solving, affective involvement and behaviour control [Epstein et al., 1983]. Four parents missed one or two items in individual subscales. Subscale scores were generated for these parents by adding together completed items and dividing by the total number of completed items to give a comparative average. One parent missed three items in the affective involvement subscale and no score was calculated for this parent. Total scores for all four subscales of the FAD were normally distributed. Means, standard deviations and ranges for each subscale are given in Table 8.1. Low scores reflect healthy functioning in each area, high scores reflect unhealthy functioning. The scores for the study sample were compared to scores on the FAD derived from a community study of families conducted by Sawyer et al. [1988]. In this study, the FAD was completed by mothers living in metropolitan South Australia. Overall, the mean scores on the FAD subscales for the current study were similar to this comparison group (Table 8.1).

4. Asthma severity.

The distribution of scores on the Asthma Severity Index (ASI) was skewed to the right, with more children in the sample having mild asthma. Values for missing items were approximated by summing the completed items and dividing by the total number of completed items [M. Rosier, personal communication, August 1997]. Seven parents missed one item and average scores were calculated for these parents. One parent missed two items and this parent was excluded from analyses using the ASI. Using the definitions proposed by Rosier et al. [1994], children were categorised as having very mild, mild, moderate and severe asthma. According to this, 28% of children had very mild asthma, 33% had mild, 31% had moderate and
8% had severe asthma. Table 8.2 shows a comparison of asthma severity of the study sample and a large community sample surveyed in 1989 in Melbourne, Australia [Rosier et al., 1994]. Children in this sample were slightly older than the children in the study sample. There were more children in the study sample with moderate and severe grades of asthma compared to the community comparison group of children. This likely occurred because the study sample was derived from a population of previously hospitalised children.

5. Parents’ familiarity with asthma.

As previously described, for the purpose of this study, parents’ familiarity with the symptoms and treatment of asthma was assessed using three factors; (i) the length of time the child had been diagnosed with asthma, (ii) previous participation in an asthma education program and (iii) whether or not other members of the immediate family (parents or siblings) have/had asthma. The length of time that children had been diagnosed with asthma at the time of data collection ranged from 6 months to 12 years, 6 months. Only 6% of children had been diagnosed within the two years prior to data collection, 40% had been diagnosed between two and five years ago and 54% had been diagnosed greater than five years ago. Forty four percent of parents reported past attendance at an asthma education program (provided by a public hospital in South Australia or a recognised community asthma support organisation). Thirty four percent of parents reported that more than one of their children had asthma and 45% reported that they or their spouse/partner had asthma currently or had been diagnosed with asthma at sometime in the past. A composite score for ‘familiarity with asthma’ was calculated for each parent using the algorithm described previously. This variable was treated as a continuous variable. The distribution of this composite variable is given in Figure 8.4.

The children with asthma making up the study sample ranged in age from 5 years, 2 months to 13 years, 7 months (mean = 8 years, 6 months, S.D. = 2 years, 4 months). The distribution of age was slightly skewed to the left. There were 73 boys and 28 girls. This ratio of 2.61:1 in the study sample is considerably higher than reported from community samples (e.g., a male:female ratio of 1.26:1 was reported by a recent Australian study for wheeze in the past 12 months [Robertson et al., 1998]). This may reflect that boys have more severe asthma than girls and that children in the study population had more severe asthma than children in the community [McNicol & Williams, 1973].

7. Socioeconomic status.

Socioeconomic data was collected for each parent and included, parent's education, parent's occupation and family income. As outlined previously, a standardised index was derived using these three variables. A summary of the socioeconomic data is given in Table 8.3. Correlations between these three markers of socioeconomic status were high (Table 8.4). The distribution of the composite standardised score showed a relatively even spread of subjects across all scores (Figure 8.5). The composite score was used as a continuous variable in subsequent analyses. Two parents did not indicate their family income and so a score on the socioeconomic index could not be derived for these parents.

Relationships Between Independent Variables

Before undertaking regression analyses, the relationships between the three psychological variables, the two disease-specific variables and the three demographic variables were examined. All variables other than child's gender were
continuous and so correlation coefficients were used to assess the strength of the linear relationship between these variables. These results are displayed in a correlation matrix (Table 8.5).

CVS scores, reflecting parents' perception of children's vulnerability, showed moderate positive correlations with family functioning. This suggested that parents from families with unclear role delineation, characterised by being over-involved, intrusive and self-centred and with chaotic and laissez faire patterns of behaviour control, perceived their children with asthma to be more vulnerable. CVS scores were moderately correlated with asthma severity as expected, with children experiencing more frequent and severe symptoms over the preceding 12 months perceived as being more vulnerable by their parents. Younger children were perceived as more vulnerable than older children. Although the prevalence of asthma is higher in younger children, there is no evidence that asthma severity is also higher. This is supported by finding a very weak correlation between children's age and asthma severity. Younger children may be perceived as more vulnerable because of their inability to manage the illness themselves and the greater role parents play in the social and emotional lives of younger children [Minuchin, 1977]. Parents of children from lower socioeconomic backgrounds perceived their children to be more vulnerable than parents with higher income, education and occupational levels. This finding may in part be because children from lower socioeconomic families have more severe asthma [Australian Institute of Health and Welfare, 1996; Bauman, Young, Peat, Hunt and Larkin, 1992]. There was a moderate correlation between Asthma Severity Index scores and socioeconomic index scores, supporting this explanation.

Scores on the VCOP, measuring parental protectiveness were not correlated with any of the other variables. Specifically, there was only a weak, nonsignificant
correlation between VCOP and CVS scores, and between VCOP and asthma severity scores. Moderate correlations were obtained between the four domains of the Family Assessment Device. This was expected because all subscales of the FAD assess different areas of family functioning. The McMaster model of family functioning predicts that families which function poorly in one area are likely to also function poorly in other areas. Significant negative correlations were also found between socioeconomic status and family functioning. Specifically, families from higher socioeconomic backgrounds had lower scores (implying better functioning) on the roles and affective involvement dimensions.

Parents’ familiarity with asthma (incorporating the length of time the children had been diagnosed with asthma, other family members having asthma and attendance at an asthma education program) was moderately correlated with asthma severity. Children with more severe asthma may have been diagnosed at an earlier age and these parents may also have had more impetus to attend asthma education sessions. Greater parental familiarity with asthma was also positively correlated with increasing age of children. This most likely reflects the length of time children have had asthma. In general, older children will have had asthma for longer. Finally, differences in scores on psychological variables and disease-specific variables and the dichotomous variable, children’s gender was examined using unpaired t tests (Table 8.6). There were no significant differences between boys and girls on any of the variables examined.

Regression Analyses Describing the Relationship Between Psychosocial Factors and Parental Asthma Management

The following section is divided into five subsections. The first three sections focus on the three subscales of the AMQ, medical assessment, external advice and home
management. The regression analyses undertaken follow the models shown schematically in Figure 8.1. In addition, two subsidiary regression analyses were performed. The first analysis aimed to examine further, the antecedents of parental perception of children's medical vulnerability. The second subsidiary analysis was undertaken in order to separate out the individual effects of parent's education, parent's occupation and family income on parental asthma management.

1. **The medical assessment subscale of the AMQ.**

Table 8.7 shows the simple regression analyses treating the medical assessment subscale as the dependent variable. The relationships between this variable and the nine independent variables were assessed individually. Higher parental perceptions of child vulnerability were significantly associated with greater parental intention to take children to be assessed by a health professional in a range of situations. Parents with lower socioeconomic scores also reported significantly greater intention to take their children to be medically assessed. The two bivariable models testing these variables were associated with high values of adjusted $R^2$ (17% and 33% respectively). In addition, higher parental protectiveness scores (greater overprotectiveness) and higher scores on the behaviour control subscale of the FAD (lower functioning) were significantly associated with higher scores on the medical assessment subscale although the $R^2$ for these models were only small to moderate in size. Child's gender and the affective involvement subscale of the FAD showed near significant coefficients in the simple regression models. Importantly and unexpectedly, the level of asthma severity was not associated with parental scores on the medical assessment subscale.

When multiple regression analyses were undertaken, two variables, parental perceptions of children's vulnerability and socioeconomic status showed the
The strongest and most consistent association with medical assessment scores (Table 8.8). The significant relationships observed between medical assessment scores and the FAD subscales were not evident once the effects of the disease-specific and sociodemographic factors had been adjusted for. Parental overprotectiveness continued to show a near significant relationship with the medical assessment subscale. Similarly, the coefficient for child's gender was significant or near significant in five of the six models. This coefficient was negative, implying that girls were more likely than boys to be taken for medical assessment with asthma symptoms. In one multivariable model, asthma severity showed a significant relationship with the medical assessment subscale of the AMQ. However, this was most likely an effect of collinearity. That is, the previously noted moderate correlation between socioeconomic status and asthma severity may have spuriously resulted in this statistically significant association. This interpretation was supported by the fact that asthma severity was not found to be significantly associated with AMQ scores in any of the other models assessed.

Finally, Table 8.9 shows the range of all possible values for the change in adjusted $R^2$ associated with all the independent variables. Column one of this table relates to models where the medical assessment subscale is the dependent variable. The first of the two percentages in the range, represents the additional variance explained in the multivariable model by each independent variable in turn. The second percentage is the variance explained by the independent variables in the simple bivariable models. For all possible combinations of variables, parental perception of children's vulnerability and socioeconomic status explained moderate to large amounts of total variance. These variables were therefore likely to be of greatest clinical importance. Child's gender and parental overprotectiveness were statistically significant variables but may not be of clinical or practical importance, both being associated with only small changes in adjusted $R^2$. 
2. The external advice subscale of the AMQ.

Similar regression analyses were undertaken treating the external advice subscale of the AMQ as the dependent variable. The simple (bivariable) analyses are given in Table 8.10. Again, higher parental perception of children's vulnerability and lower socioeconomic status were strongly associated with scores on this AMQ subscale. These relationships remained after controlling for all other disease-specific and sociodemographic variables (Table 8.11). In addition, the variable representing parent's familiarity of asthma was significantly related to the external advice subscale in both bivariable and multivariable analyses. Parents with greater familiarity with asthma (a combination of having other family members with asthma, the child having had asthma for a considerable period of time and having attended an asthma education program) reported less intention of seeking outside assistance. Similarly the behaviour control subscales of the FAD was significantly associated with the external advice subscale of the AMQ in both bivariable and multivariable analyses. Specifically, parents reporting more chaotic and laissez faire approaches towards discipline showed greater intention to take their children to be medically assessed with symptoms of asthma. Although the roles subscale of the FAD also appeared to be a statistically significant variables in the simple regression models, this association was not sustained once multivariable models were tested.

Table 8.9 shows the range of all possible values of the change in adjusted $R^2$ associated with all the independent variables for the external advice subscale (column two). As expected from the associations summarised above, parental perception of children's medical vulnerability and socioeconomic status were the
variables contributing most to increases in explained variance for this AMQ subscale.

3. The home management subscale of the AMQ.

Higher parental perception of children's vulnerability and lower socioeconomic status were found to most strongly predict higher scores on the home management subscale in bivariable and multivariable analyses (Table 8.12 and 8.13). This result was consistent with the pattern of relationships previously found with the other AMQ subscales. In addition, child’s age was found to be significantly associated with home management scores. Parents of younger children scored significantly higher on this subscale. In the model with CVS scores entered as the primary independent variable, the regression coefficient for child’s gender was also statistically significant. However this relationship is likely to be spurious because there was no association found in the bivariable analysis nor in any of the other multivariable models tested.

The range for change in adjusted $R^2$ for the models explaining differences in the home management subscale are predictable based on the associations described above (Table 8.9, column three). Parental perceptions of children’s vulnerability and socioeconomic status explained a large amount of the variance in parents’ scores on this scale. Child’s age explained a small amount of the variance.

The independent variables which were associated with moderate to large changes in adjusted $R^2$ and those associated with small changes in adjusted $R^2$ for the three subscales of the parental Asthma Management Questionnaire are summarised in Table 8.14. Overall, higher perceptions of child vulnerability and lower socioeconomic status were the most important factors consistently explaining
parental intention for all three subscales. Importantly, parental scores on the Asthma Severity Index, reflecting the frequency and intensity of symptoms experienced by children in the preceding 12 months, were not significantly associated with any subscale of the AMQ.

4. Important predictors of parental perception of children’s vulnerability to illness.

As shown in subsections 1 to 3, parental perception of children’s vulnerability to illness was a major predictor of parental asthma management. The correlation matrix given in Table 8.5 suggested that asthma severity, child’s age and socioeconomic status were associated with parental perceptions of children’s vulnerability. To test the independent significance of these variables in explaining differences in parental perceptions of vulnerability, a regression analysis was undertaken, treating CVS scores as the dependent variable, and asthma severity, child’s age and socioeconomic status as independent variables. The four family functioning subscales were not included as independent variables because theoretically a causal relationship between family functioning and parental perception of child’s vulnerability was not postulated. The results presented in Table 8.15 showed that higher levels of asthma severity, younger age of children and lower socioeconomic status were significantly associated with higher parental perception of children’s vulnerability. When the independent effects of the respondent’s education, highest of mother’s or father’s occupation and family income were assessed, educational level of the respondent was not found to be associated with perceptions of vulnerability. Instead, occupation and income were significant predictors.
5. *Parents' education, parents' occupation and family income treated as individual independent variables.*

The socioeconomic index used in the above analyses had been formed by combining the highest of mother's or father's educational level and occupation prestige score, and family income. Because socioeconomic status was found to be such an important predictor of parental asthma management, the regression analyses were repeated but this time the markers of socioeconomic status were entered as individual variables. This was to determine which marker of socioeconomic status was of most importance as a predictor of parental asthma management. Tables 8.16 to 8.18 show the regression analyses with the *medical assessment, external advice* and *home management* subscales of the AMQ, the dependent variables respectively. Because only the relationship between these markers and parental asthma management was of interest here, the table is presented as a nested regression analysis. These analyses suggested that the education level of the parent answering the questionnaire and family income were the most important predictors of parental asthma management for the *medical assessment and home management* subscales. However, when the *external advice* subscale was examined, only the respondent's education level was a significant predictor. Parents with a lower education level showed greater intention to seek external advice, after controlling for income and occupational prestige.

**DISCUSSION**

This chapter of the thesis focused on whether differences in the level of parental intention to actively manage children's asthma (AMQ scores) could be explained by a number of psychological and social factors. The key finding was that parental perception of children's vulnerability to illness and socioeconomic status together accounted for a very large proportion of the variance in parental asthma
management. Thus psychological and social variables, not disease-specific variables were found to have the strongest relationship with parental asthma management. Psychological and sociodemographic variables were of greatest importance, irrespective of which AMQ subscale was examined. The following discussion first highlights possible explanations for the associations found and second, addresses the clinical and public health implications of these findings.

The Relationship Between Psychosocial Factors and Parental Asthma Management

The two variables which were most important in explaining differences in parental asthma management were parental perceptions of child medical vulnerability and socioeconomic status of families. Parents with higher scores on the Child Vulnerability Scale and parents with lower socioeconomic scores reported significantly greater intention to take their children for medical assessment (medical assessment subscale), seek external advice or assistance (external advice subscale) and actively manage their children's symptoms at home (home management subscale).

Parental perceptions of children's medical vulnerability and parents' asthma management.

As originally hypothesised, parental perception of child vulnerability was found to be a very significant predictor of scores on the new parental Asthma Management Questionnaire. This relationship persisted even after controlling for the background severity of children's asthma. In fact, contrary to original predictions, the frequency and severity of symptoms in the past 12 months was consistently not associated with parental asthma management in any of the analyses undertaken. Thus, it
appeared that parents' perception of their children's vulnerability to illness rather than the actual number of symptoms experienced by children, better explained differences in asthma management by parents.

The subsidiary analyses undertaken, treating CVS scores as the dependent variable, allowed a better understanding of possible pathways between the factors assessed in this study. For example, these analyses revealed a significant relationship between asthma severity scores and CVS scores ($r = 0.44$). Thus, the frequency and severity of asthma symptoms may influence parental perceptions of children's vulnerability and it is this latter factor which may then impact on parental management approaches. Although causation cannot be inferred from this study, previous research supports asthma severity being an important determinant of parental perceptions of child vulnerability. For example, a number of prospective studies have shown that the presence of a significant medical condition in children can lead to enhanced parental perception of children's vulnerability [Casey, Ludwig and McCormick, 1986; Forsyth & Canny, 1991; Kemper, Forsyth and McCarthy, 1990].

However, asthma severity accounted for only 18% of the variance in CVS scores. This implies that factors other than asthma severity influence the development of parental perception of children's vulnerability. In the current study, younger age of children was also associated with greater perceptions of vulnerability. Younger children may be perceived by their parents to be more vulnerable to illness because parents feel these children are less physically robust and less resilient to illness. In contrast to the findings of this study, Thomasgard and Metz [1997] recently showed in a community based study of 300 children, that child's age was not associated with perceptions of child vulnerability. This study also used the CVS to measure parental perceptions. This negative finding may have been because their study
used a community sample of children with presumably a low rate of previous medical conditions. The relationship between heightened perceptions of vulnerability with age may be more evident in children who have experienced a previous serious illness or hospitalisation. No other studies of child vulnerability have specifically examined the relationship between children's age and the development of parental perception of children's vulnerability.

Although a relationship between asthma severity, parental perception of children's medical vulnerability and parental asthma management may exist, there is another possible explanation for why asthma severity scores were not found to be directly associated with parental asthma management. As previously noted, the major limitation of the Asthma Severity Index (ASI) which was used to rate the background asthma severity of children, is that it does not take into account medication usage by children. Thus, some children scoring low on the scale may have had minimal asthma symptoms because they were taking high doses of preventer medications. Parents may well have considered these children to have severe asthma (despite these children having low ASI scores) and as a consequence, have had higher perceptions of their children's medical vulnerability. This group of parents may thus have reported managing children's asthma more actively on the AMQ. This process may have masked a true, direct relationship between asthma severity and parental asthma management. Of the 28 children who scored in the low category of the ASI in the current study, five children (18%) were taking regular inhaled beclamethasone or budesonide as preventer medications and one child (4%) was using sodium cromoglycate but none were using fluticasone or salmeterol. Of the 34 children scoring in the mild category of the ASI, 19 (56%) were using regular inhaled beclamethasone or budesonide as preventer medications, seven children (21%) were using sodium cromoglycate and one child (3%) was using both fluticasone and salmeterol. The use of these
Preventer medications in children scoring in the low and mild categories on the ASI suggests that the exclusion of medications in the ASI is a true and not just a theoretical limitation of this measure.

**Socioeconomic status and parents' asthma management.**

The other important finding in this study was that parents in lower socioeconomic groups had significantly higher scores on all three AMQ subscales suggesting that this group of parents have greater intention to active asthma management. The direction of this relationship was opposite to that expected from the results of previous studies. Additional analyses undertaken, suggested that both parents' education and family income were significant predictors of parental responses to the medical assessment and home management subscales of the AMQ. Only parents' education was associated with the external advice subscale once the effect of the other socioeconomic indicators were controlled for. However, some caution is required when interpreting these differences between socioeconomic markers. The three markers of socioeconomic status were moderately to highly correlated with each other and also to other variables (subscales of the FAD, asthma severity etc.) in the models examined. Multicollinearity may thus have been a significant problem in these analyses. The effect of multicollinearity is to cause unpredictable instability of coefficients and their standard errors. The pattern of significance of the variables is unique to the particular data set used for the analyses. It is therefore difficult to be confident about the relative significance levels of the regression coefficients for the individual indicators of socioeconomic status (i.e., education, occupation and income). The direction of the effect is probably more important to note because this is consistent for the three indicators of socioeconomic disadvantage. This tends to strengthen the evidence that the
relationship between lower socioeconomic status and greater levels of parental intervention is a true effect and not the result of systematic bias.

As previously noted, one explanation given in the literature for the excess asthma morbidity and mortality experienced by children and adults from lower socioeconomic groups is that these groups are less active in managing asthma [Anderson, Cooper, Bailey and Palmer, 1981; Evans, 1992; Heard et al., 1997; Mitchell, 1991]. However, very few studies have directly assessed this relationship which may have led to incorrect interpretation of findings. For example, the recent study by Heard et al. [1997] reported that there were greater numbers of readmissions for adult asthma at one metropolitan hospital in Adelaide compared to another hospital. The hospital with a higher readmission rate is situated in a less privileged area of Adelaide compared to the other hospital which had a lower asthma readmission rate. These findings were interpreted as support that adults living in lower socioeconomic areas were less competent at managing asthma. However, it is equally plausible that the economically and socially disadvantaged patients actually experienced more severe asthma which was more difficult to control despite appropriate drug therapy and self-management.

Clark et al. [1990] undertook a study in the U.S. to directly assess the number of asthma management behaviours used by mothers. They found that better educated mothers and mothers eligible for Medicaid used greater numbers of asthma management behaviours compared to less well educated mothers and mothers without health insurance. Other studies from the United States have shown that parents living in poverty were more likely to use emergency services rather than general practitioners for acute management of their children’s asthma symptoms [Halfon & Newacheck, 1993]. Superficially, these results appear to be supported by the results of the current study, where parents of lower
socioeconomic status scored higher on the *medical assessment* subscale of the AMQ. However these parents also scored higher on the two other subscales; the *external advice* subscale, which describes calling for advice from relatives, friends etc., the hospital, a locum doctor or the ambulance service and the *home management* subscale, which describes active monitoring and treatment of children at home. Thus, parents in lower socioeconomic groups exhibited a pervasive tendency to greater levels of activity when managing children's illness. They did not appear to be simply over-using hospital services at the expense of initiating more active home management.

Socioeconomic status, is a complex construct and refers variously to levels of income, occupation and educational achievement. Parents of different socioeconomic groups may hold different beliefs about health and illness and it is likely that differences in these attitudes and beliefs between socioeconomic groups determine the level of parental intervention. For example, the current study showed that a highly significant relationship existed between higher CVS scores and lower socioeconomic status. An indirect pathway between socioeconomic status, parental perceptions of vulnerability and parental asthma management may well exist. When parent's education, occupation and income were analysed separately, parent's occupation and income were found to have the strongest association with parental perceptions of children's medical vulnerability (Table 8.18). The educational level of parents completing the questionnaire was not found to be associated with parental perceptions of child vulnerability to illness once the effects of occupation and income had been controlled for. Although, the study by Perrin, West and Culley [1989] using the Child Vulnerability Scale found that mothers with more education perceived their children as more vulnerable to illness, other studies have shown a reverse relationship. For example, Thomasgard and Metz [1997] reported that lower family socioeconomic status and less parental education were
associated with greater parental perceptions of child vulnerability. Similarly, a study conducted in the UK reported that patients from social classes IV and V, attending general practitioners perceived themselves to be more ill than patients from higher social classes [Martin et al. 1991]. One obvious explanation for these findings is that people living in impoverished circumstances genuinely experience more ill health. For example, there is good evidence that children from poorer backgrounds living in developed countries experience higher rates of respiratory infections, developmental delay and emotional and behavioural problems [Dowding & Barry, 1990; Campbell, 1995; Spencer, Logan, Scholey and Gentle, 1996]. Differences in rates of these conditions may explain why parents of lower socioeconomic status had higher perceptions of their children's medical vulnerability even after controlling for the level of asthma severity. However, there was no significant difference in socioeconomic index scores for children involved in the current study, with a past or current history of another chronic illness (including, eczema, prematurity, behavioural problems, neurodevelopmental delay and ear, nose and throat disorders), compared to children without these problems (Table 8.19). This may have been because of the small sample size or that a complete history of past acute and chronic illnesses for children in this study was not obtained.

However, visiting parents individually at home during the data collection phase of the current study, provided further insight into why parents in lower socioeconomic groups may perceive their children to more medically vulnerable. It appeared that parents of lower socioeconomic status may more readily acknowledge the presence of illness in their children compared to parents from higher socioeconomic groups. In fact, in these economically poorer families, where lack of material resource and education were the norm, ill health of family members appeared to be accepted as the rule rather than the exception. In contrast, advantaged families were more successful in terms of social, educational and monetary achievements. It may be
possible that these parents expect the same success in terms of physical health and wellness of family members. Such sociological differences may explain why parents with lower socioeconomic status had higher ratings of perceived medical vulnerability for their children, even after adjusting for differences in asthma severity.

Even though part of the association between socioeconomic status and parental asthma management may be explained by parental perceptions of child vulnerability, socioeconomic status was associated directly with asthma management after controlling for CVS scores. One possible factor which may account for differences in management between different socioeconomic strata may include parents' sense of confidence about managing asthma. For example, parents in lower socioeconomic groups, particularly parents with less formal education, may be less confident about their ability to manage their children's asthma thus explaining their higher scores on the medical assessment and the external advice subscales of the AMQ. However, these parents also rated more highly on the home management subscale, reflecting a greater intention to monitor and treat children in the home environment. This argues against the importance of parental sense of confidence. The role of parental confidence was not specifically examined in this study but could have been assessed by including a measure of parental self-efficacy in the series of questionnaires given to parents.

The socioeconomic differences observed in parental asthma management may also be influenced by differences in the way doctors and other health professionals counsel parents about asthma management and child health. For example, health care professionals may perceive parents in higher socioeconomic groups to have greater competence to manage their children's illness and therefore doctors may place less emphasis on the seriousness of childhood asthma when counselling
these parents. On the other hand, health care professionals may stress to parents from lower socioeconomic groups the potential dangers of asthma and the importance of seeking professional help when their children have symptoms. There is some evidence from other areas of health research that socioeconomic factors can influence the way doctors communicate with patients. For example, Martin et al. found that general practitioners perceived that they listened, examined and gave advice less to social classes IV and V compared to higher social classes [Martin et al., 1991]. Similarly, Taira, Safran, Seto, Rogers and Tarlov [1997] showed that doctors discussed diet and exercise more with high income patients than low income patients and the reverse relationship was found with doctor directed discussions about smoking. Waitzkin [1984] showed that patients who were less educated and of lower social class were given less information by doctors about their condition and treatment even though all patients had the same desire for information. Although no previous study has looked specifically at how doctors communicate qualitatively and quantitatively with parents of different social class, it seems plausible based on the cited studies and the results of the current study, that doctors may stress the implications of asthma differently to parents of different social backgrounds.

Finally, in terms of explaining why lower socioeconomic status was strongly associated with greater intention to active asthma management in the current study, the possibility of social desirability bias cannot be ruled out. Parents with lower incomes, occupational status and education may be more likely to answer the AMQ in a socially desirable way. This type of bias may have been more pronounced in this study because the person undertaking interviews with parents was a medical doctor. A 'social desirability' question ('give your child inhaled tobramycin') was included in the first draft of the AMQ and only two parents positively endorsed this item. In addition, to further explore this explanation, the
relationship between real-life asthma situations described in Chapter 7 and socioeconomic status was examined using regression analysis. Reports of real-life situations by parents may be less affected by social desirability bias than responses to the AMQ because these reports describe actual behaviour undertaken. As previously explained, only a score on the subscale home management could be computed because of the small number of parents experiencing situations in the past month. Socioeconomic status was found to be a statistically significant independent variable of the home management subscale derived from reports of real-life situations \((p = 0.05)\). Socioeconomic status explained 26% of the variance in parents' behaviour. This suggests that even when parents' behaviour is assessed in real-life asthma situations, parents in lower socioeconomic groups are more active at managing children at home compared to parents in higher socioeconomic groups. Although the presence of social desirability bias cannot be excluded particularly in the other subscales, it seems likely that a true relationship exists between lower socioeconomic status and greater parental intervention.

**Family functioning and parents' asthma management.**

The behaviour control and the roles subscales of the Family Assessment Device was associated with the external advice subscale of the AMQ. Specifically, parents from families with more chaotic and laissez faire approaches to behaviour management and poorly delineated family roles showed greater intention to telephone for help or assistance when their children had symptoms of asthma. Families characterised by few rules and regulations may be less able to make independent decisions about management when confronted with an ill child. Conversely, these parents may be less inhibited about calling on assistance from others when an emergency arises in the family. Families with very rigid rules appeared less likely to seek outside help. These families may have a greater ability
to sort out problems within the family. Alternatively, these families may feel less comfortable about including people outside the family in decisions relating to children's health or perhaps are less willing to admit to lack of expertise. Overall however, family functioning did not show a strong relationship with parental management approaches. The problem solving and affective involvement subscales were not significantly associated with any aspect of parental asthma management.

**Parental protectiveness and parents' asthma management.**

Parental protectiveness as measured by the Vulnerable Child Overprotectiveness scale, was not strongly associated with any of the three asthma management subscales. Only a weak relationship was found between parents scoring higher on this scale and the medical assessment subscale of the AMQ. General parenting style (i.e., an overprotective style) appeared of less importance in explaining differences in parental behaviour than attitudes that parents hold about their children's susceptibility to illness. This is consistent with findings of a recently published study of Thomasgard and Metz [1997]. This study examined the relationship between parental overprotection and perceived child vulnerability. Although these authors did not use the VCOP scale to measure parental overprotectiveness (instead they used the Parent Protection Scale [Thomasgard, Metz, Edelbrock and Shonkoff, 1995]), they did use the CVS to assess parental perceptions of child vulnerability. The correlation between parental overprotection in this study, and CVS scores was only 0.17. This was consistent with a correlation of 0.13 found between VCOP scores and CVS in the current study. Thus, parental overprotectiveness does not appear to be equivalent to heightened parental perceptions of children's vulnerability to illness. The results of the current study
confirm that parental overprotectiveness does not significantly influence parental approaches to chronic disease management.

**Parents' familiarity with asthma and parents' asthma management.**

Apart from parental perceptions of child vulnerability and socioeconomic status, three other factors were of relative importance in explaining differences in parental scores on individual subscales of the AMQ. Parental familiarity with asthma was negatively associated with the *external advice* subscale. Parents who reported having attended an asthma education program, whose children had asthma for a longer period of time and/or had other children or close family members with asthma, were less likely to telephone relatives, friends, doctors or hospitals for advice when their children had asthma symptoms. This finding supports the validity of the *external advice* subscale of the AMQ because one would expect that parents with greater familiarity with asthma would have less need to seek advice from those outside the immediate family.

**Children's age and gender, and parents' asthma management.**

Children's age was a significant factor in explaining differences in the *home management* subscale of the AMQ. Parents of younger children showed greater intention to monitor children closely, check children's temperature and administer cough and flu medications for coryzal and asthma symptoms. This result supported the findings of the focus group interviews conducted in the pilot phase of this study. Younger children are less able to describe physiological sensations to parents, less able to reliably interpret the meaning of symptoms and considerably less likely to be able to self administer asthma medications. Younger children may also get sicker faster because they have less physiological reserve. Parents of younger children
probably have to assess children more frequently and have to rely more on physical signs than verbalised symptoms when assessing these children. Older children are probably given more responsibility for their own asthma management within the home environment. However, children's age was not a significant factor when behaviours requiring greater parental effort (such as taking the child to hospital or to the GP) were examined using the medical assessment and external advice subscales. This probably reflects the fact that parents do not involve children in making decisions about these types of behaviours, irrespective of the age of the children.

Finally, parents showed some differences in their approaches to managing asthma symptoms depending on whether the index child was a boy or a girl. In the current study, parents reported greater intention to take girls to be medically assessed with asthma symptoms compared to boys. One other study has shown that girls who are unwell are treated differently by their parents compared to boys [Walker & Zeman, 1992]. Previous studies have suggested that preadolescent boys experience more significant asthma symptoms than girls although in this study, there was no difference in asthma severity by gender [McNicol & Williams, 1973]. No difference in parental perceptions of child vulnerability were found between girls and boys. The reason for parents showing greater intention to active asthma management in girls compared to boys is not entirely clear. This finding may reflect more general differences or biases in the way parents interact with their children of different gender.
Implications of These Findings

Clinical implications.
Although the focus of this study was measuring all asthma management behaviours relevant to parents, the clinician is primarily interested in what constitutes better or worse management. This issue needs to be clarified before the clinical implications of the results can be discussed. Better or worse management can only be defined if the outcome of children with asthma is known. This study has not attempted to measure outcomes for children primarily because of the cross-sectional study design. Causal effects between parental management and children’s health outcomes require collection of longitudinal data. The Asthma Management Questionnaire measures degree of parental intervention. Extreme levels of parental intervention may result in very good control of asthma symptoms but children may be severely limited in their participation in day to day activities and may have worse psychological and social functioning. On the other hand, very low levels of parental intervention may result in children experiencing chronic asthma symptoms and more severe and prolonged acute attacks of asthma. These children may also be at potential risk of death from asthma if parents do not recognise and treat severe symptoms. Although this study cannot determine which type of parental management is the most beneficial for children, clinicians may consider that over treatment is better than under treatment as the latter can be associated with failure to recognise and treat severe, potentially fatal asthma attacks.

Despite the fact that this study has not demonstrated whether more or less active parental management is better for children with asthma, the results of this study have important implications for clinicians. Because there are large differences in how parents manage children’s asthma and these differences do not depend on the
background severity of children's asthma, clinicians and asthma educators may
need to modify their approach to counselling parents based on other parameters.
Parents that tend towards less active treatment of children's asthma are
classified by being in higher socioeconomic groups and having lower
perceptions of their children's vulnerability to illness. The clinician needs to assess
whether parents from higher socioeconomic groups who appear to be outwardly
confident in their ability to manage children's asthma are in fact under-playing or
denying the presence of significant asthma symptoms in their children.

In contrast, parents who may be comparatively over-responding to their children's
asthma symptoms are classified by being from lower socioeconomic groups
and having heightened perceptions of their children's vulnerability to illness.
Although this study cannot determine why some parents develop a heightened
sense of child vulnerability, one plausible explanation is that clinicians have
stressed the potential severity of childhood asthma to this group of parents. The
role of this factor has been specifically assessed by Casey, Ludwig and McCormick
[1987]. They undertook a controlled intervention study to try to reduce parental
concern over minor head trauma. Although the study did not report a significant
reduction in parental anxiety by providing greater physician reassurance in the ER,
this may have been because the number of subjects was too small or in fact that
the intervention itself made the parents more anxious. The intervention may have
been more successful if a subgroup of parents (e.g., parents in lower
socioeconomic groups), had been targeted. The current study showed that parents
in lower socioeconomic groups not only tend towards greater levels of intervention
but perceive their children as more medically vulnerable. These findings may have
arisen because doctors have systematically placed greater stress on the
implications of childhood asthma when counselling parents in lower socioeconomic
groups compared to those in higher socioeconomic groups. A practical example
supporting the presence of this type of bias in clinical medicine is demonstrated by a recent emergency medicine handbook for doctors published in Australia. Guidelines are given to help emergency room doctors decide whether to admit children to hospital. As well as including physiological parameters as indications for hospital admission, “poor home situation: parents not familiar with asthma treatment, lower socioeconomic status etc.” was given as a particular reason to admit children with asthma to hospital [Browne, Choong, Gaudry and Wilkins, 1997, p.76]. The results of the current study clearly show that health care professionals should not assume that parents in lower socioeconomic groups are less competent and less active in asthma management nor less likely to attend to significant symptoms in their children. In fact these parents may have inherently lower self confidence in their ability to manage children’s asthma and this lack of confidence may be being inadvertently reinforced by medical professionals.

**Implications for asthma education programs.**

A large number of specific educational programs have been conducted in Australia and elsewhere in a variety of settings and using many inventive modalities. Some studies have aimed to increase parents’ and children’s knowledge about asthma, whilst others have aimed to increase the asthma self-management behaviour of parents and children. Although most programs have realised short term improvements in some outcomes, a recent meta-analysis of randomised control trials published between 1970 and 1991 suggested that these interventions had not reduced school absenteeism, emergency room visits, hospital admissions, asthma attacks nor lengths of hospital stay [Bernard-Bonnin, Stachenko, Bonin, and Rousseau, 1995]. One possible explanation for the lack of reduction in school absences and visits to the emergency room is suggested by the results of the current study. Some programs may have raised parental concern about asthma,
heightened parent's sense of children's vulnerability and these parents may have subsequently become more interventionist in these specific areas of management. Previous studies have assessed the family, child and health professional factors which seem to predispose parents developing heightened perceptions of children's vulnerability. However, although these factors are useful for individual clinicians treating individual children, it would be very useful to know if wider sources of information influence parental perceptions of vulnerability. For example, we do not know whether parents who have attended asthma education programs and are therefore more knowledgeable about asthma and the treatment of asthma develop higher levels of concern about their children's asthma. We also don't know whether reports in the media of near fatal or fatal attacks of asthma in children, change parental perception of children's vulnerability and hence, parental behaviour.

The current study suggests that parental perceptions of children's vulnerability rather than the level of severity of children's asthma, best predicts the level of intervention parents intend to make in regard to children's asthma. This is very important because, unfocused attempts to increase public recognition and awareness about asthma may lead to enhanced parental concern and consequent increased use of health services despite the severity of children's asthma symptoms remaining constant. If the aim of asthma education initiatives is to reduce health service use then these programs need to focus on parental decision making, reassurance, enhancement of parents' self-confidence and self-reliance. One caution however is required. The current study found that parents who intended to be highly active in one area (e.g., home management), also intended to be highly active in other areas of asthma (e.g., taking their children for medical assessment). Therefore, if education programs aim to increase the level of activity of parents in terms of home management behaviours, behaviours in the other areas of management (calling for external advice and taking children for medical
assessment) may also increase. Until prospective information is available to allow a better understanding of the impact of these specific parental behaviours on health outcomes for children (asthma symptoms, attacks, and quality of life), it is very difficult to determine whether it is wise to try to increase or decrease parental asthma management activity.

Finally, the parental Asthma Management Questionnaire, as well being a measurement tool, may be potentially useful for teaching parents about asthma management. For example, the use of common hypothetical situations, could allow health care professionals and parents to focus together on specific action pathways. This would allow parents the opportunity to think through what they would do if the situations should arise with their children and discuss with health care professionals possible ways of dealing with these situations. This approach to asthma education has advantages over giving parents general information about asthma and is analogous to the problem based learning model currently adopted by medical educationalists for undergraduate and postgraduate teaching. The information given to parents would be relevant to their own children and their own social and family circumstances and may be more likely to be remembered by parents if it is imparted in the context of specific asthma problems.

Public health implications.

The results of this study also have broader implications in terms of public health policy. These implications relate specifically to the causal debate relating to the discrepancies in health which continue to exist between advantaged and disadvantaged individuals in developed societies. Considerable evidence exists that people living in poverty in developed nations including Australia, experience significantly higher rates of morbidity and mortality [National Health Strategy, 1992;
Jolly, Nolan, Moller and Vimpani, 1991. Probably the most comprehensive publication describing and analysing this relationship was the Black Report which was undertaken in the late 1970's in the United Kingdom [Townsend & Davidson, 1982]. This report offered four explanations for the inequalities in health outcomes noted between socioeconomic groups in developed countries. In brief, the four explanations were, the artefact hypothesis, the selection/mobility hypothesis, the behavioural/cultural hypothesis and the structural/materialist hypothesis. The artefact hypothesis suggests that differences in health outcomes for children and adults living in disadvantaged circumstances simply reflect artefacts in the measurement of poverty and socioeconomic status. The social-selection argument suggests that people with poorer health naturally gravitate to lower social positions because of their ill health. The behavioural/cultural explanation argues that differences in health are a direct result of people in lower socioeconomic groups adopting unhealthy or risky behaviours such as smoking, over-eating and leading a sedentary lifestyle. The behaviouralist perspective has been the paradigm on which much medical research and current health promotional activity has been based. This explanation has had a major impact on health care policy in the UK and probably also in other developed countries. Finally, the structural/materialistic model argues that socioeconomic differences in health arise because of inequalities in resources and opportunities inherent in the structure of our societies. This argument suggests that individuals have little control over their life circumstances and therefore, for differences in their health.

At the time of the Black report, limited data was available on which to gauge which explanation was the major determinant of the inequalities in health. However, the report specifically recommended that a total and not merely a service orientated approach to health reform be taken, and that a radical overhaul of resource allocation was needed in the United Kingdom. Unfortunately the government in
office at the time, largely ignored the policy implications of the document. Over the last 10 years, many more studies have been undertaken and the results of these have been summarised by Spencer [1996] and by the National Health Strategy [1992]. Spencer suggests that the major debate is now focused on whether behavioural or structural/material factors significantly explain differences in health outcomes between different socioeconomic groups. Much medical research and health promotional activity has focused on trying to change behaviour which is known to result in worse health outcomes. For some behaviours, such as cigarette smoking, there is clearly good evidence that cessation of the risky behaviour results in improved health. However, in other areas, the relationship is not so straightforward. For example, in terms of medical compliance, health outcomes are expected to improve once compliance to medical therapy is assured. However, as described in Chapter 2, the few studies which have directly assessed long term health outcomes and compliance behaviour have shown a weak correlation between these two variables [Hays et al., 1994].

Recently, specific studies have been designed to test whether social inequalities in health are in fact the result of a higher prevalence of risky behaviours amongst those in lower socioeconomic groups. For example, Lantz et al. [1998] investigated the impact of education, income and health behaviours on the risk of dying in the next 8.5 years in a large prospective study conducted in the United States. They showed that even when analyses controlled for smoking, alcohol intake, body weight and level of physical activity, there was still a considerably greater risk of death in the lowest and middle income groups (hazard rate ratio, 2.77 and 2.14 respectively) compared to high income groups. The authors suggested that attention to deleterious environmental exposures, addressing inequities in health services and research into the differences in complex psychosocial variables (social
support, stress etc.) between socioeconomic groups would have a much greater impact on health outcome differentials than targeting risk behaviours.

The study undertaken in this thesis lends considerable support to the environmental/structural explanation. Parents of children with asthma from lower socioeconomic groups demonstrated significantly greater levels of intervention in dealing with their children’s asthma. This finding was directly opposite to that originally hypothesised based on a review of the available literature [Ames, Hayden, Campbell and Lohr, 1982; Anderson, Cooper, Bailey and Palmer, 1981; Bauman, Young, Peat, Hunt and Larkin, 1992; Clark et al., 1990; Evans, 1992; Heard et al., 1997; Maiman, Becker and Katlic, 1985; Mitchell, 1991]. Parents in lower socioeconomic groups, whether defined by income, occupation or education were more likely to be active in monitoring and treating their children with asthma and appeared to be much more likely to take them for medical assessment compared to parents in higher socioeconomic groups. If children in disadvantaged families experience greater asthma morbidity in Australia, then it is possible that other factors such as children living in relative poverty experiencing higher levels of deleterious environmental exposures, explain these differences.

**SUMMARY**

This chapter has focused on examining the relationship between psychosocial, disease-specific and demographic variables. In all analyses undertaken, parental perception of children’s medical vulnerability and socioeconomic status consistently showed the strongest association with parental asthma management. The background level of asthma severity was not associated with parental management. These findings have implications not only for clinicians but for health professionals designing asthma education initiatives. In addition, the findings suggest that
differences in asthma morbidity experienced by children from different socioeconomic groups is not due to undertreatment of asthma by parents of lower socioeconomic status.
CHAPTER NINE

CONCLUSIONS

OVERVIEW

This thesis describes the development of a new questionnaire designed to measure parental approaches to asthma management. Hypothetical scenarios were employed in the questionnaire to assess the degree of intervention or action intended by parents when their children have symptoms of asthma. An exploratory factor analysis suggested that the items comprising the questionnaire reflected three underlying latent factors or constructs. The *medical assessment* factor reflected parents' level of intention to have their children medically assessed, the *external advice* factor reflected parents' level of intention to seek outside assistance from knowledgeable others and the *home management* factor reflected parents' level of intention to treat and monitor their children in the home environment. Parental responses to the questionnaire were assessed at two points in time and the subscale scores demonstrated good test-retest reliability. The validity of the questionnaire was assessed by demonstrating that parental responses on the questionnaire were correlated with parental reports of their behaviours in recent real-life asthma situations. Furthermore, AMQ subscale scores showed significant associations with health care utilisation by children and with the number of days children had been kept home from school because of asthma.

Parental responses to the AMQ demonstrated that a large amount of variation existed between parents in their approaches to managing children's asthma symptoms. Lower socioeconomic status and higher parental perceptions of children's medical vulnerability were found to be the most important variables
explaining differences in parental asthma management. The level of severity of children's asthma was not associated with the degree of parental intervention measured using the AMQ. The results of this study therefore suggest that attitudes and beliefs held by parents are of much greater importance in predicting levels of management activity than are the number of symptoms actually experienced by children. One possible causal pathway consistent with these findings is that the level of asthma severity impacts on parental perception of children's vulnerability and it is this latter factor which most strongly predicts parents' behaviour. This study also found that parents of lower socioeconomic status perceived their children to be more medically vulnerable after controlling for the level of asthma severity. This heightened concern about the vulnerability of children by parents in lower socioeconomic groups may reflect the fact that these families more readily acknowledge illness and poor health in family members. Parents from higher socioeconomic groups may be more likely to under-play or deny the presence of significant illness in their children. Parents of lower socioeconomic status may also be less confident in their own ability to manage children's asthma and thus report greater intention to have their children medically assessed or call others for advice when children experience asthma symptoms. Finally, it is possible that health care providers emphasise the serious nature of asthma more strongly to parents from disadvantaged families and treat children from lower socioeconomic families differently to children from higher socioeconomic backgrounds. This may also explain why parents from lower socioeconomic families showed greater intention to actively manage children's asthma.

STRENGTHS AND LIMITATIONS OF THE STUDY

This study has a number of strengths. First, asthma management was assessed from a parental perspective. This was achieved by including behaviours in the
questionnaire that parents considered to be important. Focus group and individual interviews were undertaken with parents of children with asthma prior to devising items in order to obtain information about these behaviours. In addition, the scoring of the questionnaire was not based on whether parental responses approximated an appropriate asthma management plan as defined by health care providers. Instead the questionnaire was simply scored in terms of the strength of parents' intentions to undertake the behaviours listed in the questionnaire. The questionnaire therefore reflected the level of parental intervention or activity in terms of undertaking management behaviours when their children develop symptoms of asthma. To enhance the interpretation of the questionnaire and assess the role of underlying constructs or factors, an exploratory factor analysis was undertaken. The results of this analysis suggested that items in the questionnaire represented three distinct latent factors or constructs. By adopting a parental perspective in this study, a number of positive associations between parental asthma management and key psychosocial factors were found. These associations may have been masked if a more judgemental approach to scoring the questionnaire had been adopted.

The second strength of this thesis was that parents' behavioural intention was measured. Many previous studies have assessed indirect markers of parental management such as the number of hospitalisations, visits to the general practitioner and the emergency room and absences from school for asthma. However, these variables can be influenced by factors such as accessibility (e.g., availability of transport, hours of business), health care structure (e.g., inequitable access for insured and uninsured patients) and education department policy (e.g., whether teachers are willing to administer asthma medications). Therefore, as Clark and Starr-Schneidkraut noted, "management is behavior, and it is the behavior that must be measured" [1994, p.s56]. Although behavioural intention is
not the same as actual behaviour, data about what parents had done in previous asthma episodes was also collected in the current study. This procedure demonstrated a significant relationship between actual behaviour and behavioural intention which was expected on the basis of previous theory and research [Kaplan & Simon, 1990; Triandis, 1979].

Other studies which have attempted to measure parents' asthma management directly have been limited because the behaviours measured have not been assessed in the context of specific asthma situations [Clark, Feldman, Evans and Duzey, 1986; Evans, Clark et al., 1987; Fish, Wilson, Starr-Schneidkraut, Loes and Page, 1992; Hindi-Alexander & Cropp, 1984; Mesters, Pieterse and Meertens, 1991; McNabb, Wilson-Pessano, Hughes and Scamagas, 1985; McNabb, Wilson-Pessano and Jacobs, 1986; Taggart, Zuckerman, Sly, et al., 1991; Wilson, Mitchell, Rolnick and Fish, 1993]. This has meant that although a number of typologies of asthma management behaviours have been generated there has been little information available about how often or in which situations parents use various behavioural approaches. The current study utilised hypothetical scenarios in order to standardise asthma situations between parents.

One further positive feature of the new questionnaire is that the AMQ is a pencil and paper tool. It can therefore be easily and cheaply used in future epidemiological studies including studies where survey mail-outs are necessary. Two of the published measures of parental asthma management used semi-structured interviews and the administration and scoring of these measures require intensive training of interviewers [Klinnert, McQuaid and Gavin, 1997; Taylor et al., 1991].
As well as having a number of strengths, the study also has a number of limitations. The first is that the majority of the data collected thus far using the new questionnaire is cross-sectional. One implication of this limitation is that it is impossible to tell whether causal relationships exist between the psychosocial, disease-specific and demographic factors assessed and parental asthma management. Although it is difficult to imagine how greater levels of parental intervention could influence parental perception of children's vulnerability or the functioning of the family, and it is obviously nonsensical to hypothesise that parents' management influences age or gender of children, the variable, asthma severity is problematic. Although, the background severity of children's asthma may have influenced how parents manage children's asthma, more active management of the individual child may have reduced the number of asthma symptoms. Asthma severity is therefore not only an explanatory variable but also an important outcome variable. To truly assess the strength and direction of the association between the severity of children's asthma and parental asthma management, children and parents would need to be followed over time.

The other important implication of using cross-sectional data is that the relationship between parental behaviours and health outcomes for children with asthma could not be defined in this particular study. Although information was collected about previous use of health services for asthma by parents (see Chapter 7), it was impossible to draw conclusions about cause and effect. Longitudinal data would be required, ideally including information on physiological status, quality of life, level of symptoms, changes in medication requirements and health service utilisation.

The second limitation was that the sample of parents used to assess the psychometric properties of the AMQ and to explore the relationship between psychosocial factors and the AMQ, were derived from a sampling frame of
previously hospitalised children. This ensured that all children in the study had been assessed by a hospital paediatrician and therefore had been clinically diagnosed with asthma. However, the use of a hospital sample has limited the generalisability of the results. For example, the results may not apply to children from a community sample with less severe grades of asthma. Parents of children who have been hospitalised may have received more intensive asthma education compared to parents of children without a previous admission and this may have led to differences in parental asthma management. The parents who participated in the study may also have perceived their children to be more medically vulnerable because their children had been previously hospitalised compared to parents of children who had never been hospitalised. In addition to effects on generalisability, referral patterns and admission practices may have biased the results of the study. For example, parents who were highly interventionist and who also perceived their children as very vulnerable may have had a greater chance of their children having a hospital admission compared to parents who also perceived their children as more vulnerable but were not interventionist. This situation would have led to a falsely significant relationship being found between parental perceptions of vulnerability and parental asthma management. Such bias cannot be discounted until community samples of parents and children are studied.

FUTURE DIRECTIONS

The next logical step in evaluating the AMQ would be to conduct a longitudinal study to assess the relationship between parental asthma management and important health outcomes for children. Ideally, subjects would be enrolled by first screening a population sample of children for symptoms of asthma. This would overcome potential biases associated with clinic or hospital samples. The AMQ could be administered to parents of these children and this could be repeated at
one or more occasions over time. In addition, baseline asthma severity level and current medications could be recorded. Outcomes of interest would include children's quality of life, change in asthma symptoms including the number and severity of acute attacks, use of health care services such as the general practitioner, hospital emergency departments and number of hospitalisations, and days kept home from school.

The number of subjects available for the factor analysis conducted in this thesis was somewhat smaller than that recommended. Although the correlation coefficients between items were generally quite high and only a small number of factors (i.e., three) were generated, the proposed factor structure of the AMQ should be confirmed with larger sample sizes. This would ideally be done using confirmatory factor analysis. Again, it would be useful to undertake such analyses using a community sample rather than a hospital sample of children to ensure that the underlying factor structure of the AMQ was the same irrespective of which group of parents completed the questionnaire.

Another area of potential research could focus on further delineating factors which increase or decrease levels of parental intervention in terms of children's asthma management and/or levels of parental perception of children's vulnerability. For example, it is plausible that media reports of near-fatal or fatal episodes of asthma in children may have considerable impact on parental behaviour. One previous study suggested that concerns that parents have about their children may be heightened by news media reports [Stickler, 1996]. Specific asthma education programs may increase or decrease parental asthma intervention in addition to increasing parents' knowledge or awareness about asthma. This is an important area of future research because it may explain why some education programs
which have been evaluated in terms of health care service use have been found to be equivocally effective.

Another area that has been little researched to date is the qualitative nature of the doctor-parent relationship. Although there are some studies addressing certain communication aspects of this relationship, little is known about which parental characteristics influence how parents are counselled about the management of their children. There is a paucity of information about whether elements of the doctor-parent relationship can enhance parental perceptions of children's medical vulnerability and whether socioeconomic and educational characteristics of parents influence the nature of this relationship. This area could be assessed for example, by using standardised patients such that patient characteristics could be modified in a controlled fashion. Video recordings of doctor-patient interviews could then be made and later analysed in terms of potential biases on behalf of participating doctors.

The Asthma Management Questionnaire has a potential role in evaluating the impact of new asthma education programs for parents. In addition, although the new Asthma Management Questionnaire was designed to assess parents' behavioural intention, it may also prove to be a useful educational tool. As previously noted, the use of hypothetical scenarios may be an effective way of discussing management options with parents of children with asthma.

This thesis has highlighted that there is a paucity of information about socioeconomic differences in the prevalence and severity of asthma in children in Australia. If parents in lower socioeconomic groups are more likely to bring their children to hospital with asthma symptoms compared to other parents then a socioeconomic gradient in asthma prevalence may be spuriously found if hospital
separation data is used. Large, population surveys in Australia have generally relied on postcode as a marker of socioeconomic status [e.g., Volkmer, Ruffin, Wigg and Davies, 1995]. This is an indirect measure of disadvantage and ideally, questions pertaining to education, occupation and family income should be asked of each participant in the study. If it appears that true differences exist in asthma prevalence or severity by socioeconomic status in Australian children, the causes of such a difference are potential research questions. The results of the current study suggest that differences in parental behaviour are unlikely to explain differences in asthma symptoms experienced by children of different socioeconomic status. Other variables including differences in housing, nutrition, environmental pollutants, respiratory infection rates and exposure to passive smoking may explain differences in asthma prevalence and/or severity between different socioeconomic groups.

**SUMMARY**

In conclusion, this thesis has lead to the development of a new questionnaire to measure parental asthma management approaches. The questionnaire is unique in that the content of items and the scoring of the questionnaire focus on all behaviours used by parents and not just those behaviours considered important by clinicians. Initial analyses suggest that the questionnaire is reliable and valid. Using the new questionnaire, parents' perception of children's medical vulnerability and socioeconomic status were found to be highly significant predictors of approaches parents use to manage children's asthma.
The theoretical underpinnings of the parental Asthma Management Questionnaire (AMQ)

The fundamental assumption or guiding principle that underlies this thesis is that patients are not passive recipients of care and advice from health care professionals, but are active managers of their own health and well-being. Health care provision therefore requires a partnership between parents, children and health care providers. This represents a major theoretical shift in medicine, a profession which has been traditionally characterised by a paternalistic paradigm. The AMQ was developed as a measure of parents' intention to carry out behaviours in relation to their children's asthma. The unique feature of this new questionnaire is that behaviours that parents consider to be important are included in the measure. This is in contrast to previous measures of parental asthma management where the focus has been on behaviours that health care professionals considered important in controlling the symptoms of the disease. The inclusion in the AMQ of behaviours which parents consider to be important represents a parent or patient perspective of chronic disease management.

The components of parental behaviour included in the new questionnaire were derived from a model of parental asthma management proposed by Clark and Starr-Schneidkraut [1994] (see Figure 2.1). In this model, asthma management behaviours are classified into three broad groups; (i) preventive behaviours (used to prevent the occurrence of symptoms), (ii) attack management behaviours (used to treat the acute onset of symptoms) and (iii) social skills (which aim to reduce the impact of the disease on day to day activities and include discussing management
plans with other caregivers). During the initial stages of development of the AMQ, focus group and individual interviews were conducted with parents of children with asthma (see Chapter 3). Behaviours cited by parents during these interviews were categorised into the three groups described by Clark and Starr-Schneidkraut (Table 3.1) and behaviours from all three categories were included as items in the new AMQ. To assist in this process, the five scenarios of the AMQ were conceptualised as being either situations which potentially could lead to asthma symptoms for children or situations where actual asthma symptoms were described. Items in the former scenarios were generally preventive or anticipatory in nature, whereas those in the later were attack management behaviours. For example, scenario 1 describes the child preparing to undertake some form of physical activity. Preventive behaviour items in this situation include, getting the child to inhale reliever medication before the physical activity and getting the child to warm up before the activity. Scenario 2 describes the child becoming wheezy and breathless with activity. Attack management behaviour items in this situation include, stopping the child participating in the activity and getting the child to inhale reliever medication. Social skill behaviours were more difficult to identify within the scenario framework used in the AMQ. However, a number of these behaviours were included, particularly in scenario 3 (e.g., write a note to my child’s teacher to say that my child has a runny nose).

Limitations of the study

This section describes in more detail a number of the limitations of the study and augments the section in Chapter 9 of this thesis beginning on page 173.

1. The AMQ was developed to measure behavioural intention. The latter is a proxy for actual behaviour and the AMQ does not rate actual behaviour. Actual behaviour is extremely difficult to measure directly because of the practical difficulties of
undertaking naturalistic observation and because people may change their behaviour during periods of observation. These limitations become particularly powerful when studying asthma, because symptoms are often infrequent, episodic and unpredictable. However, the Triandis model of health behaviour was used to justify a theoretical link between behavioural intention and behaviour [Triandis, 1979] (see Figure 3.1). This model hypothesises that the major determinants of behaviour are behavioural intention and habit. Behavioural intention is most important when behaviours are new to the individual. Because the AMQ was based on the scenario approach, the behaviours of interest in this study were those conducted in response to asthma situations (or scenarios) and therefore would not be routine for parents. As a result, one would expect that there would be a close association between behavioural intention and actual behaviour for these non-routine behaviours.

To assess the relationship between behavioural intention and actual behaviour, parents were asked to recount behavioural approaches used in recent episodes of asthma experienced by their children. Although some evidence was found that AMQ responses and parents’ past actual behaviour were positively associated, the small sample size available for these analyses made the strength of the relationship difficult to assess for two of the three subscales of the AMQ. To try to overcome the sample size limitations (arising because only small numbers of parents had experienced asthma situations in the month before interviews were conducted), the relationship between responses on the AMQ and the number of health care visits made for asthma and the number of school absences because of asthma in the preceding two months were also compared. Overall, significant positive relationships were found between AMQ subscale scores and recent health service use and school absences (page 110). This result further supports the view that in terms of parental asthma management there is a positive association between
behavioural intention and past actual behaviour. Similar analyses were conducted by Watkins [1992] in a study comparing responses to the original scenario questionnaire of Taylor et al. [1991] and naturalistic observation of actual child behaviour (see Chapter 3, page 51). This study demonstrated significant agreement between responses to the exercise scenario and observed behaviour of children at school.

2. A limitation of the study was that the majority of the data was collected cross-sectionally. In terms of the validation of the AMQ described in Chapter 7, this has significant implications. One way of testing the validity of a measure is to compare the responses of the new questionnaire to another measure of the same construct (i.e., criterion validity). As described above, in the present study, parents were not only asked to respond to the AMQ (measuring behavioural intention) but were also asked to recount their actual behaviour in recent situations which resembled the hypothetical scenarios described in the AMQ (measuring past actual behaviour). Parents were asked these questions during the same interview period. A close relationship was found between responses to the AMQ and past behaviour for some items of the questionnaire but not for others. One explanation for this lack of agreement for some items is that the outcome of a recent past asthma situation managed by a parent could change the way in which this parent intended to manage future situations (and therefore responded to the AMQ). The only way to truly assess this possibility would be to collect prospective information about real-life situations. The cross-sectional nature of the data collected in this thesis also has implications in terms of the relationships found between psychosocial variables and parental asthma management. This complexity is further discussed on page 176.
3. This study does not include any measure of asthma outcome. One of the main reasons for measuring parental asthma management is that parents’ behaviour is hypothesised to directly influence outcomes for children with asthma. If some approaches used by parents to manage children's asthma result in better outcomes for children then these approaches could be incorporated into future asthma education programmes. This study did not attempt to investigate the relationship between parental asthma management and outcome because prospective data was not collected. This forms the logical next step in evaluating the AMQ. The choice of outcome measure would need to be carefully chosen in such a study. In the past, health care professionals have focused either on symptom frequency and severity and/or the use of health care services by children with asthma (hospitalisation, emergency room visits and visits to the general practitioner). More recently, researchers have focused on the broader impact of disease on individuals. Health related quality of life describes this construct which assesses the impact of the disorder on psychological, social and physical functioning. A quality of life measure would ideally be included in any study investigating the impact of parental asthma management on asthma outcome for children. It is plausible that some approaches used by parents to manage children's asthma may lead to poorer control of symptoms but allow children to participate more fully in daily activities. Such approaches may be criticised by health care professionals whose major focus is on symptom control. However, as health care professionals, we need to remain cognisant that chronic disease management by patients and parents involves a constant weighing up of potential benefits and drawbacks of treatment such that the quality of life of children is maximised.