University of Alberta

Adherence to Asthma Treatment in Children and Adolescents aged 7-19: A psychosocial perspective

by

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Dedication
and
Thank you

To Dr. Patrick A. Hessel,

who gave me this chance

Acknowledgments

I would like to express my sincere appreciation to my supervisors, Dr. A. Senthilselvan and Dr. D. Spady, who remained as my committee members despite my adverse circumstances and supported me throughout the project. Dr. A. Senthilselvan introduced me to multinomial logistic regression, which was ideal for my study, and Dr. D. Spady guided me by asking significant questions, which became important components of the thesis. I also like to express my gratitude to Dr. L. Hayduk, who spent hours helping me design the questionnaire, and Dr. P. Hessel, who made sure that I had enough funding and materials until I completed the entire study. This study was possible through a grant held by Dr. P. Hessel. I am indebted to Dr. D. Saunders, Dr. S. Newman, Ms. F. Hey, and Ms. K. Forbes for their hospitality. I am thankful to Mr. D. Michaelchuk, Ms. T. Whaley, Ms. H. Wells, and Ms. E. Munro at the Alberta Asthma Centre. I also wish to thank Ms. E. Neumann for her invaluable help, and Mr. G. Kubina, Ms. N. Vasquez, and Ms. B. Wolfe at the JSHS Library for their support..

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I am very happy to have been able to introduce J. Piaget (1896-1980), a man of genius, and his theory in this thesis. I feel that my mission is accomplished.

Retrospection

Remembering my grandparents, my dog Goro, and my childhood friend who was drowned when he was five and I was four, I feel I have come a long way since they gave me the breath of life. Remembering a poem I wrote for the childhood friend,

'Water was swirling under the moonlight
And his straw hat was floating on the water
Swallowing the life of my precious mate
The current was carrying his shoes upside-down
His little raft was wandering without its owner
And the river ran regardless without compassion
Silence was suddenly loud in the dark night

Searching voices disturbed the silence
And searching sticks were everywhere
But the river gave no answer to us
Hiding the life somewhere

Dawn was near
The life was found at last
Having lost its meaning and wasted its past
Night was black and water was cold
Nature finally gave us the dead'

--English 102 '86

Inspiration

Respecting two men for what they did for mankind with their extraordinary intelligence,

"The creativity is the key." *--Albert Einstein*

"As long as ideals are merely thoughts, the power that is in them remains ineffective even if they are thought with the greatest enthusiasm and the firmest conviction."

--Albert Schweitzer

Ehrfurcht vor dem Leben (Reverence for life)

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CHAPTER 1

Introduction

The current study attempts to examine poor adherence to asthma treatment in children and adolescents aged 7 to 19 years in Alberta. To examine poor adherence, a self-reported asthma perception questionnaire, designed to measure poor adherence and its psychosocial predictors, has been developed. Poor adherence is defined as the extent to which children and adolescents agree with the statement in the questionnaire that they take less asthma medications than what their doctor prescribes. The questionnaire uses a perceptual approach which attempts to measure what children and adolescents perceive or believe, not what is objectively true to others.

1.1 Background of the Problem

Asthma is the most common chronic lung disorder and a leading cause of school absenteeism among children and adolescents in North America. Approximately 17 million people in the United States and 1.5 million people in Canada suffer from it (Burkhart, 2001; Health Canada, 1996; Hessel, 1996), and one-third of them are estimated to be school-age children and adolescents. Health Canada (1996) reported that asthma affected approximately 13% of all students aged 5 to 19 years across Canada. In spite of effective asthma medications, asthma (symptom) prevalence has been reported to be high among them.

Currently, a cure for asthma has not been found although some children "grow out of it." However, if asthma is properly diagnosed and controlled, most people with asthma can lead a nearly normal life (Asthma Victoria, 2001). Conversely, without proper control by medication, asthma could considerably limit daily activity. Taking asthma medications as prescribed is critical in order to avoid morbidity from asthma which often results in emergency room visits. However, it

has been reported that as much as 50% of school-age children and adolescents are not taking their asthma medications as prescribed (Creer, 1993; Milgrom, 1996).

Some researchers (Brown, 2001; Higgins, 1998; Kyngas, 2000) have investigated poor adherence rates among children and adolescents, but no studies have compared them testing the significance of the difference between them. These researchers also examined risk factors for poor adherence and found that psychosocial factors such as perception of one's asthma, attitudes towards the treatment of asthma and self-efficacy beliefs (one's feelings about one's ability to use asthma medications) exert more influence on adherence than do demographic or background factors such as age, sex, and severity of asthma, especially in adolescence. They emphasized that more research was needed to investigate psychosocial factors in relation to adherence to asthma treatment.

1.2 Purpose of the Research

The general purpose of this research is to gain better understanding of poor adherence to asthma treatment among children and adolescents. The first objective is to calculate the rate of poor adherence for children and for adolescents and examine if they differ significantly. The second objective is to determine the risk factors for poor adherence. The third objective is to examine and compare these risk factors between children and adolescents. The findings will provide an insight into the nature of barriers children and adolescents experience when they take asthma medications.

1.3 Research Questions

Using self reports, the current study attempts to answer the following questions.

1. What are the rates of poor adherence in children and in adolescents?
2. Is there a significant difference in the rates of poor adherence between children and adolescents?

3. What are the predictors of poor adherence among children and adolescents?
4. Do psychosocial variables predict poor adherence in children and adolescents equally?

1.4 Definitions of the Terms used in the Research

Asthma, in this study, is considered to be present when there is a positive parental response to the questions, "Does your child currently have asthma?" and "Was this confirmed by a doctor?" in a follow-up telephone interview. Children and adolescents had to be on medication for asthma. Several studies reported good correspondence between self-reports and clinical assessments (Rennie, 1996; Senthilselvan, 1993; Venables, 1993). Rennie et al. (1996) observed 89% agreement between clinical examination by a respiratory physician and parental reports. Senthilselvan et al. (1993) and Venables et al. also (1993) found that their questionnaire provided "a valid index of asthma for epidemiological purposes."

Asthma medication includes all the medications prescribed in asthma treatment, collectively in child reports (e.g. controller, anti-inflammatory agents such as corticosteroids and reliever or rescuer medication such as β2-agonists) in relation to asthma adherence.

Asthma severity or control is determined as a child or an adolescent perceives it as "mild," "moderate," or "severe." He or she is instructed to select "mild" if "asthma seldom interferes with everyday life," "moderate" if "asthma occasionally interferes with everyday life," and "severe" if "asthma seriously interferes with everyday life."

Poor adherence is reported, for the purpose of this study, as the degree to which a child or an adolescent agrees with the statement "I usually take asthma medication less than my doctor would like me to take." Poor adherence is a continuous variable, but in calculating the rate of poor adherence and in

examining its predictors in a Multinomial Logistic regression model, it is categorized into three values. Those who "strongly disagree" and "disagree" are grouped together as "Good," those who select "neutral" remain as "Neutral," and those who "agree" and "strongly agree" are grouped together as "Poor." The poor adherence scale is designed to measure "poor adherence" rather than "good adherence."

Adolescents are defined as children aged 12 years or older according to the theory of cognitive development proposed by Piaget (Inhelder, 1958). The theory claims that adolescents possess the cognitive capacity called "formal operation" that differs from the cognitive capacity called "concrete operation" that children possess. Adolescents are further divided into two groups: younger adolescents aged 12 to 14 years and older adolescents aged 15 to 19 years.

1.5 Conceptual Issue: Adherence

WHO (2003) defines adherence as "the extent to which a person's behaviour—taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed recommendations from a health care provider." Poor adherence is not a new concept. Hippocrates, as early as circa 450 B.C., advised to physicians to "keep watch also on the fault of patients which often make them lie about the taking of things prescribed" (Tebbi, 1993).

Adherence has been studied from scientific perspectives including medicine, public health, nursing, psychology, and health economics for over 50 years. During this period, several terms including compliance, concordance, and adherence, have been utilized to define the concept.

Adherence was first conceptualized as "compliance" and is now a significant issue in medical research. Compliance was first defined by Sackett (1976) as the "extent to which patient behavior coincides with the clinical recommendation of health care providers." The term "compliance" was more frequently used than the term "adherence" in 1970s. Since the mid-1990s, the term "adherence" has

become common in the literature and has been defined differently from "compliance" by some researchers (Drotar, 2000; Kyngas, 2000; Rapoff, 1997). These researchers argue that adherence emphasizes active participation and self-control, and is less authoritarian than compliance.

In the current study, "adherence" is used preferably and defined differently from "compliance" because "adherence" concerns motivated behavior rather than merely acceptance which "compliance" concerns. The concept "motivation" is important in long-term self-management because without "motivation," asthma management, which involves routine tasks of taking medication, may not be successful

1.6 Summary

This chapter has introduced the background of the problem of poor treatment adherence in children and adolescents with asthma, the purpose of the research, research questions, the definitions of the terms used in the research, and discussion on the concept of adherence.

The literature presents enough evidence that child and adolescent adherence is poor. The current study attempts to investigate factors that may contribute to poor adherence to asthma treatment in children and adolescents aged 7 to 19 years. This study may shed light on the nature of barriers that they are experiencing when they take asthma medication. It focuses on psychosocial factors based on the assumption that they play an important role in poor adherence. It uses "psychologic theorizing" or psychological theories to explain the results.

The next chapter, Chapter 2, presents a comprehensive literature review concerning asthma and adherence to asthma treatment in detail.

CHAPTER 2

Literature Review

The literature review focuses on two broad themes in order to collect information to investigate poor adherence to asthma treatment in children and adolescents with asthma. The two broad themes are asthma and adherence to asthma treatment.

For the purpose of this literature review, the relevant descriptive and empirical literature has been searched for, collected, and reviewed, in the disciplines of medicine, public health, nursing, education, psychology, and sociology or social sciences. The material was published mainly between1990 and 2004, except for several classic articles.

Computer searches were guided by the use of the keywords: "asthma," "compliance/adherence," "children" and "adolescents," and conducted in the following databases: Medline, Pub Med, and Eric.

2.1 History of Asthma

Asthma is a chronic inflammatory disorder of the airway. In response to a trigger, the inflamed airways would start to narrow due to contraction of the smooth muscle around the airway and secretion of excess mucus onto the airways (Clark, 1996). These events could lead to asthma symptoms such as coughing, wheezing, chest tightness, and breathlessness (Chung, 2000; Holgate, 1998).

The word, "asthma" comes from the Greek word "ασθμα," meaning "panting," or difficulty in breathing (Barnes, 1998). References to asthma can also be found in ancient Egyptian, Hebrew, and Indian medical writings (Pearce, 1998). It was also defined in 460 B.C. by Hippocrates (Lieberman, 1999).

Many symptoms of a severe attack of asthma were recognized in 200 A. D. as follows: "if from running or gymnastic exercises, the breathing becomes difficult, it is called asthma; the patients also pant for breath; the symptoms of its approach are heaviness of the chest...difficulty breathing in running...and troubled with cough" (Lieberman, 1999).

Galen, a physiologist in the 2nd century, ascribed the origin of asthma to "phlegm falling on the lungs" and supposed that "thick and viscid humors" were responsible for blocking the passage of air into the lungs (Porter, 1971). Later, van Helmont, a 17th century scientist, would disagree with Galen, describing "asthma seizes one suddenly just as if a rope were tied about a man's neck" (Lieberman, 1999). Interestingly enough, what these two physicians described characterizes the two very features of asthma as understood today: excess mucus secretion limiting airflow in the airway and limited gas exchange because of smooth muscle contraction constricting the airway. However, the underlying inflammation was not recognized at either time.

In the 12th century, a physician recognized the importance of viral respiratory tract infections in severe asthma attacks, describing the onset of asthma: "It starts with a common cold, especially in the rainy season, and the patient is forced to gasp for breath, depending on the duration of the onset, until the phlegm is expelled, the flow completed and the lung well cleared" (Lieberman, 1999).

In the 20th century, after immunological or allergic aspects of asthma were recognized for the first time, a final definition of asthma, which represents the most current consensus, was developed. This definition was different from the previous ones in its recognition and emphasis on the inflammatory component of asthma (Barns, 2002; Gershwin, 2001). This observation of inflammation was possible because the bronchoscope became available allowing physicians to actually look at the airway lining. A current operational definition of asthma, based on underlying pathophysiology, is as follows (Lieberman, 1999):

> Asthma is a chronic inflammatory disorder of the airways in which many immune and inflammatory cells, including mast cells and T lymphocytes, may play a role. In susceptible individuals, this inflammation causes recurrent episodes of wheezing, breathlessness, and coughing, particularly at night and/or in the early morning. Symptoms are usually associated with widespread but variable airflow limitation that is at least partly reversible either spontaneously or with treatment. Inflammation also causes an increase in airway responsiveness to a variety of stimuli. Understanding the condition of asthma rather than trying to define it is important in order for health care providers to be able to treat the various unfavorable symptoms of asthma.

Understanding asthma and symptoms of asthma as well as the reasons for them came a long way from a visual observation of "panting" or "gasping for breath" to a serological observation of allergic origin of asthma and finally to an insightful observation of physiology of asthma manifested as inflammation in the airways. Many scientists have contributed to reaching the current understanding of asthma.

2.2 Epidemiology of Asthma

Many epidemiological studies of asthma have contributed to the understanding of asthma, but there are problems associated with asthma epidemiology. First, there is no universal definition or diagnostic criteria to identify those with asthma (Pearce, 1998). Surveys of asthma prevalence suffer from the lack of a clear definition of asthma and of a reliable and reproducible instrument to define asthma. The International Study of Asthma and Allergies in Childhood (ISAAC) questionnaire (Asher, 1995) was developed, but the problem still exists: the level of awareness of the symptoms may differ from community to community. Second, it is difficult to measure the incidence rate. Incidence rate is preferred when etiology of asthma is being investigated. In order to calculate an incidence rate, a cohort study must be used. A cohort study requires intensive long-term monitoring, and even when this design is used, it is difficult to establish the exact date of onset of asthma. Therefore, cross sectional (prevalence) studies are usually used to describe asthma epidemiology.

Asthma prevalence has increased for the past several decades. The trajectory of increasing prevalence of asthma seems to have continued until the early 1990s (Arif, 2004; Asthma Victoria, 2001; Mannino, 1998; Sullivan, 2003). A UK study (Sears, 1997) reported that from between 1964 and 1989, the prevalence of wheezing among 7-year-olds had doubled from 10% to 20%. Likewise, the prevalence of childhood asthma in Taiwan (Hsieh, 1988) consistently increased from 1.3% in 1974 to 5.8% in 1985. In Australia, Peat et al. (1994; 1999) reported a rise from 12.9% to 19.3% between 1982 and 1992.

Recent studies (Anderson, 2004; Senthilselvan, 2003), however, suggest that asthma prevalence has reached a plateau or even declined. Senthilselvan et al. (2003), for example, reported that asthma prevalence in Saskatchewan was stable and even showed a sign of decreasing in 1997 and 1998 after a significant increase during the period of 1981 and 1996 (Senthilselvan, 1998). Similarly, a British (Anderson; 2004) study and Australian (Robertson; 2004; Toelle, 2004) studies recently also observed a significant reduction in asthma prevalence.

Asthma affects more than 1.5 million Canadians, one third of which are estimated to be school-age children. In 1996, Health Canada (1996) reported that overall across Canada, 9.7% to 18% of all students surveyed from elementary schools to high schools had asthma. In Alberta, the prevalence was 13%. Hessel et al. (1996) also observed that 13% of the school children aged 7 to 13 years in Fort Saskatchewan, Alberta, had a physician's diagnosis of asthma at some time.

Asthma prevalence has been reported to be high among young boys. According to several studies (Clark, 1999; Hessel, 1996; Seiffge-Krenke, 1998), boys seem to be more likely than girls to develop asthma by a ratio of about 3 to 2. In Canada, Hessel et al. (1996) found asthma to be more prevalent among boys than girls by approximately 1.6:1.0 in children and adolescents aged 7 to 13 years. Seiffge-Krenke (1998) reported a similar result in the United States. This phenomenon changes by adulthood, and asthma has the same prevalence in both sexes. This may reflect that boys are more susceptible than girls for asthma

possibly due to their small airways and differential hormonal effects at puberty, that girls are less likely to lose their asthma, or that girls develop asthma later. It could also mean that girls' asthma might be under-recognized or under-diagnosed in childhood and that their asthma might become worse later.

In summary, asthma is the most common childhood lung disorder (Asthma Victoria, 2001; Millar, 1998). Asthma epidemiology has been studied mainly by using prevalence or cross-sectional studies. Although asthma prevalence seems to be stable in several countries including Canada, the observed prevalence is still high in Alberta (Alberta Lung Association, 2001; Hessel, 2001). High prevalence of asthma among children and adolescents means either they are developing asthma at high rate or they have asthma for a long period of time or a combination of the two. Prevalence is also influenced by the questions used to identify those with asthma. Only risk factors can be identified from cross-sectional studies, and causal mechanism cannot be determined from them. Table 2.1 shows major known risk factors for developing asthma.

Table 2.1: Major known risk factors for developing asthma

Risk factors	Result	References
Sex	Asthma is more prevalent among male children although by adulthood more females have asthma.	Weiss, 1995 Hessel, 1996 Mauer, 2000
Age	One third of those who have asthma are children under 19. Children under 5 are at high risk.	Welsh, 1999 Senthilselvan, 2003
History of Allergy Or Asthma	Atopic children who are regularly exposed to the allergens are at great risk of developing asthma. Children whose parents, especially mother, have asthma are greater risk.	Chung, 2000 Lenney, 2003 Mavele-Manuel, 2004

2.3 Severity and Control of Asthma

The concept "severity" should be differentiated from the concept "control" of asthma (Boulet, 1999; Fuhlbrigge, 2004). "Severity" describes the underlying condition in the absence of asthma treatment. "Control" on the other hand describes the clinical status of asthma in the presence of the treatment. However, these two concepts tend to overlap significantly.

In a clinical setting, objective assessment of asthma and its severity is obtained by a combination of measurements including the severity and frequency of symptoms, variability of peak flow measurement, and lung function tests (O'Byrne, 2001). In a research setting, symptom questionnaires are mostly used to assess asthma and its severity.

The criteria for successful asthma control are 1) less than 4 times a week daytime symptoms, 2) less than once a week night-time symptoms, 3) normal physical activity, 4) mild, infrequent exacerbations, 5) no absence from school, 6) less than 4 doses of short-acting β2-agonist per week, and 7) more than 85% of personal best in peak flow (O'Byrne, 2001).

Responsibility to control asthma includes adherence to asthma treatment and identification and avoidance of risk factors that trigger asthma attacks. Adherence to asthma treatment or taking asthma medications according to doctors' recommendations is crucial in order to reduce underlying inflammation in the airways, which can give rise to various asthma symptoms in response to various triggers.

Avoiding allergens such as dust mites and animal dangers and irritants such as smoke may significantly reduce the frequency of symptoms and decrease the need for asthma medication. They can be avoided by washing bed linen and blankets weekly in hot water. Avoiding humidifiers and carpets especially in a bedroom may also reduce frequency and severity of symptoms. Getting rid of pets and avoiding passive or active smoking are also recommended (Cook, 1997; O'Byrne, 2001).

2.4 Genetics of Asthma

Although genetic factors seem to contribute significantly to the development of asthma (Harris, 1996), a "gene" for asthma has not been found. Currently, asthma is considered to be influenced by multiple genes and environmental factors rather than a single gene or a singe environmental factor. Some factors related to asthma symptoms are related in one part of a gene, while others are related to atopy and located in another part of the gene or on another gene.

Some specific regions of chromosomes 5 and 11 have been analyzed, and they have been found to be associated with allergy-associated genes. It has been found that the regions of chromosome 5 are linked with bronchial hyperresponsiveness to histamine. Chromosome 11 has been found to have a location of an atopy gene for a high-affinity IgE receptor (Cookson, 1995).

Croner et al. (1982) found that 70% of newborn infants with elevated cord IgE levels developed definite atopic disease including asthma before the age of 18 months compared with 4.9% of other infants. However, 56% of those who developed atopic disease had not had high cord blood IgE levels. Therefore, they were unable to conclude that elevated IgE would lead to the development of atopy.

Some studies (Lenney, 2003; Mavale-Manuel, 2004) observed a strong association between maternal asthma and developing asthma. While the finding sounds compelling from a genetic point of view, there are other factors to be considered and examined such as intrauterine environment and hormonal interaction between the mother and the fetus. The mother's health behaviour, severity of her asthma, and asthma medications that she was taking to control her asthma might have confounded the association between the gene and asthma had they been included in the analysis. Moreover, when a child is very small, the mother's or family history of asthma is one of the most important diagnostic criteria of asthma, rather than "it just happens to be," since many of the tests such as lung function tests cannot be performed at that age.

A strong familial association observed in epidemiologic studies does not always mean that the predictor is directly controlled by the gene. A gene seldom acts on its own but often acts closely interacting with the "right" environment, host, and time (Neffen, 1999). Without a sound understanding of the genes and their direct influence on the development of asthma, it would be difficult to establish the genetic links. Because these genetic links are not strong enough to demonstrate the specificity of the gene to asthma development, it is still premature to assume asthma is going to be inherited. It would be more reasonable to assume that "mother's asthma" predisposed the fetus to asthma than to assume that the fetus was carrying a replica of her "asthma" gene.

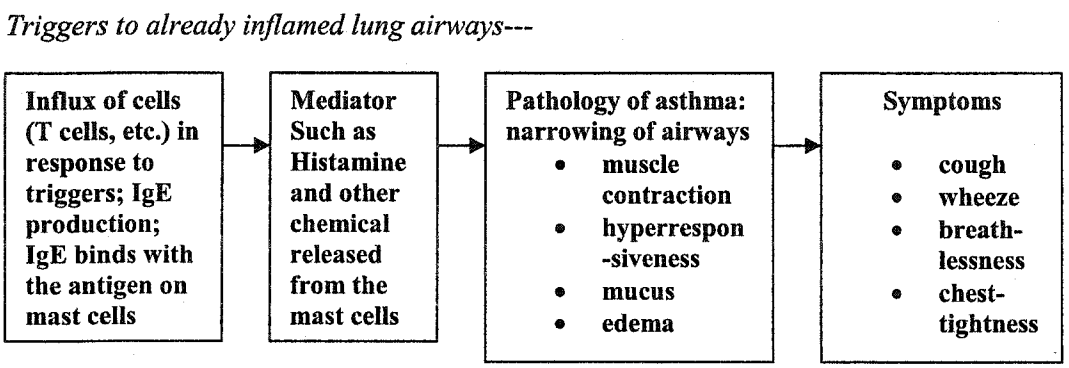
2.5 Pathophysiology of Asthma

In a well-accepted scenario (Gershwin, 2001), asthma is induced by an inducer, such as an allergen or a virus (Folkerts, 1998), followed by a latency period from the time of exposure to the inducer to the time when the symptoms appear. However, the latency period is difficult to estimate. It is difficult to obtain the exact date of exposure to the first trigger that leads to chronic inflammation, hence asthma development, because it is difficult to identify the first trigger.

A more detailed scenario (Chung, 2000) of developing asthma is that one encounters an allergen which causes the immune system to produce or over-produce IgE for the allergen. Upon encountering an allergen, antigen presenting cells let T-lymphocyte know that "this" foreign substance is invading the body, and the body responds by making antibodies or IgE molecules. On the surface of a mast cell, IgE binds with the antigen. Upon binding with IgE and the antigen, the mast cell releases a substance such as histamine, which causes the lining to swell and the smooth muscle around the airway to contract thus constricting the airway. After several hours, a special type of T-lymphocyte or T-Helper Type 2 cells call for inflammatory cells causing inflammation. The initiation of chronic inflammation or the development of asthma is difficult to detect.

Figure 2.1 summarizes the (common) sequential events leading to asthma symptoms or attacks after chronic asthma has been developed. When a trigger irritates an asthmatic or inflamed lung, a series of events occur. The trigger is considered by the body as "a foreign" substance, and the immune system starts to work. Ironically, the immune system that is supposed to protect the body against the disorder may actually be "causing" the disorder in asthma (Holgate, 1999).

Figure 2.1: Cellular sources, mediators, pathology and symptoms of asthma



2.6 Treatment of Asthma

Medications used in the management of asthma can be classified as relievers or controllers because of the way each type of medicine works: to relieve symptoms quickly or to reduce or control the inflammation that is always present (O'Byrne, 2001). Basically, asthma medicines keep airways in the lung open so that air can be transported in and out of the lung easily.

Relievers are referred as "bronchodilators." They act by relaxing the muscles that surround airways, opening bronchial tubes in the lung so that breathing becomes easy (O'Byrne, 2001). Therefore, they help to stop asthma attacks after they have started. They are usually prescribed in an inhaler (aerosol) form but are also available as liquid, tablets, capsules, and fluid for injection.

An example of bronchodilators is the short-acting β2-agonist. β2-agonists stimulate the sympathetic nervous system and act on receptors located in nerve endings inside the lungs provoking specific β2 receptors in muscles to reverse the action of constricting, opening up the airway tube (Gershwin, 2001). It is often recommended that bronchodilators such as Ventolin or salbutamol be taken before exercise (O'Byrne, 2001).

However, if they are taken too often (more than 1 canister per month) and for too long especially if used after the attack has already started, it can lead to poor asthma control (O'Byrne, 2001). They have side-effects including muscle tremor, tachycardia (rapid heart beat), and restlessness (O'Byrne, 2001). Long-acting beta-agonists such as salmeterol are a "longer" version of short-acting β2-agonists with the duration of action of more than 12 hours (O'Byrne, 2001).

Controllers, the other class of asthma medication, are "anti-inflammatory" medications, which help to control the air-way inflammations and prevent asthma attacks from starting. This is the difference from relievers, which help to stop asthma attacks after they have already started. Since airway inflammation was recognized in asthma, anti-inflammatory medications became increasingly important in the treatment of asthma. Anti-inflammatory medications operate inside the airways most likely in bronchioles, where inflammation begins. They work to keep the airway open to prevent asthma attacks by limiting the influx of cells that cause airway inflammation.

Examples of the controllers or anti-inflammatory medication are inhaled corticosteroids (ICS) including fluticasone and budesonide. Studies (Kerstjens, 1992; Milgrom, 1996) have consistently shown that these anti-inflammatory medications reduce airway inflammation so that lung function may improve, bronchial hyperresponsiveness may decreases, and the frequency and severity of asthma symptoms are reduced. ICS are known to have some side-effects including yeast infection in the mouth and possible impact on growth if they are used for a long period of time (O'Byrne, 2001).

In addition to ICS, there are medications that are designed to reduce inflammation. Mast cell stabilizers called cromones such as cromoglycate and nedocromil sodium, for example, are long-term medications that reduce symptoms of early stages of asthma with fewer side effects than ICS (O'Byrne, 2001). Antihistamines and antileukotrienes block the effects of histamine and leukotriene respectively; decongestants reduce nasal congestion by narrowing blood vessels in membranes lining the nose thereby decreasing swelling, inflammation, and mucus production in nasal passages.

2.7 Treatment for Children and Adolescents

Treatment for children and adolescents is similar to that for adults. Children and adolescents are often treated with a combination of more than one type of inhaled medication. For example, β2-agonists which provide quick relief of asthma symptoms are often prescribed with inhaled corticosteroids which counteract inflammation and prevent asthma symptoms to develop (O'Byrne, 2001).

Kaarsgaren et al. (1994) compared the pattern of asthma medications prescribed between 1983 and 1991 in England and found the most common pattern was a β2-agonist with a corticosteroid. Corticosteroids use rose from 24% to 59%, and 95% of them were administered by inhalation only. The use of theophylline which was popular in 1980s fell dramatically from 50% to 33% in 1991 and is steadily decreasing.

The age at which a child takes asthma medications independently is variable. Kaarsgaren et al. (1994), asking 65 parents and children (41 parents and 24 children and adolescents) "who was responsible for treatment?" found that above the age of 10 years virtually all the children and adolescents had free access to their medication and were taking their asthma medication independently, while below the age of 5 years, no children did. Between the age of 7 and 10 years, both parents and children took the responsibility or parents still supervised their children.

Children are likely to be unaware of the purpose of the medications as well as its efficacy. Children may experience unpleasant taste or smell from asthma medication itself or its propellant depending on which medication, which manufacturer, or which method of delivery that they used, and it may influence their adherence. Adolescents, however, may be aware of the purpose of the medication, in addition to an unpleasant taste or smell (Creer, 1992).

2.8 Adherence

Adherence is defined as "the extent to which a person's behaviour such as taking medication corresponds with agreed recommendations from a health care provider (WHO, 2003)." It is well documented that poor adherence is a serious health care problem among children and adolescents. In his review of 10 pediatric asthma adherence studies Creer (1993) found the adherence rate to average 48%.

In Kyngas' study (1999), 42% of the adolescents aged 13 to17 years with asthma reported that they adhered fully to asthma treatment, 42% reported that they were in the category of satisfactory adherence and remaining 18% reported poor adherence. Milgrom et al. (1996) found that the average child adherence rate was approximately 50%, which was higher than the reported adolescent adherence rate of about 40% (Cromer, 1989).

2.9 Measuring Adherence

There has been a controversy as to how to obtain a reliable measurement of adherence. Objective methods such as blood, saliva, and urine assay do not always reflect the long-term adherence. Self-reported adherence, although it has been reported to be unreliable by some researchers (Bender, 1997; Burkhart, 2001; Erickson, 2001), provides useful indicators of one's own assessment of adherence. Contextual information collected from children and adolescents themselves may reveal the nature of the barrier that they experience when they take medications.

It would be ideal to collect both objective and self-reported adherence to examine the nature of the barriers they are experiencing, but it may not always be possible because of cost, time, and other problems. Objective measures can be used to corroborate the subjective reports if the reports are consistent with the objective measures.

2.10 Objective Adherence Measures

The most common methods are listed below.

1) Biologic (serum, urine, and saliva) assays:

   Biologic assays are considered to be the most objective measure of adherence to medications for certain drugs (Chmelik, 1994; Eney, 1976). However, this method is not suitable for measuring long-term adherence. Even if the test is positive on one day, it does not mean that one is always taking the medicine.

2) Microprocessor-based technology:

   This method refers to commercially available computer devices installed in an inhaler that record date and doses; every time a patient uses his/her inhaler, it records the time and doses. Currently, this method is considered to be one of the most accurate and reliable non-invasive methods in assessing adherence. However, if one cannot use an inhaler properly, the medicine does not get to the lung and may not be effective.

3) Pharmacy data:

   In this method, one's pharmacy refill histories of 6 to 12 months are obtained by parents or researchers and can be compared with reported amount; "adherence ratio" can be calculated to examine the agreement between the two measures. Several researchers (Erickson, 2001; Jones, 2003; Sherman, 2000) used this method and found it to be valid. However, refill histories do not guarantee that one actually takes the purchased medication.

2.11 Self-reported Adherence

Some researchers (Burkhart, 2001; Bender, 1997) reported that self-reported adherence was not reliable. Burkhart et al. (2001), in a randomized, controlled clinical trial of the effectiveness of an asthma self-management program, examined the relationship between self-reported and electronically monitored adherence in children with asthma and found that self-reported adherence was not reliable or they overestimated their adherence. The children overestimated their adherence possibly because they wanted to please their doctors, since they were recruited from pediatric practices. Bender et al. also (1997) found that the participants overestimated their adherence and argued that self-reports of adherence were influenced by the setting in which the information was collected. The desire to please the physician could lead patients to exaggerate reports of medication use.

Creer (1993) stated "because there is no evidence to suggest that adhering patients misrepresent themselves as poor-adherers, self-reports of poor-adherers identify the honest poor-adherers." Erickson et al. (2001) investigated the association between self-reported poor adherence and objective measures and found that reported poor adherence was indeed reliable. Their study showed 85% agreement between self-reported poor adherence and poor adherence based on pharmacy data. If a researcher focuses on poor adherence rather than (good) adherence and examine its predictors, he or she may be able to identify the "true" barriers of adherence to asthma treatment.

In addition, when questionnaires are presented in a non-threatening manner, children and adolescents or their parents may report the "true" adherence and their concerns that they have about medical treatment. Children and adolescents or their parents may not directly report to their healthcare provider that children and adolescents are not taking their asthma medications as prescribed, but they may provide the "honest" report if other questions that may "justify" their health behaviour are included in the questionnaires.

2.12 Risk Factors for Poor Adherence

Age and sex have been studied in relation to adherence. Age has been reported to be a risk factor for poor adherence by some researchers (Jonasson, 1999; Strunk, 2002). Jonasson et al. (1999) found that children aged less than 9 years old had significantly better adherence than older children aged 9 years or older. Strunk et al. (2002) reported that for every 2-year increase in age (5 to 12 years) a child was twice as likely to have a commitment problem with the protocol. Creer (1993) and Kyngas (1999) indicated that adolescents might deny severity of asthma and, therefore, they might be at increased risks of poor adherence. Tebbi (1993) reported that older adolescents aged 17 or older had better adherence than the younger adolescents aged 16 years or younger. Jonasson et al. (1999) and Strunck et al. (2002) found no significant difference in adherence between sexes.

A focus group study of adolescents (Slack, 1995) found that many adolescents wanted to assume complete responsibility for taking their medications. They did not like to be reminded by their parents when to remember to take the medication especially when they did remember it. They also commented that the nurses at school would not allow them to use their inhalers. They had difficulty obtaining permission from their teachers to use their asthma medication at school. They complained that their teachers had little understanding of the role of medication in controlling asthma. Some of the adolescents confessed that they were embarrassed to use their inhaler in public (Slack, 1995). If their need for autonomy is not understood by others, it may exert a negative impact on their adherence to asthma treatment.

Much research has been performed on the relationship between knowledge about asthma and adherence, and some studies (Blessing-Moore, 1994; Bursch, 1999; McQuaid, 2003) have shown that knowledge alone is not enough to predict adherence. The concept of self-efficacy beliefs in relation to knowledge has been extensively studied by Bandura (1997). He argues that self-efficacy beliefs play

an important role in the way adolescents "orchestrate" their knowledge leading to adherence.

Table 2.2 shows a list of the known psychosocial risk factors for poor adherence.

Table 2.2: Psychosocial risk factors for poor adherence

Risk factors	Results	References
Characteristics of asthma medication	Bad taste and smell, large size, and weight of the asthma medication may lead to poor adherence. Certain methods of medication delivery may promote adherence.	Slack, 1995 Iqbal, 2004
Autonomy in adolescence	When adolescents do not feel that their autonomy is considered, they may not adhere.	Conway, 1998 Slack, 1995
Knowledge Self-efficacy	Lack of knowledge of asthma coupled with lack of self-efficacy causes poor adherence.	Bursch, 1999
Cost of asthma medication	Some cannot afford asthma medication, and as a result, they do not adhere.	Wilcock, 1998
Relationships Communication Support	Poor relationships and lack of support and communication with parents, doctors, and peers can cause poor adherence.	Camelo-Nunes, 2001 Fiese, 2003
Forgetting to take medication	Both children and parents may forget that they need to take asthma medication.	Creer, 1993
Denial of asthma Perception of asthma	Denial or inaccurate or negative perception of asthma may cause poor adherence.	Fritz, 1990 Kyngas, 2000
Medication side-effects	Worry about or experiencing side-effects from asthma medication may result in poor adherence.	Conway, 1998
Commitment Motivation	Lack of communication and motivation may cause poor adherence.	Kyngas, 2000

2.13 Adolescence and Psychosocial Factors

The word adolescence comes from Latin, meaning "to grow into maturity (Rice, 1999)." It is the period of growth between childhood and adulthood, and is considered as a bridge between the two periods. It is well documented that adolescence is an important transitional period every child goes through in order to reach his or her adulthood (Arnett, 2001).

Adolescence starts at approximately 12 years of age (Arnett, 2001; Piaget, 1969; Randolph, 1999; Seiffge-Krenke, 1998) and coincides with puberty, a period of sexual maturation, which varies between sexes. This period also has a significant role in cognitive development or development of intelligence (Piaget, 1969). The following excerpt (Arnett, 2001) shows how Plato and Aristotle viewed it:

> "Plato argued that there was no point in beginning education prior to adolescence because the child's mind was too undeveloped to learn much. He claimed that the child's education in science and math should be delayed until adolescence."
>
> "Aristotle, Plato's student, viewed children as similar to animals, in that both were ruled by the impulsive pursuit of pleasure. He also argued that it was only in adolescence that one would become capable of exercising reason and making rational choices."

The growth of intelligence may influence an adolescent's ability to think differently from a child. For example, a child can only see a tangible thing such as color of the medication and may refuse to take it because he or she does not like the color. Adolescents, however, may be able to think about the effects of the medication and focus on the benefit or efficacy of the medication because they are able to think or conceptualize abstractly without looking at or touching the concept or they may be able to reason that taking medication may or may not improve their asthma. Piaget (1969) termed this ability of adolescents "formal operation," the (cognitive) capacity for abstract thoughts.

This newly acquired capacity or intelligence may influence a child's adherence behavior through his or her perception of psychosocial factors such as treatment alliance with their parents and doctors, attitudes, and treatment efficacy. Creer (1993) and Kyngas (1999) have observed that psychosocial factors have more influence on adherence to asthma treatment than do demographic or background variables especially in adolescence.

Researchers (Camelo-Nunes, 2001; Creer, 1992; Palardy, 1998) have indicated that adherence could be improved by good relationships between children and adolescents, and their parents and health care providers. They also emphasized the importance of motivating them to actively participate in their self-management together with parents and health care providers. Positive support of parents and friends has been found to be important to promote adherence in several studies (Fiese, 2003; Kyngas, 2000; Slack, 1995). Although parents continue to play the role of primary caregivers, emotional support that peers provide is important especially in adolescence.

As a child grows, he or she takes a multitude of new social roles and becomes independent from parents. At the same time, he or she prepares for these social roles physically, physiologically, psychologically, and cognitively, which must be taken into consideration in self-management of asthma. Recognition and implementation of these various levels of maturity in a self-management protocol is critical for children and adolescents to successfully manage their asthma symptoms.

Although the adherence rate of adolescents is reported to be lower than that of children on average, or the average adherence rate "drops" as a child's age reaches adolescence, adolescence alone is not a causal factor for it. Studies (Seiffge-Krenke, 1998; Slack, 1995) have shown that some adolescents are adherent to their treatment. Adolescence may be linked to the certain cognitive capacity as Piaget claims that may influence adolescents' decision-making process through perception rather than directly linked to adherence behaviour.

2.14 Summary

Asthma is a serious childhood airway disorder among school-age children and adolescents worldwide (Asthma Victoria, 2001). Despite effective asthma medications to control asthma symptoms, the prevalence of asthma symptoms is still high. This suggests a need to examine adherence to asthma treatment. Research shows that adherence among children and adolescents is poor, and that adolescent adherence rate is lower than that of children (Fortherningham, 1995). It has been also reported that psychosocial factors are at least partially responsible for the low adherence rate observed in adolescents.

Poor adherence is not a new concept. It was recognized by Hippocrates around 450 B. C. (Tebbi, 1993). However, it was only 50 years ago that the subject became a significant issue in medical research as chronic illnesses became common. Health care providers started to find that their patients did not improve their health despite effective medications that they prescribed (Rapoff, 1997). The healthcare providers investigated adherence to the treatment and found that poor adherence explained why their patients did not get well (Rapoff, 1997).

Recently some health care researchers (Clark, 1999; Dunbar-Jacob, 1995; Kostes, 1998) emphasized the importance of the cognitive capacity in relation to adherence. However, few (Kyngas, 1999) have applied it in the predictions of poor adherence to asthma treatment in children and adolescents. The author (of this thesis) hypothesized that as a result of a "stage" inequality in the cognitive capacity, children and adolescents had differential psychosocial experiences which might lead to differential degrees of adherence to asthma treatment.

It is, therefore, the author's interest to find out if in fact a poor adherence rate of adolescents is lower than that of children in Alberta as well and whether psychosocial factors play an important role in predicting poor adherence to asthma treatment especially in adolescence.

The next chapter, Chapter 3, presents overview of the methodologies used in the research in terms of study design, data collections, and data analyses.

CHAPTER 3

Methods and Procedures

This Chapter presents the procedure used to recruit participants, design, setting, ethics, and data collection and analysis.

3.1 Objectives

The objectives of the current study were to determine the following:

1) Self-reported poor adherence rates for children and adolescents taking medications for the treatment of asthma
2) Risk factors for poor adherence in those children and adolescents
3) Difference in psychosocial factors between those children and adolescents

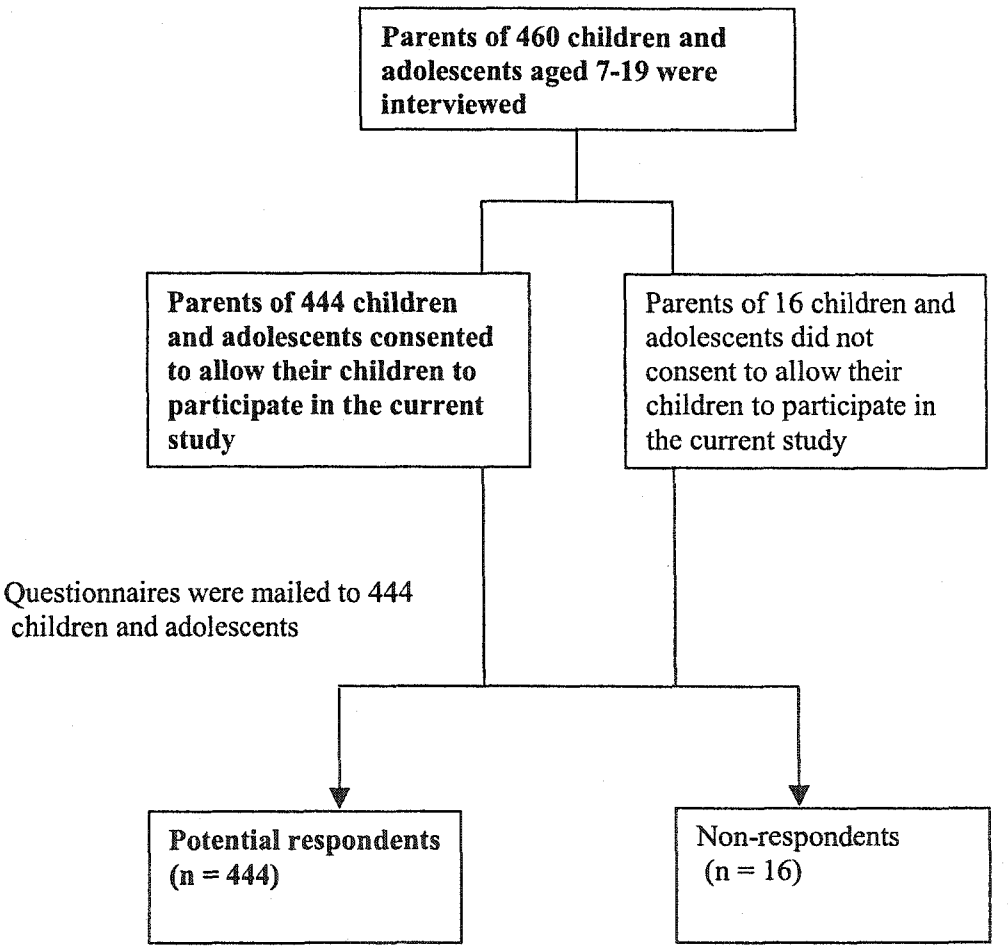
3.2 Initial Cross-sectional Study

Schools in two Alberta communities, Red Deer, and Medicine Hat, were randomly selected in an attempt to document the prevalence of asthma among students aged 5 to 19 years in 1999. Initially a take-home survey was distributed to and returned by parents of approximately 5,000 students in each community. The prevalence of asthma in Red Deer was found to be 12.8%, and the prevalence of Medicine Hat was found to be 17.0% (Hessel, 2001). A random sample of responding students with asthma, 592 from Red Deer and 443 (total of 1035) from Medicine Hat, were selected for a case-control study conducted in 1999. Two years later in 2001, parents of the case-control group were contacted by telephone. Parents of 460 agreed to participate in a follow-up interview. The eligibility criteria included 1) having physician-diagnosed asthma, 2) being aged 7 to 19 years, 3) currently being on asthma medication, and 4) having at least one asthma attack in the previous year.

During this second interview, parents were asked if they would allow their children to participate in the current study. Parents of 444 (out of 460) agreed and provided mailing addresses so that the questionnaire could be sent to their children. One month after the telephone interview was completed, questionnaires were mailed to 444 children and adolescents. The following flow chart shows the procedure.

Figure 3.1: Selection procedure

The second follow-up telephone interview



3.3 Inclusion and Exclusion Criteria

Inclusion and exclusion criteria for the current study are listed in Table 3.1.

Table 3.1: Inclusion and exclusion criteria for the current study

A participant
1) must have been older than 7 years old and younger than 20 years old at the time of the telephone interview, which took place in the spring of 2001.
2) must have current doctor-diagnosed asthma at the time of the interview in 2001.
3) must be receiving asthma treatment at the time of the interview in 2001.
4) must have participated in the 1999 survey and identified as having asthma.
5) must have at least one asthma attack past 12 months prior to the interview in 1999.
6) must have lived in Red Deer or Medicine Hat, Alberta in 1999.

3.4 Design

The study described is a cross-sectional study nested in a cohort study.

3.5 Setting

The current study took place in two communities, Red Deer and Medicine Hat, in the province of Alberta. Red Deer is a community of approximately 60,000, located in the centre of the province, and surrounded by agricultural land, light industry, and oil and gas activity (Hessel, 2001; Red Deer, 2004). Medicine Hat is a community of approximately 35,000, located in the southern part of the province, and surrounded by grain farming with some gas and oil activity (Hessel, 2001; Medicine Hat, 2004).

3.6 Ethics

The questionnaires (self-addressed and self-stamped) were mailed to children and adolescents from the Alberta Asthma Centre at the University of Alberta in the spring of 2001, and had been approved by the Health Research Ethics Board Panel B at the University of Alberta. Both parents and their children were informed in a letter (see APPENDIX II) attached to the questionnaire that their answer would be used in the research, that their identity would not be used for any publications, that all the information obtained was confidential, and that their participation was voluntary.

3.7 Data Collection

The data were collected using a perception questionnaire "School-Age Asthma Perception Questionnaire" (see APPENDIX III). The questionnaire was administered to children and adolescents, and the data obtained from the questionnaire were supplemented by the telephone interview with their parents conducted by the Population Research Laboratory at the University of Alberta (see APPENDIX I). All the demographic and background variables except for Asthma Severity were collected from the telephone interview. All the psychosocial variables were collected from the questionnaire that was based on a theoretical model of adherence.

The questionnaire was formatted using 5-point Likert scales from "Strongly Disagree" to "Neutral" and "Strongly Agree" and was consistently used in every item throughout the questionnaire including the outcome variable "Poor Adherence." For the purpose of the current study, 10 psychosocial variables, Asthma Knowledge, Asthma Triggers, Parent Reminding, Medication Side-effects, Asthma Perception, Medication Self-efficacy, Self-esteem, Number of Treatment, Asthma Duration, and Doctor Response, were selected. These psychosocial scales measured how things appeared to children and adolescents or what they perceived or believed.

The questionnaires were sent to 444 children and adolescents, whose parents had consented to allow their children to participate in the current study. Those children and adolescents were instructed to return the questionnaire to the Alberta Asthma Centre at the University of Alberta.

1) *Demographic and background variables*

Four demographic and background variables were all selected from parental reports except for Asthma Severity.

a) Age was calculated (to two decimal points) as the difference in years between children's birth date and the date when questionnaires were returned (recorded every Friday). Age was then classified into three groups: 7 to 11 years (children), 12 to 14 (younger adolescents), and 15 to 19 years (older adolescents).
b) Sex was reported by parents in the telephone interview in 2001.
c) Mother's Education was reported by parents in 2001
d) Asthma Severity was reported by children and adolescents in 2001

2) *Psychosocial variables*

a) Asthma Knowledge: I know a lot about asthma
b) Asthma Trigger: There are many things that trigger my asthma
c) Parent Reminding: My parents reminds me to take asthma medication
d) Medication Side-effects: I experience side-effects
e) Asthma Perception: Asthma is not a big deal
f) Medication Self-efficacy: I know how to use inhalers so that my asthma medication goes to my lung.
g) Self-esteem: I feel good about myself
h) Number of Treatment: I have to take many asthma medication
i) Asthma Duration: I have had asthma for a long time
j) Doctor Response: My doctor answers my questions about asthma

3) Outcome variable: Child report

The outcome variable has been re-coded as "Good ('strongly disagree' and 'agree' to the statement)," "Neutral," and "Poor ('strongly agree' and 'agree' to the statement)." This scale (among several scales) was used because it measured poor adherence rather than adherence.

k) Poor Adherence: I usually take less than what my doctor prescribes

3.8 Validity of the Questionnaire

The questionnaire, a self-report instrument "School-Age Asthma Perception Questionnaire" was developed from the hypothetical model in consultation with faculty members at the University of Alberta including a pulmonary epidemiologist, a biostatistician, a pediatrician, a sociologist, and a child psychologist. As for the medication adherence measure (adherence measure is limited to medication adherence), the questionnaire employed a 5-point Likert scale and was designed to measure the extent to which children and adolescents do not adhere for various reasons from their perspective. Questions related to side effects and self-efficacy beliefs were designed similarly to those already tested in other studies and were obtained with permission (Bursch, 1999; Wong, 1998).

The Supervisory Committee reviewed all of the questions for face validity. Construct validity was established by reviewing the concepts included in the questionnaire vis-à-vis the existing literature on adherence in general and related to asthma, and the broader asthma literature (e.g. indicators of control, problems associated with asthma, asthma treatment). This literature and the expertise of the Supervisory Committee were also used to establish content validity.

Concurrent validity was established by comparing responses to the self-administered questionnaire with similar questions asked in the telephone interview (e.g. by comparing question #2: "There are many things that trigger my asthma," with the list of triggers from the telephone survey).

3.9 Data Analysis

All the data were analyzed using the Statistical Package for the Social Sciences software version 11.0 (SPSS Inc. Chicago, IL USA) on an IBM-compatible notebook computer (SONY VAIO, 2001). The descriptive statistics were presented by way of cross-tabulation. The risk factors that predicted the poor adherence of children and adolescents with asthma were examined using Multinomial Logistic regression, which is appropriate for this study because the outcome variable Poor Adherence takes on more than two values.

Objective 1: Poor adherence rate

To obtain poor adherence rates, the outcome Poor Adherence was re-scaled from 5-point (continuous) to 3-point (categorical), "Poor," "Neutral," and "Good" for the purpose of calculating poor adherence rates and examining risk factors for poor adherence. Children and adolescents who selected "strongly agree" and "agree" to the statement: "I usually take less asthma medications than what my doctor would like me to take" classified as "Poor." Poor adherence rates were calculated by those who were categorized as "Poor" divided by the total participants. The differences in the poor adherence rates between children and adolescents were analyzed using chi-square tests to see if the rate difference would be significant.

Objective 2) and 3): Risk factors for poor adherence

To examine risk factors for poor adherence, Multinomial Logistic regression (MLR) analyses were used. In the current study, MLR was used to estimate odds ratios for statistically significant demographic and psychosocial predictors for poor adherence to asthma treatment.

In building the main effects model, the purposeful selection method was used. This strategy involves several steps: unadjusted or univariable MLR and adjusted or multivariable Multinomial Logistic regression. In a univariable MLR model,

the predictors were examined one at a time. Predictors with p value based on chi-square of less than 0.2 were selected. In adjusted or multivariable MLR, identification of significant predictors whose p-values based on chi-square and Wald's tests less than 0.05 were selected. The odds ratios for those significant predictors were estimated.

3.10 Summary

In order to examine poor adherence in children and adolescents, participants were recruited from an existing cohort. The data were collected by way of questionnaire and analyzed to determine the rates of poor adherence and the risk factors for poor adherence. The final model was obtained after analyzing four demographic and background and ten psychosocial variables by using a Multinomial Logistic regression method. The rate of poor adherence and the identified risk factors for poor adherence were further examined to see if they differed significantly between children and adolescents.

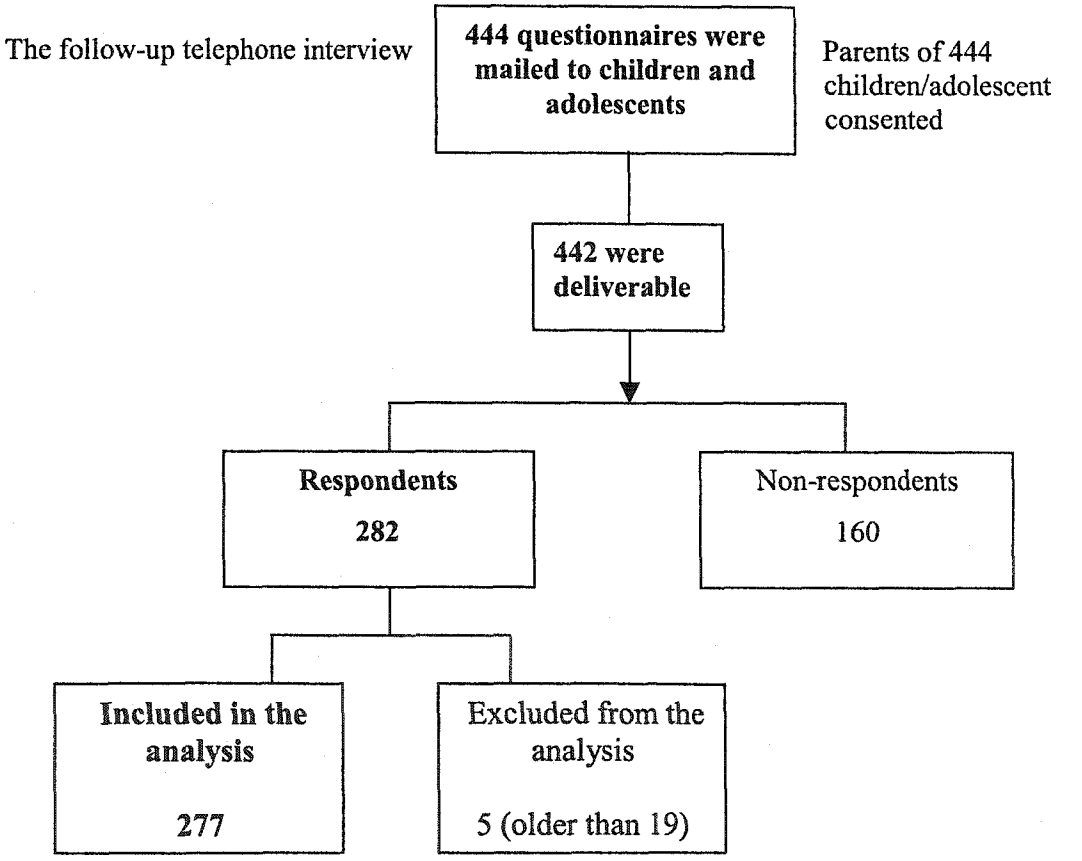
The next chapter, Chapter 4, presents the results of the research.

CHAPTER 4

Study Results

Of the parents of 460 children and adolescents interviewed in the follow-up interview, 444 agreed to allow their children to participate in the current study. Questionnaires were mailed to their children. The response rate was 64%, or 282 responded. Five were excluded because they were older than 19. Figure 4.1 shows the procedure and result.

Figure 4.1: Research participants



4.1 Respondents and Non-respondents

To examine whether the reasons for non-response were significantly related to the outcome under study, a proxy measure reported by parents was used for the outcome. The respondents and the non-respondents did not differ significantly in terms of adherence as shown in Table 4.1. The two groups differed significantly in emergency room visits, motivation at school and in sport, and parental marital status. Only 9% of the parents of the respondents were divorced or separated while 20% of the parents of the non-respondents were divorced or separated.

Table 4.1: Respondents and non-respondents*

	Respondents N = 282	**Non-respondents N = 178**	**Significance****
	Mean (SD) or %	**Mean (SD) or %**	**p-value**
Mean age (yrs)***	13.5 (3.3)	13.3 (3.3)	0.54
Sex (male %)	58.5	57.3	(0.98)
Town (Red Deer %)	46.1	43.3	(0.58)
Adherence on-schedule (4-1)	1.4 (0.7)	1.3 (0.6)	0.17
Missed school days (days)	0.7 (1.6)	1.2 (7.6)	0.36
Emergency room visits (days)	0.2 (0.6)	2.1 (1.5)	<0.01
Motivation at school (1-4)	2.9 (1.1)	2.2 (1.1)	<0.01
Motivation in sport (1-4)	3.0 (1.1)	2.3 (1.5)	<0.01
Parental marital status (divorced or separated %)	9.0	20.0	(<0.01)

*The information was derived from the parental-report in 2001.
**For significance, *t* tests were used, and chi-square test-results were in the bracket.
***Age was calculated by using the interview date only for the comparison.

4.2 Descriptive Statistics

Demographics: age and sex distribution

After the inclusion and exclusion criteria were met, 277 participants were identified out of 282 respondents. The mean age of entry to this study was 13.7 years. (This value differed from the mean age in Table 4.1 because it was calculated by using the response date instead of the interview date.) One third of the eligible participants were under 12 years.

The Age-Sex distribution of the participants is shown in Table 4.2. Seventy percent of the children were male; 54.5 % of young adolescents were male; 51.5% of older adolescents were male. The proportion of male decreased as the age increased. The sex or gender difference in poor adherence decreased from younger adolescence to older adolescence.

Table 4.2: Age-Sex distribution of the participants

	Children (7-11) N = 99		**Adolescents (12-14) N = 77**		**Older Adolescents (15-19) N = 101**	
	n	**%**	**n**	**%**	**n**	**%**
Sex						
Male	69	69.7	42	54.5	52	51.5
Female	30	30.3	35	45.5	49	48.5

Asthma severity

Approximately 60% of participants had mild asthma, and the remaining 40% had either moderate or severe asthma. Those with severe asthma (2%) were grouped with those with moderate asthma.

Asthma medications

As shown in Table 4.3, in the current study, the most often used asthma medication is Ventolin or salbutamol (35.5%), followed by Flovent or fluticasone (25.4%). Ventolin or salbutamol is a bronchodilator, and Flovent or fluticasone is a corticosteroid. Many of their children also reported that they took two kinds of inhaled asthma medications, bronchodilators and corticosteroids.

Asthma medications are mostly delivered by way of inhalers including a regular inhaler, a turbohaler, and a diskhaler. In the current study, these three forms of inhalers were grouped together, and only the names of the medications were listed separately.

Table 4.3: Most often used asthma medications

Name	Type	%
Ventolin (salbutamol)	Bronchodilator	35.5
Flovent (fluticasone)	Corticosteroid (inhaled)	25.4
Pulmicort (budesonide)	Corticosteroid (inhaled)	13.6
Singulair (montelukast)	Antileukotriene	7.7
Bricanyl (terbutaline)	Bronchodilator	4.2
Others:		13.6
Non-inhaled corticosteroid; Inhalers; Beclovent/Becloforte (beclomethasone); Serevent (salmeterol); Accolate (zafirlukast); Intal (sodium cromoglycate)		

Asthma triggers

Parents reported that 27% of their children had 7 to 10 asthma triggers. Approximately 30% of the participants had more than 10 asthma triggers. The maximum number of asthma trigger was reported to be 19.

Psychosocial variables

Table 4.4 shows the mean and standard deviation of psychosocial variables. Asthma Duration has the highest value, 4.2, and Medication Side-effects has the lowest value, 2.0.

Table 4.4: Mean and standard deviation of psychosocial variables*

	Mean	Standard Deviation
Asthma Knowledge	**3.5**	**0.9**
Asthma Trigger	**3.3**	**1.2**
Parent Reminding	**3.3**	**1.3**
Medication Side-effects	**2.0**	**1.2**
Asthma Perception	**3.4**	**1.3**
Medication Self-efficacy	**3.9**	**1.0**
Doctor Response	**3.0**	**0.9**
Self-esteem	**4.3**	**0.9**
Treatment Number	**2.3**	**1.1**
Asthma Duration	**4.2**	**1.0**

*All the psychosocial variables have minimum value of 1 and maximum value of 5

Degree of adherence stratified

1) Demographic and background variables

Table 4.5 shows the degree of adherence stratified by demographic and background variables. Among those who reported to be poor adherers, 20.9% were children aged 7 to 11 years, 31.3% were younger adolescents aged 12 to 14 years, and 47.8% were older adolescents aged 15 to 19 years. Among the poor adherers, 53.7% were males while 56.2% of adherers were males. While 67.3% of the mothers of the poor adherers attended or graduated from college, 65.5% of the mothers of the adherers attended or graduated from college. Among the poor adherers, 65.2% had mild asthma while 50.4% of adherers had mild asthma.

2) Psychosocial variables

Tables 4.6a, 4.6b, and 4.7c show the degree of adherence stratified by the psychosocial variables. While 59.7% of poor adherers reported that their parents reminded them to take asthma medication, only 45.3% of adherers did. While 23.9% of poor adherers experienced medication side effects, 14.6% of adherers experienced medication side-effects. While 62.7% of poor adherers did not feel that they experienced medication side-effects, 78.4% of adherers did not feel that they did. Among poor adherers, 64.1% thought "asthma is not a big deal," while among adherers 41.8% thought "asthma is not a big deal." (Only 13.5% of poor adherers, as compared with 38.0% of adherers, considered asthma as a serious problem.) While 7.5% of poor adherers did not believe that they could use their inhalers correctly, 2.2% of adherer did not believe that they could use their inhalers correctly. (If "neutral" was added to those who did not feel that they could use their inhalers correctly, approximately 20% of poor adherers were not sure if they could use their inhalers correctly while about 13% of adherers were not sure if they could use their inhalers correctly.) While 12.0% of poor adherers did not feel that they had asthma for a long time, 6.2% of adherers did not feel that they had asthma for a long time.

Table 4.5: Distribution of demographic characteristics by degree of adherence

	Degree of Adherence		
	Poor	**Neutral**	**Good**
	N = 67	**N = 78**	**N = 130**
	%	**%**	**%**
N = 275*			
Age**			
7-11	20.9	33.3	44.6
12-14	31.3	25.7	27.7
15-19	47.8	41.0	27.7
Sex**			
Male	53.7	66.7	56.2
Female	46.3	33.3	43.8
Mother's Education**			
7-12th grade	10.3	4.1	7.4
High School graduate	22.4	23.0	27.1
College attended	10.4	12.1	13.9
College graduated	56.9	60.8	51.6
Asthma Severity***			
Mild	65.2	70.5	50.4
Moderate and Severe	34.8	29.5	49.6

*There two missing values in each variable except for Asthma Severity, which had four missing values.
**Information regarding Age, Sex, and Mother's Education was provided by parents.
***Information regarding Asthma Severity was provided by children and adolescents.

Table 4.6a: Distribution of psychosocial factors by degree of adherence

	Degree of Adherence		
	Poor	**Neutral**	**Good**
	N = 67	**N = 78**	**N = 130**
	%	**%**	**%**
Asthma Knowledge*: I know a lot about asthma			
1 "Strongly disagree"	4.5	1.3	3.8
2 "Disagree"	13.4	14.1	12.8
3 "Neutral"	32.8	23.1	24.7
4 "Agree"	40.3	51.3	42.3
5 "Strongly agree"	9.0	10.2	16.9
Asthma Trigger*: I have many asthma triggers			
1 "Strongly disagree"	4.5	7.7	6.9
2 "Disagree"	25.3	25.6	23.8
3 "Neutral"	19.4	23.1	20.0
4 "Agree"	29.9	32.1	29.3
5 "Strongly agree"	20.9	11.5	20.0
Parent Reminding*: My parents remind me to take asthma medication			
1 "Strongly disagree"	11.9	7.7	13.9
2 "Disagree"	13.5	16.7	21.6
3 "Neutral"	14.9	26.9	19.2
4 "Agree"	41.8	34.6	23.8
5 "Strongly agree"	17.9	14.1	21.5
Medication Side-effects*: I experience side-effects from asthma medications			
1 "Strongly disagree"	35.8	46.2	46.9
2 "Disagree"	26.9	30.8	31.5
3 "Neutral"	13.4	16.6	6.9
4 "Agree"	19.4	3.8	11.5
5 "Strongly agree"	4.5	2.6	3.1

Table 4.6b: Distribution of psychosocial factors by degree of adherence (continued)

	Degree of Adherence		
	Poor	**Neutral**	**Good**
	N = 67	**N = 78**	**N = 130**
	%	**%**	**%**
Asthma Perception**: Asthma is not a big deal for me			
1 "Strongly disagree"	6.0	5.1	17.8
2 "Disagree"	7.5	19.2	20.2
3 "Neutral"	22.4	15.4	20.2
4 "Agree"	31.3	34.7	24.0
5 "Strongly agree"	32.8	25.6	17.8
Medication Self-efficacy*: I know how to use an inhaler			
1 "Strongly disagree"	3.0	0.0	1.5
2 "Disagree"	4.5	0.0	0.7
3 "Neutral"	11.9	7.7	3.1
4 "Agree"	32.8	34.6	36.2
5 "Strongly agree"	47.8	57.7	58.5
Self-esteem**: I feel good about myself			
1 "Strongly disagree"	3.0	1.3	3.1
2 "Disagree"	4.5	0.0	2.3
3 "Neutral"	11.9	5.2	7.7
4 "Agree"	41.8	36.4	34.6
5 "Strongly agree"	38.8	57.1	52.3
Number of Treatment*: I have to take many asthma medications			
1 "Strongly disagree"	26.9	34.6	20.8
2 "Disagree"	38.8	34.6	45.4
3 "Neutral"	13.4	16.7	12.3
4 "Agree"	19.4	12.8	13.8
5 "Strongly agree"	1.5	1.3	7.7

Table 4.6c: Distribution of psychosocial factors by degree of adherence (continued)

	Degree of Adherence		
	Poor	**Neutral**	**Good**
	N = 67	**N = 78**	**N = 130**
	%	**%**	**%**
Doctor Response*: My doctor answers my questions about asthma			
1 "Strongly disagree"	0.0	1.3	3.1
2 "Disagree"	6.1	1.3	1.5
3 "Neutral"	24.2	35.9	20.0
4 "Agree"	39.4	34.6	36.9
5 "Strongly agree"	30.3	26.9	38.5
Asthma Duration*: I have asthma for a long time			
1 "Strongly disagree"	3.0	3.8	0.8
2 "Disagree"	9.0	6.4	5.4
3 "Neutral"	10.4	16.7	4.6
4 "Agree"	37.4	35.9	30.0
5 "Strongly agree"	40.3	37.2	59.2

*N = 275: there were two missing values.
**N = 274: there were three missing values.

4.3 Poor Adherence Rate

Overall poor adherence rate

Table 4.7 shows overall poor adherence rate. In calculating poor adherence rates, those who agreed to the statement were identified as poor adherers, those who selected neutral as neutral, and those who disagreed to the statement were identified as adherers. Poor adherence rate for all the participants, therefore, was 25%.

Table 4.7: Poor adherence rates (re-scaling from 5-point to 3-point)

	Frequency n	**Percentage (Rate) %**
N = 275*		
1) " Strongly agree" or "Agree" to the statement: I usually take less than what my doctor would like me to take	67	24.3
2) "Neutral"	78	28.4
3) "Strongly disagree" or "Disagree" to the statement: I usually take less than what my doctor would like me to take	130	47.3

*There were two missing values

Age (group)-specific poor adherence

Table 4.8 shows age groups, children, younger adolescents, and older adolescents, stratified by degree of adherence, poor, neutral, and good. It shows the rate or proportion of poor adherence within each age group. The rate of poor adherence was 14.3% for children, 27.2% for younger adolescents, and 32.0% for older adolescents. The rate of poor adherence increased as age increased ($p = 0.01$). The rate difference between children and younger adolescents was 12.9%, and the rate difference between children and older adolescents was 17.7%.

Table 4.8: Distribution of age by degree of adherence**

	Degree of Adherence					
	Poor		Neutral		Good	
	n	%	n	%	n	%
Total N = 275*						
Age						
7-11 (N = 98)	14	14.3	26	26.5	58	59.2
12-14 (N = 77)	21	27.2	20	26.0	36	46.8
15-19 (N = 100)	32	32.0	32	32.0	36	36.0

*There were two missing values.
**p-value based on chi-square was 0.01

Age- and Sex-specific poor adherence

Age-specific poor adherence shown in Table 4.8 is further stratified by sex (161 boys and 114 girls), and the result is shown in Table 4.9. It shows distribution of degree of adherence by age and sex. In children, 16.2% of the boys were poor adherers while 10% of the girls were poor adherers. In younger adolescence, 21.4% of the boys were poor adherers while 34.3% of the girls were poor adherers. In older adolescence, 31.4% of the boys were poor adherers while 32.6% of the girls were poor adherers.

Table 4.10 shows that only the difference in degree of adherence between older adolescents and children was statistically significant. The difference in degree of adherence between younger adolescents and children was not statistically significant.

Table 4.9: Distribution of degree of adherence by age group and sex

	Degree of Adherence					
	Poor		Neutral		Good	
	n	%	n	%	n	%
Children 7-11						
Male (N = 68)	11	16.2	20	29.4	37	54.4
Female (N = 30)	3	10.0	6	20.0	21	70.0
Younger Adolescents 12-14						
Male (N = 42)	9	21.4	14	33.3	19	45.3
Female (N = 35)	12	34.3	6	17.1	17	48.6
Older Adolescents 15-19						
Male (N = 51)	16	31.4	18	35.3	17	33.3
Female (N = 49)	16	32.6	14	28.6	19	38.8

Table 4.10: Significance of difference in degree of adherence between age groups

	Children 7-11 p-value*	Adolescents 12-14 p-value*	Adolescents 15-19 p-value*
Children 7-11	-	0.09	0.002
Adolescents 12-14	-	-	0.35
Adolescents 15-19	-	-	-

*p-value was based on the chi-square tests (2 degree of freedom each)

Child-reported and parental-reported poor adherence

Table 4.11 shows correlation between child report and parental report for poor adherence. In male children and adolescents, the correlation steadily decreased from 0.428 in children to 0.116 in younger adolescents and to 0.051 in older adolescents. In female children and adolescents, it decreased from 0.283 in children to 0.111 in younger adolescents but increased to 0.273 in older adolescents.

Table 4.11: Correlation between child and parental reports of poor adherence

	Correlation
Children	
Male	0.428
Female	0.283
Younger adolescents	
Male	0.116
Female	0.111
Older adolescents	
Male	0.051
Female	0.273

Table 4.12a shows mean of adherence obtained from parental report, for each degree of poor adherence reported by their children, which was used to measure

poor adherence. Among those who selected "Strongly Disagree," meaning "very good adherence," the mean of adherence reported by their parents was 1.3, which was between 1:"all" and 2:"most" of asthma medications that their children were taking. Both reports were consistent. Among those who selected "Disagree" meaning "good adherence," the mean of adherence was 1.4. Both reports were consistent. Among those who selected "Neutral," the mean was 1.3. Among those who selected "Agree" and "Strongly Agree," the mean was 1.8 and 1.7 respectively. Those two levels of adherence were not consistent in the two reports. The correlation coefficient between the two reports was 0.200 (significant).

Table 4.12a: Distribution of parental report of poor adherence by child-report of poor adherence

	Mean (SD) **Poor adherence** **(Parental-report)** **1 – 4**
N = 275*	
Poor Adherence	
(Child-report)	
1 "Strongly Disagree"	1.3 (0.5)
2 "Disagree"	1.4 (0.6)
3 "Neutral"	1.3 (0.6)
4 "Agree"	1.8 (1.2)
5 "Strongly Agree"	1.7 (0.9)

*There were two missing values.

Multinomial Logistic Regression Analysis

Unadjusted or univariable analysis

Table 4.13 shows unadjusted analysis for all the variables in the study. Only the statistically significant variables ($p<0.2$) were selected for further analysis.

Table 4.13: Selection of predictors for multivariable multinomial logistic regression

Variable	Likelihood Ratio Test	Degree of Freedom	Significance p-value	Decision to Include
Age	12.69	4	0.009	IN
Sex	3.11	2	0.21	OUT
Mother's Education	3.54	6	0.74	OUT
Asthma Severity	9.33	2	0.009	IN
Asthma Knowledge	2.06	2	0.36	OUT
Asthma Trigger	1.56	2	0.46	OUT
Parent Reminding	1.49	2	0.47	OUT
Medication Side-effects	6.13	2	0.047	IN
Asthma Perception	16.74	2	<0.001	IN
Medication Self-efficacy	7.37	2	0.03	IN
Self-esteem	6.84	2	0.03	IN
Number of Treatment	3.64	2	0.16	IN
Asthma Duration	12.91	2	0.002	IN
Doctor Response	2.75	2	0.25	OUT

Adjusted or multivariable analysis

Table 4.14 shows the results from the adjusted multinomial analysis. From this list, non-significant variables (p>0.05) Asthma Severity, Self-esteem, and Treatment Number were excluded. Medication Side-effects was included in the model despite the insignificant p-value (0.07) based on chi-square, since the p-value based on Wald's test was significant (0.026). Therefore, in the initial multinomial logistic regression, Age, Medication Side-effects, Asthma Perception, Medication Self-efficacy, and Asthma Duration were included in the model.

Table 4.14: Significance of predictors in the initial multinomial logistic regression

Variable	Likelihood Ratio Test	Degree of Freedom	Significance p-value	Decision to Include
Age	13.43	4	0.009	IN
Asthma Severity	1.88	2	0.39	OUT
Medication Side-effects*	6.45	2	0.07	IN
Asthma Perception	9.76	2	0.008	IN
Medication Self-efficacy	6.27	2	0.043	IN
Self-esteem	1.99	2	0.37	OUT
Number of Treatment	0.32	2	0.85	OUT
Asthma Duration	6.60	2	0.04	IN

*Medication side-effects was included in the model because p-value based on Wald's test was significant

Assessment of the predictors which were removed previously

Several selected predictors previously excluded were brought back to the model one at a time and assessed their significance with the variables that were already in the model being controlled. Among them, Parent Reminding was found to be significant and was included in the model. Therefore, the final model included six variables, one demographic and five psychosocial variables: Age, Parent Reminding, Medication Side-effects, Asthma Perception, Medication Self-efficacy, and Asthma Duration.

Table 4.15 shows the significance of the six predictors for poor adherence based on likelihood ratio tests as well as degree of freedom in the final multinomial logistic regression.

Table 4.15: Significance of predictors in the final multinomial logistic regression

Variable	Likelihood Ratio Test	Degree of Freedom	Significance p-value	Decision to Include
Age	17.54	4	0.002	IN
Medication Side-effects	6.29	2	0.04	IN
Asthma Perception	15.89	2	<0.001	IN
Medication Self-efficacy	8.11	2	0.02	IN
Parent Reminding	7.09	2	0.03	IN
Asthma Duration	9.44	2	0.009	IN

Final Model

The final model and the coefficients are shown in Table 4.16a and 4.16b. Table 4.16a shows odds ratios of the predictors for poor adherence included in the final model. Table 4.16b shows the odds ratio for "Neutral" group.

In Table 4.16a, the final model included one demographic variable, Age, and five psychosocial variables: Medication Side-effects, Asthma Perception, Parent Reminding, Medication Self-efficacy, and Asthma Duration. All the variables except for Medication Self-efficacy and Asthma Duration had positive influence on poor adherence. An increase in Age, Medication Side-effects, Asthma Perception, or Parent Reminding promoted poor adherence or hampered adherence. A decrease in Medication Self-efficacy or Asthma Duration promoted poor adherence. In Table 4.16b, age group of 15-19 (OR: 2.43), perception of asthma (OR: 1.30) and duration of asthma (OR: 0.62) were predictors for "Neutral."

Table 4.16a: Odds ratios for poor adherence compared with good adherence

Variable	Odds ratio	95% CI		Significance p-value
		Lower	Upper	
Age				
7-11	1.00			
12-14	2.81	1.18	6.67	0.02
15-19	5.15	2.21	11.99	<0.001
Medication Side-effects	1.35	1.02	1.79	0.03
Asthma Perception	1.69	1.28	2.24	<0.001
Medication Self-efficacy	0.64	0.43	0.95	0.03
Parent Reminding	1.41	1.07	1.86	0.01
Asthma Duration	0.70	0.50	1.00	0.05

Table 4.16b: Odds ratios for "Neutral" group compared with good adherence group

Variable	Odds ratio	95% CI Lower	95% CI Upper	Significance p-value
Age				
7-11	1.00			
12-14	1.25	0.59	2.65	0.56
15-19	2.43	1.18	4.99	0.02
Medication Side-effects	0.96	0.72	1.26	0.74
Asthma Perception	1.30	1.28	2.24	0.03
Medication Self-efficacy	1.15	0.76	1.77	0.51
Parent Reminding	1.25	0.98	1.60	0.07
Asthma Duration	0.62	0.45	0.86	0.003

Interaction

There was no interaction among predictors in the model.

Confounding

No variables which were previously excluded from the model were found to be confounders in the model.

Model fit

Pearson Chi-square is less than 0.01, which means that all the variables in the model contribute to the model fit. Goodness-of-fit Chi-square is 0.098 which is more than 0.05 indicating that the model matches the data reasonably.

Risk factors for poor adherence

Table 4.16a shows odds ratios (OR) and 95% confidence intervals (CI) of the predictors for poor adherence. The most powerful risk factor was age. Older adolescents aged 15 to 19 were at the highest risk. Older adolescents were five times more likely to be poor adherers than children. Younger adolescents were almost three times more likely to be poor adherers than children.

In addition to age, perceptions of asthma, medication side-effects, parental reminders to take asthma medications, lack of medication self-efficacy, and short duration of asthma were found to be risk factors for poor adherence. As one unit increased in perception of asthma, a 1.7-unit increase was observed in poor adherence. As one unit increased in medication side-effects, a 1.4-unit increase was observed in poor adherence. As one unit increased in parental reminders to take asthma medications, a 1.4-unit increase in poor adherence was observed. As one unit in duration of asthma or medication self-efficacy increased, approximately 30% reductions in poor adherence was observed.

When "Neutral" group was compared with "Good" adherent group, older adolescents were at highest risk (OR = 2.4) but the risk was not as high as it was in "Poor" Adherence. Older adolescents were 2.4 more likely to select "Neutral" (over "Good") than children. Although perception of asthma was significant, its impact was small. The OR was less than 2. Duration of asthma was significant, and its impact was significant. The OR was 0.6. Duration of asthma had a protective effect on "Neutral": long duration promoted adherence or short duration promoted neutral.

Stratified analysis

Table 4.17a and Table 4.17b show the results of the stratified analyses. The stratified analyses were performed based on the hypothesis that children might have different reasons for poor adherence than adolescents.

Five psychosocial variables were significant in the model, but the homogeneity of the significance across the three age groups was not tested. Instead, a stratified analysis or an analysis within each age group across all three groups using the same model was performed. The results are the following.

1) Children

None of the psychosocial factors were significant in children. Short duration of asthma was a risk factor for "Neutral." The odds ratio was 0.60 (CI: 0.37-0.99).

2) Adolescents

Risk for poor adherence was the highest in older adolescents as shown in Table 4.16a and 4.16b in both "Poor" and "Neutral" groups compared with "Good" group. The odds ratio for poor adherence was 2.81 for younger adolescents and 5.15 for older adolescents compared with children. Medication side effects were predictors in Table 4.16a, but not shown to be a predictor in the stratified analyses. The stratified analyses also show that perception of asthma was significant in older adolescents but not in children or younger adolescents. The odds ratio was 2.69 (CI: 1.44-5.03). Medication self-efficacy was significant only in younger adolescents. The odds ratio was 0.45 (CI: 0.20-0.98). Parental reminders to take asthma medications were significant only in older adolescents. The odds ratio was 3.06 (CI: 1.49-6.29). Duration of asthma was significant only in older adolescents. The odds ratio was 0.47 (CI: 0.23-0.70).

The model explained 40% of poor adherence in older adolescents. This portion of poor adherence in older adolescents was explained by perception of asthma, parental reminders to take asthma medications, and duration of asthma.

Table 4.17b shows age group specific analysis for "Neutral" group compared with "Good" group. No psychosocial factors were risk factors for "Neutral" in younger adolescents. Perception of asthma was a risk factor for "Neutral" in older adolescents. The odds ratio was 1.76 (CI: 1.07-2.89).

Table 4.17a: Age group specific analysis for "Poor" adherent group with "Good" adherent group

	OR	95% CI Upper	95% CI Lower	Significance p-value
Children 7-11 (n = 98)				
Medication Side-effects	1.26	0.73	2.19	0.41
Asthma Perception	1.54	0.92	2.58	0.10
Medication Self-efficacy	0.62	0.34	1.12	0.11
Parent Reminding	1.44	0.80	2.60	0.23
Asthma Duration	0.86	0.45	1.63	0.64
Adolescents 12-14 (n = 77)				
Medication Side-effects	1.16	0.72	1.85	0.54
Asthma Perception	1.51	0.97	2.34	0.07
Medication Self-efficacy	0.45	0.20	0.98	0.045
Parent Reminding	1.03	0.69	1.53	0.90
Asthma Duration	0.81	0.43	1.51	0.50
Adolescents 15-19 (n = 100)				
Medication Side-effects	1.51	0.87	2.61	0.14
Asthma Perception	2.69	1.44	5.03	0.002
Medication Self-efficacy	0.58	0.23	1.46	0.25
Parent Reminding	3.06	1.49	6.29	0.002
Asthma Duration	0.47	0.23	0.70	0.04

Table 4.17b: Age group specific analysis for "Neutral" group compared with "Good" adherent group

	OR	95% CI Upper	95% CI Lower	Significance p-value
Children 7-11 (n = 98)				
Medication Side-effects	1.09	0.70	1.71	0.70
Asthma Perception	0.99	0.68	1.43	0.95
Medication Self-efficacy	1.28	0.66	2.49	0.46
Parent Reminding	0.93	0.60	1.46	0.76
Asthma Duration	0.60	0.37	0.99	0.046
Adolescents 12-14 (n = 77)				
Medication Side-effects	0.86	0.52	1.41	0.54
Asthma Perception	1.41	0.92	2.16	0.11
Medication Self-efficacy	0.81	0.35	1.89	0.63
Parent Reminding	1.34	0.91	1.98	0.14
Asthma Duration	0.62	0.34	1.14	0.12
Adolescents 15-19 (n = 100)				
Medication Side-effects	0.94	0.54	1.65	0.84
Asthma Perception	1.76	1.07	2.89	0.03
Medication Self-efficacy	1.22	0.50	2.96	0.66
Parent Reminding	1.48	0.89	2.49	0.16
Asthma Duration	0.62	0.32	1.21	0.13

4.4 Summary

The overall prevalence or rate of poor adherence was approximately 25%. The rate of poor adherence increased as children became older, or as children became adolescents. The rate of poor adherence was 14% for children, 27% for younger adolescents, and 32% for older adolescents.

The final model included age, perception of asthma, medication side-effects, lack of self-efficacy in using inhalers, parental reminders to take asthma medications, and short duration of asthma as risk factors for poor adherence. An older adolescent was at high risk, more than five times as high as a child, for poor adherence. A younger adolescent was also at high risk, almost three times as high as a child, for poor adherence.

When the children and adolescents were stratified by age group, medication side-effects were not a risk factor for poor adherence. Psychosocial factors were found to be risk factors for poor adherence only in adolescence. Perception of asthma, lack of self-efficacy in using inhalers, parental reminders to take asthma medication, and short duration of asthma were risk factors for poor adherence in adolescence. A younger adolescent who did not think that he or she could use his or her inhaler properly was also at risk for poor adherence. An older adolescent who underestimated the seriousness of asthma, who felt that his or her parents often reminded him or her to take asthma medications, or who did not feel that he or she had had asthma long enough was also at risk for poor adherence.

CHAPTER 5

Discussion and Conclusion

This chapter provides a discussion and conclusion. A discussion of research methods and findings is presented.

5.1 Discussion

The aim of the current study was to calculate the rate of poor adherence to asthma treatment and to investigate the importance of psychosocial factors, in addition to demographic and background factors, in the prediction of poor adherence in children and adolescents aged 7 to 19 years in Alberta. Their prevalence (or rate) of poor adherence was found to be 25%, and this finding involved various factors. The current study examined demographic, background, and psychosocial variables as risk factors for poor adherence.

Validity of the current study

The current study's validity was assessed in several ways including the assessment of the method of selection of the participants, the response rate, the generalizability, and the power of the study. Although the original cohort had been randomly selected, there were several issues associated with the method that needed to be addressed.

The initial cohort was recruited by using a two-stage cluster sampling method. Elementary, secondary, and high schools were randomly selected in two Alberta communities, Red Deer and Medicine Hat, to examine asthma prevalence. All the students in these schools were included. Take-home surveys were distributed to the students so that their parents could answer them. Parents of approximately 5,000 students from each community, who included children and adolescents with

and without asthma, responded to the initial survey. The average (school) response rate was approximately 85%. From these students, those with and without asthma were randomly selected for a case-control study. Those students aged 5 to 19 years who had ever had asthma were the initial cohort. (Although all their parents were interviewed, and data were collected from them, only those who had current, physician-diagnosed asthma were selected for the current study.)

Two years later in 2001, the parents of those asthmatic children were contacted for a follow-up telephone interview. During the interview, they were asked if their children could participate in the current study. Questionnaires were mailed to children and adolescents whose parents had agreed. By sending letters, the author tried to encourage as many as possible to respond to the survey, but after the second request the response rate was still 64%. The author then attempted a telephone interview with those who had not responded, but ethical approval to interview them was not received from the University of Alberta Health Research Ethics Board Panel B. Therefore, the final response rate was 64%.

Since as many as 36% of the questionnaires were not returned, the author examined the difference between the respondents and the non-respondents in order to avoid possible non-response bias in relation to the outcome factor or (poor) adherence. By using a proxy, adherence was compared between respondents and non-respondents, and these two groups were found not to differ in terms of adherence to asthma treatment.

About 10% of the responses had at least one missing value. This problem might have threatened the validity of the findings. Therefore, a letter and the page where missing values had been found were mailed asking those who had missing values to answer all the questions. This letter significantly improved the quality of the data, resulting in minimal missing values.

The current study may not have external validity or generalizability, especially for children and adolescents with severe asthma. The participants were selected only from an existing cohort, which was much smaller than the initial cohort.

Therefore, the study might have missed many children and adolescents who were not in the cohort and also those who were in the cohort but did not respond to our survey. Many children and adolescents with severe asthma, and who might have had problems with taking asthma medications, might have been missed.

In order to collect the data, the parents were instructed to advise their children to answer the questionnaire, which the children were not directly asked to complete. Parental instruction might have influenced the children's answers, but the author thought this approach might ensure that the questionnaire would be answered and returned promptly.

The current study was not able to reject the null hypothesis that children and younger adolescents were the same in terms of poor adherence rate, although the rate difference between children and older adolescents was significant. A significant difference might have existed between children and younger adolescents, but the study did not have adequate power (less than 0.80) to detect the rate difference between them (Rosner, 2000).

In spite of the problems discussed above, the author feels that the study was able to examine the rate of poor adherence for children and adolescents and to determine the difference between them. The study was also able to identify risk factors for poor adherence to asthma treatment and compare them between children and adolescents. In comparing the rate of poor adherence and risk factors for poor adherence in children and adolescents, using the same questionnaire was critical to obtain valid results.

Respondents and non-respondents

The author tried to use all the available and relevant variables for both respondents and non-respondents. Ensuring that the two groups did not differ in terms of poor adherence was critical. Since no common variable could be used to compare them, a proxy reported by parents was used. The mean adherence did not differ between the two groups. If the mean adherence of respondents had

been significantly higher than that of non-respondents, the rate of poor adherence estimated in the current study might have been underestimated. Non-respondents were sicker and less motivated than respondents. Non-respondents had significantly higher mean of emergency room visits than respondents. However, mean is sensitive to extreme values and might not be a good statistic in this case. Possibly, those who were sick might not have felt that asthma medications were helping them and hence were not motivated to participate in the current study.

The children and adolescents might have had many reasons for not responding to the survey even though their parents had wanted them to. Since the school term was almost over and summer vacation was near, the children and adolescents probably did not have enough time to answer the questions, as many as 38 and more, before going away for the summer. Children and adolescents living with a divorced parent might have gone away for the summer to visit their other parent and forgotten to take the questionnaire with them.

Asthma epidemiology

The initial survey (Hessel, 2001) in 1999 found that the prevalence of asthma was higher in Medicine Hat (17.0%) than Red Deer (12.8%). In the current study, approximately an equal number of respondents were from each community. According to the survey, in both Red Deer and Medicine Hat, the prevalence was higher for boys than girls below the age of 15 years and higher for girls between the ages of 15 and 19 years. That reflects the well-known fact that asthma is more prevalent among boys than girls in childhood and that both sexes have approximately equal or that girls have higher prevalence in adolescence.

The current study cannot determine asthma prevalence. However, knowing that there were more non-respondents who were boys below the age of 12 years than those observed in other age groups, the proportion of boys below the age of 12 years observed in the current study might be biased towards the same phenomenon.

Asthma medications

In the questionnaire, children and adolescents were asked about their most frequently used asthma medication. However, several key questions were not answered. First, the medicine's delivery method e.g., regular inhaler, turbuhaler, or diskhaler was not asked about in the questionnaire. Those inhalers' differences in shape and function might have affected adherence (Iqbal, 2004). Second, the current study could not investigate whether children and adolescents actually followed the correct procedure so that the asthma medicine was deposited in the respiratory tract when they took the medicine. Third, many of the children and adolescents reported only the name of the most often used medication and did not answer the question about the number of doses, which might have also affected adherence. Some answered by indicating "inhaler" without providing the name of the medication, and those answers were categorized along with "others."

Sherman et al. (2001) investigated asthma medications in relation to poor adherence and found that the odds ratio for poor adherence was 2.0 for fluticasone (corticosteroid) relative to montelukast (antileukotriene). Although fluticasone was the most often used asthma controller medication in the current study, the use of a particular medicine in relation to poor adherence was not investigated since many participants used more than one medicine.

Poor adherence (rate)

In calculating the rate of poor adherence, the author was faced with two possible definitions of it because the scale to measure poor adherence, "Poor Adherence," was categorized into three values: "Poor," "Neutral," and "Good" instead of "Poor" or "Good." Those who selected "Agree" and "Strongly Agree" were classified as "Poor," those who selected "Neutral" as "Neutral," and those who selected "Disagree" and "Strongly Disagree" as "Good" adherers. The first definition excluded "Neutral" from the "Poor" adherers, and the second definition included "Neutral" in "Poor" adherers.

According to the first definition, children and adolescents reported, compared with the literature's finding, a rather low rate of poor adherence to asthma medication use. The rate of poor adherence was 14% for children, 27% for the younger adolescents, and 32% for the older adolescents. The rate of poor adherence increased as age increased. It was found that the rate difference (13%) between children and the younger adolescent was not statistically significant, perhaps because this study included only 77 younger adolescents and did not have adequate power (less than 0.80) to detect the difference. The rate difference (18%) between children and older adolescents was statistically significant.

The second definition of poor adherence included those who selected "Neutral" on the statement. In this definition, it was assumed that those who selected "Neutral" might have been reluctant to admit that they were not adhering to their asthma treatment. By using this definition, the author found that half of all the children and adolescents were poor adherers. The author also found that the rate of poor adherence increased as the age increased as in the first definition.

Since the current study focused on poor adherence, the author decided to use only the first definition to calculate poor adherence rates. The author also examined the results in the stratified Multinomial Logistic regression analyses and felt that "Neutral" was a unique group and different from "Poor" group, and therefore, it was reasonable to use only the first definition. However, by using only the first definition, the poor adherence might have been underestimated.

Although the rate of poor adherence increased as age increased, the data of the current study could not determine that age caused poor adherence. The current study did not observe children as they grew up to be adolescents. Therefore, the current study found only that age was associated with poor adherence. In addition, although the current study grouped adolescents aged 15 years together with those aged 19 years, they might not be the same in terms of poor adherence. Tebbi (1993) reported adolescents aged 17 to 19 years adhered better than younger adolescents.

Demographic and background risk factors

Among the demographic and background factors that were investigated, only age was found to be a predictor for poor adherence. This result could be explained by various age-related factors including the levels of the participants' cognitive development and parental supervision. Age was calculated by subtracting a child's birth date from the date when the child responded to the survey, and not from the date when the parent was interviewed. The author wanted to be as precise as possible about the children's age because the current study involved developmental issues. Although sex was not a predictor for poor adherence, gender difference was observed in poor adherence.

1) Age-related factor: cognitive capacity

In the current study, an adolescent was defined as one who is 12 years old or older according to the theory of cognitive development proposed by Piaget. According to Piaget, adolescents are able to think hypothetically and in a future-oriented way. This form of thought, "formal operation" is qualitatively different from that of children, who can only manipulate tangible things.

Although puberty differs between the sexes, Piaget did not find any profound gender differences in cognitive development in children and adolescents. Probably there was a difference, but the difference was not as profound as the difference between children and adolescents, and perhaps he did not think it was important. Therefore, sex difference was ignored in defining children and adolescents. Children were defined as those aged 7 to 11 years, and adolescents were defined as those aged 12 years or older. Adolescents were further divided into two groups: 12 to 14 (younger adolescents) and 15 to 19 (older adolescents) because there were 178 adolescents as opposed to 99 children.

No scientific evidence indicates that the age of 12 years denotes the beginning of the formal operational stage, but psychologists such as Elkind (1999) interviewed children as they grew up and demonstrated that they entered into the

stage at the age of approximately 12 years. He asked children what certain proverbs meant, and they could interpret them correctly only after they had reached 12 years of age. Elkind (1999) observed a marked difference in the same child at the ages of 10 and 14 years. This may correspond to biological events such as the marked increase in neural connections (Johnson, 1997).

The author wanted to conduct the current study to compare the cognitive capacity between children, according to Piaget, in the "concrete operational" stage and adolescents in the "formal operational" stage, in relation to poor adherence. Some researchers (Creer, 1993; Kostes, 1998) who studied adherence behaviour of adolescents suggested that adolescents might differ from children in terms of the cognitive capacity which might influence their adherence behaviour. However, so far, no adherence studies included the cognitive capacity as a predictor. It might have been difficult to find a scale that could measure it.

The author found the standardized tests and wanted to administer them to children and adolescents to measure their cognitive capacity. However, the tests were very complicated and time-consuming, and hence the author decided not to use them. Instead, the author decided to use psychosocial variables thinking the difference in psychosocial variables between children and adolescents, if found, might explain that there were some differences in the cognitive capacity between them. The result might not explain the cognitive capacity indirectly.

Seifert and Hoffnung (2000) emphasized the importance of a child's stage of cognitive development, stating that "a child's ability to integrate perception into beliefs is often determined by the stage of cognitive development." Although they did not identify the ability, they were probably referring to "formal operation." An adolescent's ability to integrate perceptions into beliefs, for example, could be determined by the presence of "formal operation," which might also enable an adolescent to "translate" beliefs into poor adherence. If so, the finding that the psychosocial variables that measured perceptions (and beliefs) predicted poor adherence only in adolescents makes sense.

2) Age-related factor: parental supervision

Several studies (Conway, 1998; Fiese, 2003) indicated that parental supervision promoted adherence. Pediatric adherence to asthma treatment might involve developmentally dynamic behaviour. As children grow, responsibility for administering asthma medications might shift from total parent management for young children, to shared management for young adolescents, and to complete self-management for older adolescents.

Children would be more likely than adolescents to be supervised by their parents, and the difference might explain why the rate of poor adherence was lower in children than in adolescents. In some cases, however, the parents might believe that their children were old enough or responsible enough when they were quite young and might be expected to manage the administration of their medication. In other cases, the parents might be working, and their children might need to take care of themselves, or someone else might assume that responsibility.

Adolescents who were not supervised by their parents might develop their own attitudes, which might have contributed to poor adherence. Poor adherence among children might have been a result of parental decision not to adhere possibly because of their belief about asthma medications being unsafe (Rand, 1994) whereas adolescents might decide not to adhere based on their own experiences. Rapoff (1999) suggested that adolescents' decision not to adhere might come from an incomplete understanding of the nature of asthma and the need to take medications in the absence of symptoms.

3) Sex

In the current study, sex was not a predictor for poor adherence. Jonasson et al. (1999) and Strunk et al. (2002) also observed no significant association between sex and poor adherence. Although the sex differences were not significant, they were interesting in the context of the current study. Parents reported that, among

older adolescents, girls were more adherent than boys, but did not make the same report for younger adolescents. The reports by children and adolescents and by their parents showed that older adolescent girls were more adherent than boys while younger adolescent girls were not.

What could happen to girls during the transitional period from younger to older adolescence? Possibly, girls might become more independent before boys and want to show that they can take care of themselves. They might agree more with their parents about self-care and develop better communication with them (Seiffge-Krenke, 1998). The result might be better supervision by parents and, therefore, better adherence among girls than among boys.

On the other hand, adolescent boys might become more separated (emotionally) than adolescent girls from their parents (Gilligan, 1996), possibly resulting in less parental supervision and, hence, poorer adherence. Parents might assume that their sons were old enough to take good care of themselves and might not supervise them. The author feels that boys are given more "freedom" than girls, and that girls tend to be more closely supervised or protected by parents than boys.

The differences might also be explained by gender difference in social domain, time of sexual maturity or puberty, language skills, and moral development (Gilligan, 1996). Gilligan (1996) used the word "interdependent" to describe mature girls and "independent" to describe mature boys. As they approach adulthood, not only biological difference but also social and psychological differences may become pronounced. Although gender differences are interesting to discuss, gender was not associated with poor adherence.

4) Location

Those who lived in Red Deer were not distinguished from those in Medicine Hat in the current study. The variable "Town" was examined to see if a location made a significant difference in predicting poor adherence, but it was not significantly

associated to Poor Adherence and was removed. It was, however, possible that two towns had different asthma education programs that influenced motivation of children and adolescents to adhere to asthma treatment. In addition, their ethnic or cultural background which might have differed between the two towns and influenced poor adherence was not included in the analyses.

5) Others

Neither mother's education nor severity of asthma was a predictor of poor adherence in the final model. Most mothers attended or graduated from college, and mother's education was insignificant in an unadjusted analysis. Asthma severity, however, was significant in an unadjusted analysis but observed to be confounded by duration of asthma in an adjusted analysis. It was duration of asthma rather than asthma severity that contributed to poor adherence.

Psychosocial risk factors

Psychosocial factors could be related to cognitive capacity. Therefore, they could also be considered as age-related factors. These factors were known to affect adherence in adolescence and, in the current study, were found to be important risk factors for poor adherence only in adolescence.

1) Knowledge and self-efficacy

Knowledge of asthma was not a predictor, but self-efficacy was a predictor for poor adherence in younger adolescents. It is possible that "knowledge" was prerequisite for or implied in "self-efficacy." Those results are consistent with the finding by Bursch et al. (1999) that knowledge alone does not promote adherence and that self-efficacy with knowledge promotes adherence. Bandura (1997) states that without self-efficacy knowledge does not play a role in adherence behaviour. Bandura (1997) also argues that people with the same knowledge can demonstrate different levels of performance or bahaviour

depending on how they "orchestrate" or process their knowledge. He claims that self-efficacy beliefs play an important role in the way people "orchestrate" their knowledge that generate capabilities which lead to behaviour. An adolescent who felt that he or she knew how to use their inhaler probably also felt that he or she knew a lot about asthma, but one who felt that he or she knew a lot about asthma did not necessarily feel that he or she knew how to use his or her inhaler.

2) Medication side-effects

The perceived medication side-effects were associated with poor adherence. This finding was reasonable and consistent with a finding by Conway (1998). In stratified analyses, the factor was not a predictor. In order to detect the (small) effect observed in the analyses, the current study needed a larger sample size for each group. In the current study, this variable like others, is considered to be a psychosocial variable because the perceptions and beliefs about the medication side-effects rather than the side-effects themselves were measured.

3) Perception of asthma

Another psychosocial predictor was perception of asthma. This factor was found to be important especially in older adolescence. An older adolescent's failure to recognize that asthma was a serious problem might have resulted in failure to take asthma treatment seriously, which might have in turn influenced their decision not to adhere when he or she did not experience asthma symptoms. If an adolescent took asthma seriously, he or she might seek its treatment seriously.

Older adolescents might be sensitive to the effects of self-perception of asthma (Arnett, 2001). Asthma probably creates negative self-perceptions, and hence they may not want to think that asthma is a big deal. Therefore, the word "health" instead of "disease" should be used in relation to asthma and its medications. The statement "Asthma medications are to improve health" is more positive than "Asthma medications are to control asthma symptoms."

4) Parental reminders to take asthma medications

Another psychosocial risk factor was parental reminders to take asthma medications. Parents might exert a positive impact by not reminding older adolescents to take asthma medications but perhaps by only encouraging. This was consistent with what adolescents in a Focus Group study by Slack and Brooks (1995) reported. In their study, adolescents were not happy when their parents reminded them when adolescents remembered on their own. Possibly, when parents reminded their adolescent children, they might have said it without making sure that their children did remember. Perhaps, adolescents liked parents to recognize their need for autonomy or for being treated like an adult.

5) Duration of asthma

The study found that (perceived) short duration was associated with poor adherence in both younger and older adolescents. That makes sense if having asthma for a long time meant that children and adolescents had enough time to know about the inflammatory nature of asthma and consequently adhered better to asthma treatment. In childhood parents might need to understand the nature of asthma in order for children to adhere to the treatment while in adolescence a different approach should be taken, and the focus should be on an adolescents' own understanding.

Health Belief Model

The Health Belief Model (HBM) was developed, using "psychologic theorizing," to explain and predict preventive health-related behaviour (Janz, 1984) and considered to be the beginning of theory-based research in health behaviour. The HBM was designed to predict health-related behaviour in terms of identifiable perceptual or belief patterns, which could be barriers to adhering to treatment.

The results obtained from the current study can be viewed within the HBM framework. The current study found several barriers including medication side

effects, parental reminders to take asthma medications, perception of asthma, lack of medication self-efficacy, and short duration of asthma. An adolescent might be thinking, "I do not feel that I can use my inhaler correctly," "My parents always remind me to take my asthma medication, and I really do not like that," "I do not think asthma is a big deal," "Why do I need treatment when I do not have any symptoms?," "I have not had asthma for very long and do not know what it is about," or "I do not really understand what my asthma medications are for." These perceptions and beliefs can be considered as risk factors for poor adherence because they create barriers to adherence to asthma treatment.

Health care providers should try to explain the medication side-effects along with the positive outcome so that adolescents could understand the benefit of taking asthma medications. Health care providers should also explain the chronic or inflammatory (and serious) nature of asthma as a cause of asthma symptoms, as well as the need to take the medication in the absence of asthma symptoms. Emphasizing the prevention of asthma symptoms and the treatment of the chronic nature of asthma could be important and could be done in the context of asthma education. The importance of adhering to corticosteroid, for example, should be emphasized in the same context. In asthma education, language implying "autonomy" would be critical in order to interest adolescents.

Scale from continuous to categorical

Each scale (question) of the questionnaire was initially designed for a linear regression analysis. In the current study, the outcome variable Poor Adherence was treated as a continuous variable in the descriptive statistics, but it was treated as a categorical variable in calculating poor adherence rates and in estimating odds ratios in the final Multinomial Logistic regression model. Changing from Linear to Multinomial Logistic regression, the author needed to re-scale Poor Adherence, measured with 5-point Likert (continuous), to a categorical variable that took on three values, "Good," "Neutral," and "Poor

By allowing Poor Adherence to be a continuous variable, the author took a risk of missing the values between the discrete numbers. Some children and adolescents might have wanted to choose somewhere between "Agree" and "Strongly Agree," or between "Neutral" and "Agree," but they could not. Therefore, the author did not think it was problematic to re-categorize those five values to three values. The findings might have systematically shifted the mean either towards adherence or towards poor adherence.

Interaction

Although there was no interaction observed between age and the psychosocial variables (possibly because of insufficient sample size) in Multinomial Logistic regression analysis the author suspected that there was a difference or an age- or stage-inequality in impact of psychosocial factors. In other words, the author did not think that the psychosocial factors affected all the age groups equally. Therefore stratified analyses were performed.

As the author hypothesized, a stage-inequality was detected in the stratified analyses. The finding that psychosocial factors were significant only in adolescence suggested the need to perform stratified analyses. The author felt that adolescence or formal operation by itself was not a risk factor poor adherence but that its presence affected the effect of perceptions and beliefs on poor adherence. Seifert and Hoffnung (2000) might say that adolescents' (but not children's) perceptions could be integrated into certain beliefs. Bandura (1997) might argue that those beliefs could be "translated" into a failure to adhere. The author concludes that adolescents' perceptions can be integrated into their beliefs and then translated into a failure to adhere to asthma treatment.

Adherence to asthma treatment and asthma control

Although the current study identified perceived barriers or risk factors for poor adherence, it failed to address whether poor adherence to asthma treatment could

lead to morbidity from asthma. Not all poor adherence might lead to poor asthma control, but it was assumed, based on a result from a study conducted by Milgrom et al. (1996), that poor adherers were likely to experience more days of wheezing and more asthma attacks resulting in emergency visits and missed school days. Whether poor adherence leads to poor asthma control requires further study.

Self-report

By choosing to assess adherence solely by using self-reports, the author encountered the problem that children and adolescents might overestimate their adherence to present a good impression of themselves. Therefore, the author decided to focus on their report of poor adherence rather than adherence. Consequently only those who agreed to the statement "I usually take less asthma medications than my doctor would like me to take" were classified as "poor" adherers. Those who admitted that they were not adhering were very likely to be "honest" poor adherers.

Because the current study used self-administered questionnaires, the author wanted to ensure that the children and adolescents to whom questionnaires had been mailed answered them. The author had no way of doing so, but some factors indicated that the reports were likely to be their own. Some children, for example, wrote their signature on the last page of the questionnaire. Some adolescent girls wrote, "Good luck with your research." Some children spelled "Flovent" as "Flowvent" or spelled "Ventolin" as "Ventolen." One adolescent boy wrote, next to the statement "I feel good about myself" (self-esteem), "This has nothing to do with asthma!" The hand-writing clearly was the children's and not their parents'. One parent wrote that she had answered the name of the most often used asthma medication because her child could not spell it correctly.

In spite of the problems inherent in self-report, the author gained a better understanding of children and adolescents than would have been obtained through only objective methods such as biological assays or pill counts. It was already

known from previous studies that children and adolescents, especially adolescents, were poor adherers, and understanding the barriers that contributed to poor adherence was important to the approach. The author thought self-administered questionnaires would allow adolescents to have privacy and autonomy so that they could feel comfortable reporting honestly.

Parental report and child report of adherence

A slight discrepancy was found between the parents' and children's reports of adherence. The mean adherence reported by the parents was lower in "bad" adherence than in "worst" adherence reported by their children. It should have been higher in "bad" than in "worst" reported by their children. However, the discrepancy was not critical since "worst" and "bad" were grouped together.

This slight discrepancy might have resulted because the reports by children and adolescents and those by their parents were obtained at slightly different times. The average difference between them was approximately 0.17 years. A slight change in the participants' adherence might have occurred during this short period of time.

Summary of limitation

The current report described only part of the poor adherence issue: adherence to asthma medication use. If "avoidance of asthma triggers" or "doctors appointment" as an outcome, the rate of poor adherence and risk factors for poor adherence might have been different. However, the author felt that taking asthma medications was important to control the clinical nature of asthma and decided to examine poor adherence to asthma treatment. In addition, there were more adherence studies that examined adherence in "medication use" than in "avoidance of asthma triggers" or "doctor's appointment," and the author thought the study results would be more meaningful if the medication use was investigated than otherwise.

Although self-report was a powerful method in finding barriers it did not always measure adherence accurately. It would have been ideal to use an objective method such as pharmacy data to corroborate the finding, but because of cost and time, such information was not obtained. Although there was no way of examining whether they had reported adherence accurately, those who had reported as poor adherers were very likely to be poor adherers.

Recruiting participants from an existing cohort had both an advantage and a disadvantage. It was advantageous because the study had a higher response rate than what it could have obtained through an alternative method such as advertisement. Lower response rate would have resulted in a smaller sample size and therefore a less valid result. It was a disadvantage because other children and adolescents who were not in the cohort were missed. "Higher response rate" was chosen over "generalizability." Hennekens and Buring (1987) suggested that validity from high response rate was more important than generalizability. That made sense because there was no sense in generalizing a result that was not valid.

In spite of all the limitations, the current study has provided significant insight regarding issues that may affect children's and adolescents' adherence to asthma treatment. The author feels that the study was able to capture some of the differences in cognitive development between children and adolescents. Adolescents' perceptions of barriers can be integrated into beliefs that they exist, which then can be "translated" into poor adherence, whereas a child's perceptions and beliefs may not be able to go through the same pathway. Therefore, adolescents' perceptions or beliefs should not be treated as those of children.

Unfortunately, however, the questionnaire might not have captured the difference between perceptions and beliefs. The author had no way of determining whether the degree to which children and adolescents agreed to the statements in the questionnaire reflected what they merely perceived or what they strongly believed. However, the author trusted that they honestly reported what they thought.

5.2 Conclusion

There was a profusion of literature concerning adherence to asthma treatment. While many studies found adherence rates of children and adolescents were low and suggested the need for further studies, very few such studies were carried out. In addition, such studies that were actually carried out only examined either children or adolescents and, therefore, were unable to compare children and adolescents in terms of poor adherence rates and risk factors for poor adherence. The current study included both children and adolescents and was able to compare them and found that indeed adolescents were poorer adherers than children. It also found psychosocial variables to be significant only in adolescence.

The question is "how much did psychosocial factors account for poor adherence?" The importance of psychosocial factors in predicting poor adherence was not as significant as what we expected. Kyngas (2000) examined psychosocial variables using Binary Logistic regression and found the explained variance or R-square in her model to be almost 80%. The current study found R-square to be only 40% even in adolescence. However, she included motivation as a predictor, while the author did not, because it was highly correlated with poor adherence. If the variable motivation was included in the current study, R-square would have been much bigger than what was obtained for the model.

The current study supports the literature's finding that psychosocial factors are important risk factors for poor adherence observed among adolescents. The importance of psychosocial variables in the prediction of poor adherence in adolescents suggests that intervention might be able to change their perceptions before they become integrated into negative beliefs and "translated" into poor adherence. The author feels that identifying and understanding psychosocial "avenues" or pathways through which psychosocial factors operate and can lead to poor adherence are important. More studies are needed to find the conditions under which the psychosocial process can be modified in order to improve health.

This concludes the thesis.

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APPENDIX I: Telephone Interview with Parents

Child Asthma Survey
Administered to Parents

CATI Telephone Questionnaire

1	Telephone Number	
2	CATI Record Number	
3	Interviewer's Name	
4	Date	
5	Start Time	
6	Finish Time	

Population Research Laboratory
University of Alberta

Spring 1999/2001

Introduction and Request for Interview

Hello, my name is _____ and I am calling (long distance) from the Population Research Lab at the University of Alberta on behalf of the Alberta Asthma Centre. May I please speak with _____?

INTERVIEWER NOTE: IF PARENT UNAVAILABLE, SCHEDULE CALLBACK IF POSSIBLE. (CTRL-END TO TERMINATE).

PRESS 'I' TO CONTINUE

Last November (you/your son/daughter _____) completed a school Health survey about asthma (for your son/daughter_____ and consented to a follow-up phone call). We are calling today to do a follow-up interview with you about your child. Over the next few weeks, we will be talking with 1200 parents of children with and without asthma. The results of this study will give researchers a better understanding of factors associated with asthma and lead to better care and treatment of children with asthma.

The interview could take about 30 minutes, depending on the questions that apply to your child. Is now a convenient time?

INTERVIEWER NOTE: PRESS 'I' IF RESPONDENT WILL DO INTERVIEW NOW. IF NOT CONVENIENT TIME, ARRANGE CALLBACK TIME (CTRL-END)

Before we start, I would like to assure you that your participation is voluntary and that any information you provide will be kept confidential and anonymous. If there are any questions you do not wish to answer, please feel free to point these out to me and I'll go on to the next question. You of course have the right to terminate the interview at any time.

No one can identify individual answers in this study. If you have any questions about the survey, you may call (collect) to Dennis Michaelchuk, Research Project Manager at the Alberta Asthma Centre (at 780-407-7097) or Cathy Drixler, Project Coordinator at the Population Research Lab (at 780-492-4659) for further information.

NOTE TO INTERVIEWER: Record start time of interview.

Questions in the 1st interview with parents used for this research

1. How old was your child when his or her asthma symptoms first started?
2. When was your child born?
3. What is the sex (gender) of your child?

Questions in the 1st and 2nd interview with parents used as references for this research

1. Has your child ever had asthma?
2. Was this confirmed by a doctor?
3. How old was your child when his or her asthma symptoms first started?
4. How many attacks of asthma has he or she had in the last 12 months?
5. In a typical week, how many times does he/she take beta-agonists such as Ventolin, Serevent, or Maxair? That is, how many puffs does your child take in a typical week?
6. How many triggers does your child have?
7. How many inhaled asthma medications does your child have to take?
8. In a typical week, how often during the day does your child have asthma symptoms such as coughing, wheezing, or chest tightness?
9. Is your child limited in the amount of kind of physical activity because of his or her asthma?
10. In the past two months, how many days did your child's asthma symptoms keep him/her away from school?
11. How many times has your child visited the emergency room because of asthma problems in the last 12 months?
12. If you have asthma, how would you rate the overall severity of your asthma? (a question was also asked if the person is mother or father of the child)
    1) mild
    2) moderate
    3) severe

13. If your spouse has asthma, how would you rate the overall severity of your spouse's asthma?
    1) mild
    2) moderate
    3) severe

14. What is your current marital status?
    1) married/common-law
    2) divorced
    3) never been married

15. What is your education level?
    1) up to 12th grade
    2) high school graduate
    3) college attended
    4) college graduate

16. What is your spouse's education level?
    1) up to 12th grade
    2) high School graduate
    3) college attended
    4) college graduate

17. What are the medications that your child took in the last 12 month?

    _____

18. If your child is prescribed medicines for his/her breathing that need to be taken on a regular basis, does he/she normally take:
    1) all of the medicine
    2) most of the medicine
    3) some of the medicine
    4) none of the medicine

19. If your child is prescribed medications that are only taken when his/her breathing gets worse, does he/she normally take them:
    1) always when his/her breathing gets worse
    2) most of the time
    3) sometimes
    4) none of the time

20. (only 2nd interview) I am interested in how motivated your child is to do things. With regard to school work, would you say he/she is …
    1) highly self-motivated
    2) fairly self-motivated
    3) often motivated by others
    4) usually motivated by others
    5) don't know

21. (only 2nd interview) With regard to sports, would you say he/she is …
    1) highly self-motivated
    2) fairly self-motivated
    3) often motivated by others
    4) usually motivated by others
    5) don't know

APPENDIX II: Cover Letters

May 11, 2001

Dear

Researchers at the University of Alberta and the University of Calgary than you very much for your participation in this important Asthma study. The study began with a short take-home survey followed by a telephone interview in the spring of 1999. Recently, you participated in a telephone interview with the Population Research Laboratory at the University of Alberta, and the study we are conducting now is part of the final stage of the Asthma study in your community.

With the cooperation of the parents of children with asthma in your community, substantial information has been gained over the last two and half years. This study will help us better understand a number of issues regarding asthma in your community: percentage of school children with asthma, management of asthma, services and support for children with asthma.

In the enclosed survey, we would like to address the questions to your child. We would like to know what your child feels about asthma.

Please ask your child to complete the attached survey. This last survey would be most helpful in understanding the impact of asthma on children in your community. Please ask your child to return the completed survey in the enclosed self-addressed stamped envelope.

The decision to complete the survey is voluntary. All the details you provide will be kept confidential.

The study is made possible through funding from the Alberta Heritage Foundation for Medical Research, Merck Frosst Pharmaceuticals, Hoechst Marion Roussel/3M and Astra Pharma, Inc.

If you have any questions, please contact Mr. Dennis Michaelchuk at 407-7097.

Thank you for your help.

Sincerely,

Patrick A. Hessel, Ph. D.
Director of Epidemiology
Alberta Asthma Centre
University of Alberta

June 14, 2001

Dear Parent/Guardian:

We mailed a questionnaire to you and your child approximately four weeks ago, but have not received the completed questionnaire yet. If your son/daughter completed the questionnaire and already sent it back, we thank you both very much for your participation.

If the questionnaire has not been completed and mailed, we would be grateful to receive it at your earliest convenience. We have enclosed a second questionnaire and a stamped return envelope. We realize this is a busy time of the year for you and your family, with the school year ending and holidays approaching, but if your son/daughter would complete and mail the questionnaire, it would help us immensely. For this part of the research to be valid, we need a high percentage of completed questionnaires.

Thank you again for your time and participation.

Sincerely yours,

Patrick A. Hessel, Ph. D.
Director of Epidemiology
Alberta Asthma Centre
University of Alberta

APPENDIX III: School-Age Asthma Perception Questionnaire

School-Age Asthma Perception Questionnaire

ID number

Dear PARENTS: If your child has difficulty with reading and understanding any of the following questions, please read each question to your child so that your child can choose the number that best describes how she/he feels. Please then ask your child to circle the most appropriate number. Please do NOT answer for your child.

1. Strongly disagree = This statement is very unlike me or is not at all like me.
2. Disagree = This statement does not describe me or is not like me.
3. Neutral = This statement is neither like me nor unlike me.
4. Agree = This statement is somewhat descriptive of me or is somewhat like me.
5. Strongly agree = This statement describes me very well or is very much like me.

1.		I know a lot about asthma (Asthma Knowledge)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
2.		There are many things that trigger my asthma (Asthma Trigger)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
3.		The adults in my school would help me participate in school activities even if I was having asthma problems (School Support)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
4.		I believe that careful control of my asthma now will benefit my health in a few years (Medication Benefit)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00

5.		It is up to me to take care of my asthma now (Responsibility)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
6.		My family sometimes cannot pay for all of my asthma medicine (Medication Cost)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
7.		I make a real effort to take my asthma medicine as prescribed (Motivation)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
8.		My parents often remind me to take my asthma medicine (Parent Reminding)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
9.		I do not feel comfortable taking asthma medication when my friends are around (Peers)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
10.		In the past 2 days, I had no asthma symptoms such as coughing and wheezing (Asthma Control)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
11.		Without my asthma medication, my asthma would be worse (Treatment Efficacy)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00

12.		Without my asthma medication, my asthma would be the same (Treatment Efficacy 2)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
13.		I avoid a sport or other activity because of my asthma symptoms (Activity Limitation)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
14.		I usually take less asthma medicine than my doctor would like me to take (Poor Adherence)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
15.		I usually take more asthma medicine than my doctor would like me to take (Poor Adherence 2)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
16.		I usually take exactly as much asthma medicine as my doctor would like me to take (Adherence)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
17.		I usually become restless, get a headache, or have other side effects after I take my asthma medication (Medication Side-effects)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
18.		I always carry my inhaler wherever I go (Commitment)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00

19.		My doctor, my parents, and I all agree on what to do about my asthma symptoms (Agreement)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
20.		Asthma is a big deal for me (Asthma Perception)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
21.		I know how to use my inhaler so that medicine gets into my lung (Medication Self-efficacy)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
22.		I feel that I can properly use my asthma medication during a bad asthma attack (Self-efficacy)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
23.		When I have an asthma attack, I do not know what to do (Self-efficacy 2)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
24.		I have been to an emergency room many times for my asthma in the past 12 months (Asthma Control)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
25.		I never miss any appointments with my doctor for my asthma (Adherence)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00

26.		I panic when I have bad asthma symptoms (Panic)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
27.		My asthma treatment is too complicated (Asthma Treatment)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
28.		My doctor changes my asthma treatment very often (Asthma Treatment 2)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
29.		When I start to have symptoms, I know that I will be better soon after taking my asthma medication (Treatment Efficacy 3)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
30.		My parents encourage me to take asthma medication as prescribed (Parent Encouragement)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
31.		I can tell when I am about to have an asthma attack from how I feel inside (Locus)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
32.		When I get short of breath, I often get too upset to do much about it (Panic 2)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00

33.		My doctor always answers my questions I have about asthma (Doctor Response)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
34.		I feel good about myself (Self-esteem)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
35.		I have to take many kinds of asthma medication (Number of Treatment)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
36.		I have had asthma for a long time (Asthma Duration)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
37.		I know when to take my asthma medication (Medication Self-efficacy 2)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00
38.		When I have an asthma attack, I know I will be fine after taking my asthma medication (Treatment Efficacy 4)		Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5			Don't know 00

CONTINUED ON TO THE NEXT PAGE

1) What is the name of the asthma medication you take MOST OFTEN? _____

2) How often were you asked to take THIS MEDICNE by the doctor? Choose the best one.

_____only when you need it
_____on a regular schedule
_____other—please specify _____

3) If you need to take THIS MEDICINE on a regular schedule, please describe how often and how much you are supposed to take each time _____

4) If you are supposed to take THIS MEDICINE on a regular schedule, do you have to take it (choose the best one)

_____once daily
_____twice daily
_____more than twice daily
_____I do not have to take my medication on a regular schedule

5) Your SEVERITY of asthma is (Choose the best one)

_____Mild:	my asthma seldom interferes with my everyday life
_____Moderate:	my asthma occasionally interferes with my everyday life
_____Severe:	my asthma seriously interferes with my everyday life

THIS IS THE END OF THE SURVEY

THANK YOU VERY MUCH FOR YOUR PARTICIPATION