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The Knowledge, Behaviour, Fears and Concerns of Adolescents with Asthma: A Descriptive Study

by

Heather Margaret Wells 

A thesis submitted to the Faculty of Graduate Studies and Research

in partial completion of the requirements for the degree of Master of Nursing

Faculty of Nursing

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Dr. Carolyn Ross, Supervisor

Dr. Anne Neufeld

Dr. Barbara Paulson

Thesis Approval Date: January 27, 2000

Abstract

The purpose of this exploratory , descriptive study was to add to the existing knowledge base regarding the asthma-specific knowledge, behavior, fears and concerns of adolescents with asthma. A pulmonary physician's database was used to identify eligible adolescents, aged 13-18, who had an asthma diagnosis. Three self-reports, designed to measure the variables of interest, were mailed to the adolescents. The response rate was 21% with a sample size of 27 subjects. Descriptive statistics were used to summarize the results, frequencies were used to summarize interval and categorical data. Correlational procedures were used to explore relationships. It was found that the adolescents overall scored favorably on the asthma-specific knowledge, with some exceptions such as side effects of medications and action plan use. The sample scored favorably on most of the behaviour tool, with the exceptions of trigger avoidance and symptom intervention domains. The sample was concerned about having activity limitations and were fearful of dying because of asthma. The results of this study are discussed in relation to the current literature and the implications for nursing practice.

Dedication

This thesis is dedicated to my family:

And you will succeed?
Yes! You will indeed!
(98 and 3/4 percent guaranteed)
Kid you 'll move mountains!
So...
Be your name Buxbaum or Bixby or Bray
or Mordecai Ali Van Allen O 'Shea,
You 're off to Great Places!
Today is your day!
Your mountain is waiting.
So... get on your way. Dr. Seuss

Your love, support, and encouragement has been immeasurable. Thank you for believing that I can move mountains.

Acknowledgments

"It is the supreme art of the teacher to awaken joy in creative expression and knowledge." Albert Einstein.

Foremost, I would like to acknowledge Dr. Carolyn Ross, my supervisor for her encouragement and dedication to this project. I am indebted to her for providing expertise and countless hours reviewing and discussing my thesis. I also extend my appreciation to my thesis committee members, Dr. Anne Neufeld, and Dr. Barbara Paulson. Thank you for sharing your experiences and encouraging me to think in different ways.

"What we need is more people who specialize in the impossible." Theodore Roethke.

I am very appreciative of the ongoing support from the staff of the Alberta Asthma Centre, Shawna, Dean, Alyson, and Eva. I am particularly indebted to Shawna for her encouragement, you truly specialize in the impossible.

"I not only use all the brains I have but all that I can borrow." Woodrow Wilson.

I am very grateful of Dr. F. MacDonald's willingness to participate in this study and for entrusting me with his patients. I would like to extend my thanks to Anita Mergl for her assistance in the data collection; Joanna Tomkowicz for her assistance with data analysis; and Dr. Andrew Cave for allowing me to use the EABS.

"The object of education is to prepare the young to educate themselves throughout their lives." Robert Maynard Hutchins.

I would like to acknowledge the following organizations and individuals: The National Health Research and Development Program, Caritas Health Group, University of Alberta Hospital Foundation, Walter H. Johns. Their support of young researchers was an asset to this project and to my studies.

" Go confidently in the direction of your dreams. Live the life you have imagined.." Henry David Thoreau

I extend my thanks to Jason for being understanding and for believing I could achieve my goals; especially during the final stages of my thesis and program.

"The better part of one's life consists of his friendships." Abraham Lincoln.

Thank you to my friends for their ongoing support. I would particularly like to thank Tania for her incredible encouragement and amazing perspective.

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Chapter 1

Background and Statement of the Problem and Purpose

Asthma is an airway disorder "characterized by paroxysmal or persistent symptoms (dyspnea, chest tightness, wheeze and cough), with variable airflow limitation and airway hyperresponsiveness to a variety of stimuli" (Ernst, FitzGerald & Spier, 1996, p.89). The incidence of asthma among adolescents is reported to be between 15 and 18% (Forrero, Bauman, Young, Booth & Nutbeam, 1996; Forrero, Bauman, Young & Larkin, 1992; Hessel, Sliwkanich, Michaelchuk, White, & Nguyen, 1996). Adolescents with asthma compared to non-asthmatics are less happy about life, experience more somatic symptoms and express more concerns about loneliness and depression (Forero, et. al, 1996). The morbidity and mortality associated with asthma are reported to be rising worldwide (Wilkins & Mao, 1993).

It is recognized that providing individuals with asthma effective educational interventions is an important approach to increasing asthma-specific knowledge and behaviour and reducing the morbidity and mortality associated with asthma (Clark, 1989; Ernst, FitzGerald & Spier, 1996). Numerous studies have been conducted that focus on the assessment of the educational needs (Guyatt, Juniper, Griffith, Feeny & Ferrie, 1997; Juniper, 1997) and the impact of educational interventions on children and adults with asthma (Bernard-Bonnin, Stachenko, Bonin, Charette & Rousseau, 1995; Devine, 1996). Few educational interventions are available targeting the adolescent population. Little is known about the educational needs and concerns of adolescents with asthma (Sawyer & Bowes, 1996). Such knowledge would provide

direction for the development of cost effective educational interventions designed to meet the needs of the adolescent with asthma. The purpose of this study was to add to the existing understanding about the asthma-related knowledge, behaviour, fears and concerns of adolescents with asthma.

Theoretical Framework

Social Cognitive Theory (SCT) will be used as a framework to guide an exploration of adolescents' knowledge and self-management behaviour pertaining to asthma. This theory predicts behaviour, identifies how humans change their behaviour and anticipates the outcomes (Clark & Zimmerman, 1990). According to SCT, individuals are able to self-reflect and self-regulate their behaviour (Maddux, 1995). Individuals are not merely passive responders to their environment (Maddux, 1995). Human behaviour is motivated to achieve specific goals and is intentional.

The SCT is based upon five assumptions of human behaviour (Bandura, 1986). Infants are believed to possess reflexes which demonstrate a potential for learning. Individuals have a symbolizing capacity to assign symbols to experiences which guide future behaviour. Individuals are capable of forethought, the ability to predict the results of behaviour. Bandura also states that humans are capable of vicarious learning, learning through the experiences of others. Finally, individuals are capable of evaluating their own thoughts and behaviours, this is called reflective self-consciousness. These five assumptions guide the SCT to describe human behaviour throughout the life span.

Bandura sees adolescence as a difficult time, however it is not necessarily

excessively turbulent, as some theorists hypothesize (Mitchell, 1986). Adolescence occurs gradually according to the SCT. Adolescents learn from their parents' values and beliefs and their past experiences. This cumulative learning guides the individuals behaviour. Since individuals gain from their previous experiences, an older adolescent may have a different personal standard to compare behaviour than a younger adolescent. Each individual uses personal standards (the norms, values and previous experiences) to determine the likelihood of engaging in a certain behaviour. Therefore the age of the individual is important as the experience of the individual impacts their decisions regarding their behaviours.

Behaviour is determined by an interaction between the environment, person, and behaviour (Bandura, 1986; Sigelman & Shaffer, 1991). This system is interdependent as the three factors influence the behaviour of individuals and also impact each other. For example, a change in the environment may affect both the person and behaviour. This triad is influenced by a variety of factors such as: the ability to self - regulate, knowledge gained from observational learning and both positive and negative reinforcement experienced (McGhan, Wells & Befus, 1998). Behaviour is based upon the rewards and punishments experienced in the environment (Blum, 1998). To understand the behaviour of any individual this theory states we must understand this triad and the interplay among the three factors (Maddux, 1995).

Person variables include competencies, interpretation or meaning, expectancies (behaviour outcome expectancy, stimulus-outcome expectancy, & self-

efficacy expectancy) and subjective values. Knowledge and competency do not translate into performance unless there is incentive to do so. The person needs to believe that behaviour will yield something valued.

From the health care professional's perspective, the goal of asthma self-management behaviour is to maximize the control of asthma and reduce the morbidity associated with asthma. In order to self-manage asthma maximally, asthma-specific knowledge is needed. However, according to SCT, person variables determine how a situation is analyzed and which behaviours are chosen. Person variables such as fears or concerns about asthma, age, gender, number of years since diagnosis, perceived asthma severity are factors that would be expected to impact on the meaning or interpretation of having asthma for the individual. Since meaning impacts on the translation of knowledge into behaviour, it seems important to explore the extent to which these factors interact with the translation of asthma-specific knowledge to asthma self-management behaviour in adolescents.

The SCT has been used extensively in the development and implementation of asthma education to identify methods of impacting individuals behaviour (McGhan, Wells, & Befus, 1998). Self-regulation is a particularly important concept to asthma management (Clark & Zimmerman, 1990). Bandura states that individuals engage in particular behaviours not only for the external outcomes, but also for intrinsic reasons (Bandura, 1986). Much of human behaviour is conducted to achieve outcomes which will impact the future, rather than immediate rewards. This process of self-regulation includes three components; self-observation, judgmental process and self reaction.

Self observation involves the individuals being attentive to their own behaviours in a variety of circumstances. The judgmental process involves the decision of the individual whether the behaviour is positive or negative. In asthma management positive behaviours would include behaviour which has a positive impact on the illness, for example, using preventative medication and avoiding precipitants of asthma.

Negative behaviour would include behaviour which has a negative impact upon the disease, such as smoking. The potential behaviour is evaluated against the personal standards of the individual and can vary widely. The self reaction component leads to the motivation of the individual to engage in a particular behaviour. This may also manifest as goal setting. In the instance of asthma management the use of preventor medication is an example of self-regulation. The individual engages in the behaviour (taking the medication) with the future outcome of reduced morbidity (such as decreased symptom experience and increased activity level), judges the behaviour as a positive health behaviour, and the individual may determine that they are experiencing fewer asthma symptoms, therefore reinforcing the behaviour. Thus, health education needs to consider both the process of behaviour and the outcome of behaviour (Clark & Zimmerman, 1990).

Definition of Terms

Asthma

Asthma is a disorder of the airways which is characterized by limitation in airflow and airway hyperresponsiveness with paroxysmal or persistent symptoms such as wheezing, coughing, shortness of breath and dyspnea (Ernst, FitzGerald, & Spier, 1996).

Adolescents

Adolescents are individuals between the ages of thirteen and eighteen years.

Knowledge

Knowledge is the understanding of asthma, including the following nine domains identified by the Canadian Consensus Guidelines of Asthma Care: self monitoring and self-regulation of medication therapy, basic pathophysiology of asthma, precipitant avoidance and management, medication use and actions, effective use of inhaler devices, monitoring strategies, the use of an action plan, and potential complicating conditions (Ernst, FitzGerald, & Spier, 1996). This concept is measured by the self-administered Asthma Knowledge Questionnaire (FitzClarence & Henry, 1991).

Behaviour

Behaviour is asthma - related choices and actions an individual with asthma exhibits including preventative medication behaviour, health promotion behaviour, precipitant avoidance, communication behaviour and symptom interventions. This variable will be measured by the self-administered Edmonton Asthma Behaviour

Scale (Cave, Leong-Sit, Hauptman & Krupa, 1997).

Fears and Concerns

According to Beck & Emery (1985) "fear involves the intellectual appraisal of a threatening stimulus' (p.9). A person's fears arise from referral to a set of circumstances that are not currently present, but may occur at some point in the future. The degree of fear experienced can be low, moderate or high. Concern is equivalent to a low degree of fear.

Chapter 2

Literature Review

The literature review is presented in two sections. The first section provides a brief overview of adolescents and health, the prevalence and cost of asthma, and the impact of asthma education on health outcomes. This initial section is offered as important background for the primary focus. The second section offers an integrated analysis of the previous research pertaining to the variables of interest: asthma specific knowledge, behaviour, and fears and concerns. A summary of the literature review highlights the gaps in our current understanding in these areas. The primary source of the literature reviewed in the area of asthma specific knowledge and behaviour was drawn from published articles identified using the health data base, MEDLINE. Keywords used to search the data base included: adolescent asthma, asthma knowledge, asthma behaviour, asthma education and adolescent medicine.

Adolescents and Health Issues

It is well documented that adolescence is a period of transition, preparing the individual for the responsibilities of adulthood. The term adolescence means "to grow into maturity" (Whaley & Wong, 1993). Adolescence is a period of significant hormonal and body changes and additional psychosocial stressors which have not been experienced in childhood (Blake, 1997). Adolescence requires the adjustment of the individual to the changes within the individual and the growing expectations of others. Adolescent development includes the development of a group identify, in which the individual desires to be a member of a group (Whaley & Wong, 1993).

The adolescent emulates the behaviour of the group and conform less to the behaviours of the parents. The significance of the peer group becomes extremely important to the adolescent and there is a desire to conform to this group. Adolescents also begins to develop a personal identity which is a time consuming process and often a confusing time for adolescents. The adolescent must have adequate time to accept this new identity and release their childhood identity. All individuals do not experience adolescence in the same manner, there are many variations in their individual development and growth (Whaley & Wong, 1993).

Health promotion programs and literature focusing on the adolescent population have tended to be limited to preventing negative behaviour such as smoking, substance abuse, and unprotected sexual practices. These programs primarily target all adolescents and aim at preventing the population from engaging in unhealthy behaviour. In addition to this health promotion literature, adolescent diabetes management literature also provides insight into adolescent health. Several studies have been conducted which evaluate the impact of providing social support as a method of improving diabetes management (Blake, 1997). These programs have been found to be an effective method of assisting adolescents to overcome feelings of anxiety, anger, and frustration (Blake, 1997). These programs did not provide formal education, rather a mechanism of social support.

Prevalence and Cost of Asthma

One potential difficulty with estimating prevalence of asthma is that there is not a universally accepted standardized definition of asthma as previously mentioned, and, therefore, there is much room for variability (Ernst, FitzGerald, & Spier, 1996). Thus, it is difficult to make accurate comparisons and integrate this research. A

possible reason for the limited research focusing on adolescents with asthma is there is a belief in the medical community that children outgrow asthma by adolescence (Roorda, 1996). However, a review of the literature revealed that asthma persists into adulthood in 30 - 80% of the individuals (Roorda, 1996). "Asthma is almost as common in adolescence as it is in young children and more common than it is in adults" (Price, 1996, p. S13). Risk factors associated with asthma persisting into adolescence and adulthood include: female gender, onset of asthma after two years of age, greater than 10 episodes of asthma in childhood, decreased peak expiratory flow rate as a child and parental atopy (Sawyer & Bowes, 1996).

Asthma is the most common chronic disease of childhood and adolescence, which has shown an increase in incidence in recent years (Sacher & Danon, 1994). A study conducted in the Capital Health Region (although it did not include Edmonton proper) determined that a junior high school in Sherwood Park had a rate of 19% of students with a history of having asthma and 15% of students currently having asthma, based on parental responses (Hessel et al., 1996). The prevalence reported by Hessel and colleagues (1996) are similar to those reported in New Zealand and Australia of 17% and 18% respectively (Forero, et al., 1996; Forero, et al., 1992).

Asthma is often under-diagnosed, particularly in adolescents (Price, 1996). There is also a tendency for asthma to be mistreated, which may cause an increase in symptom experience and activity limitations (Smith, Malone, Lawson, Okamoto, Battista, & Saunders,1997). Hessel and colleagues (1996) discovered that Alberta demonstrated a four times higher prevalence of deaths related to asthma than Manitoba and Saskatchewan combined in 1992-94 (Wilkins & Mao, 1993).

Asthma costs the Canadian health care system per annum an estimated $504

to $648 million (Krahn, Berka, Langlois, & Detsky, 1996). Treatment of asthma costs as much as infectious diseases, hematologic diseases, congenital defects, perinatal disease, home care and ambulance use combined (Krahn et al., 1996). This estimate include both the direct costs (i.e. medication, hospitalization, etc.) and indirect costs (i.e. lost work days, transportation to medical appointments, etc.). In addition to the cost in dollars, asthma exacts important personal costs in terms of morbidity and mortality.

Asthma Education

Asthma education is identified as an essential component of the overall management of asthma by the Canadian Consensus Guidelines for Asthma Care (Ernst, FitzGerald & Spier, 1996). While little research has explored the impact of asthma education on morbidity and mortality in adolescents with asthma, several studies have been conducted focusing on the adult and child populations. The results of several studies demonstrate that adults who have received asthma education are more knowledgeable about asthma and asthma treatment, show an increase in skills pertaining to self-management and medication use, an increase in adherence to recommended treatment regimes and a decrease in morbidity (Clark 1989, Cote, Cartier, Robichaud, Boutin, Malo, Rouleau, Fillion, Lavallee, Krusky, & Boulet, 1997, Devine, 1996, Tettersell, 1993, Wilson & Starr-Schneidkraut, 1994, and Clark & Nothwehr, 1997). Asthma education has been found to be an effective method of improving knowledge and behaviour of adults with asthma.

Tettersell (1993) conducted a study of adolescents and adults that determined asthma specific knowledge possessed by individuals is related to the patients' abilities to manage acute asthma episodes. Kolbe, Vamos, Gergusson, Elkink and Garett

(1996) discovered that the relationship between knowledge and behaviour is weak. They also determined that skills may be gained over time, thus suggesting education which is offered at intervals may be more effective. Therefore, it is necessary to assess and evaluate both knowledge and behaviour related to asthma management at intervals to determine the effectiveness of the educational interventions and to address both knowledge and behavioural issues.

Many studies have also been conducted which focused on the outcomes of self-management asthma education for children (Bernard-Bonnin, et al., 1995). A significant finding of a meta-analysis of childhood asthma education conducted by Bernard-Bonnin et al. (1995) was that the education had little influence on morbidity outcomes such as hospitalization rates. It is significant to note that neither knowledge nor behaviour were considered as outcome measures in the analysis as the authors felt the measurements were not comparable (Bernard-Bonnin et al., 1995).

Outcome measures which focus on hospital rates, emergency room visits, and other morbidity outcomes are somewhat difficult to evaluate as two families will not manage similar episodes in the same manner (Bernard-Bonnin et al., 1995). One parent may rely heavily upon emergency care while another manages asthma episodes very effectively at home. Also, criteria for hospitalization is not standardized between centres and also change over time due to recent health care restructuring and shorter hospital stays. It has also been suggested that education may contribute to an enhanced awareness of symptom experience and therefore, the individual is more likely to seek medical intervention. Thus, the increase in knowledge may actually lead to an increase use in medical care, which would be seen as a negative outcome in educational intervention trials.

The researchers stated that future research of the effectiveness of these educational programs should not focus on morbidity and mortality outcome measures, rather should focus on intermediate outcomes such as knowledge and behaviour. Outcome measures such as knowledge and behaviour may be more effective at evaluating educational interventions as they are less likely to be effected by confounding and personal variables. Thus, they are a more direct method of evaluating asthma education. Therefore, knowledge and behaviour are important factors to consider when assessing the need for educational intervention, in addition to use as outcome measures.

Knowledge

One factor that may contribute to asthma related morbidity is the lack of asthma - specific knowledge (Spykerboer, Donnelly, & Thon, 1986). There are many misconceptions about asthma and its management held by parents of children with asthma, particularly concerning asthma treatment, prognosis and general medical information (Moosa & Henley, 1996). For example, 60% of parents believed that inhaled medications would weaken their child's heart, 75% stated medications could become addictive and ineffective when used regularly, and 80% of parents believed asthma is a difficulty of inspiration (Moosa & Henley, 1996). Spykerboer, Donnelly & Thong (1986) discovered that 40% of parents of children with asthma stated their children should be restricted in their outdoor activities. These misconceptions in addition to lack of knowledge may cause decreased adherence to treatment and contribute to poor attitudes towards asthma management (Moosa & Henley, 1996). In addition, parents may pass these misconceptions to their children, impacting their asthma knowledge and management behaviours.

Adults with asthma have stated they have a desire to acquire information regarding their illness and its management (Gibson, Talbot, Toneguzzi & Population Medicine Group, 1995). However, the researchers also identified that adults with asthma do not wish to make the health - related decisions. The study participants felt that their health care providers are the most effective primary decision makers for their health. This may be because they do not feel confident in their abilities to make decisions. Educational interventions aim to address this by providing information to empower individuals to enable healthy decision making.

Using the Asthma Knowledge Questionnaire, Gibson, Henry, Vimpani and Halliday (1995) determined that asthma knowledge was limited in both adolescents with asthma and their teachers, neither group had received formal educational interventions prior to testing. The researchers discovered that there appeared to be particularly poor knowledge regarding preventative behaviour for asthma and exercise - induced asthma. Preventative behaviour includes using daily preventative medications, monitoring symptoms and peak flows and precipitant avoidance (avoiding possible asthma triggers). Preventative behaviour is an essential component of effective asthma management. Similar to findings with adults (Gibson, Henry, et al., 1995), adolescents with asthma identify that they would like to have access to information concerning asthma and its management (Slacks & Brooks, 1995). This is significant as it identifies possible areas requiring further educational intervention.

Behaviour

Individuals with asthma have the ability to impact their illness through their behaviour (Cave, Leon-Sit, Hauptman & Krupa, 1997). For the purpose of this study,

asthma - related behaviour refers to the following five domains: preventative behaviour, health promoting behaviour, precipitant avoidance, communication behaviour, and symptom intervention (Cave, Leong-Sit, Hauptman & Krupa, 1997). It has become increasingly important in asthma literature to encourage individuals with asthma to implement self-management behaviour strategies as identified in the Canadian Consensus Guidelines, including self-monitoring, preventative medication use and precipitant avoidance to improve the asthma outcomes (Ernst, FitzGerald, & Spier,1996).

Engaging in appropriate preventative medication behaviours can reduce the occurrence of acute exacerbations of asthma, symptom experience, and reliance upon emergency interventions (Ernst, FitzGerald, & Spier, 1996; Cave, et al., 1997). Preventative medication requires most individuals with asthma to take medication (usually inhaled corticosteroids) daily for life. Health promotion (such as diet, exercise, smoking and alcohol use) consists of behaviours that promote a healthy lifestyle. Precipitant avoidance requires individuals to identify possible allergic (i.e. cats, horses, dust) and non-allergic (i.e. emotions, cold air) triggers which may precipitate asthma symptoms. Individuals then need to implement strategies of avoidance or management of these triggers. Precipitants of asthma symptoms are not always the same for every individual with asthma, and therefore, careful assessment is required. Communication behaviours include individuals' interactions with health care providers, family, friends and others regarding their asthma. It refers to their ability to openly communicate with these individuals regarding their asthma. Symptom intervention refers to individuals' behaviours in response to symptom experience, including taking appropriate reliever medication and seeking help as

necessary.

Relevant to the health promotion domain, the results of one study showed smoking cigarettes and consuming alcohol were more common in adolescents with asthma than in non-asthmatics (Forero, et al. 1996). This is a significant finding given cigarette smoke is a recognized precipitant of asthma symptoms. Further, alcohol consumption is often used as a method of coping with emotional difficulties and is also often a result of peer pressure (Forero, et al. 1996). These researchers also concluded that adolescents with asthma were more likely to have feelings of loneliness, unhappiness and depression. These findings are important as symptoms such as depression and loneliness are significant risk factors for asthma - related morbidity (Forero, et al. 1996).

Another factor which can contribute to asthma - related morbidity is adherence to prescribed medical regime. Adherence to treatment regime is an important behaviour in determining healthy outcomes for individuals with chronic illness. Adherence is essential to the successful management of asthma, as it often requires long - term, daily preventative therapy. Adherence is more than simply medication compliance; it also requires engaging in monitoring of symptoms, trigger avoidance and collaboration with health care providers. A focus group of 28 individuals aged 13 to 17 determined that adolescents with asthma tend to have positive attitudes towards medication and consider themselves compliant (Slack & Brooks, 1995). They did, however, identify that remembering to take medications was often difficult and that they disliked using medications in public settings. Although this may appear to be contradictory, it is possible for an individual to be generally compliant, while finding it difficult to remember medications. Adherence

may also require adolescents to depend on parents for financially supporting the expense of health care and to take medications in public settings (Price, 1996). Adolescents identified that the cost of medication is a barrier to taking daily preventative medicine (Slack & Brooks, 1995). Adolescents with asthma stated that it was embarrassing to require medication in a public setting (Slack & Brooks, 1995).

Forero et al. (1992) discovered that fewer than 50% of participants aged 12 to 21 used preventative medication, based on self-reports. This could be attributed to either physicians failing to prescribe the medication, or adolescents failing to take the medications regularly, the study did not clarify this issue. Only nine percent of participants in this survey stated that they had both a peak flow meter and an action plan, which are important components of preventative behaviour, although not considered essential for individuals with mild or pure exercise induced asthma. This demonstrates sub - optimal care, as the focus is primarily on crisis management, instead of preventative measures. The Canadian Consensus Guidelines for Asthma Care identified the necessity of providing an individualized action plan in collaboration with monitoring of symptoms and peak expiratory flows for most individuals (Ernst, FitzGerald, & Spier, 1996).

Research exploring issues such as chronic illness and health promotion in adolescents have discovered that increases in knowledge improve both attitudes and behaviours of individuals (Gibson, Shah & Mamoon, 1998). High asthma - specific knowledge is correlated with a sense of internal locus of control by adolescents with asthma (Gibson, Henry, et al., 1995). Knowledge is a determinant of behaviour, high knowledge is correlated with effective management behaviours (Gibson, Talbot, et al., 1995). Therefore, asthma knowledge is a necessary prerequisite for both the self -

efficacy of the individuals and effective asthma management behaviours.

Summary of the Literature Review

The results of studies indicate the prevalence of asthma among adolescents is similar to that of children and greater than the prevalence among adults (Forero et al., 1992; Hessel et al., 1996). Given the developmental challenges unique to adolescents, an increase in our understanding of asthma specific knowledge, behaviour, fears and concerns from the adolescents' perspective would provide important ground work for the development of educational interventions to meet the needs of adolescents. Asthma education has been shown to increase asthma-specific knowledge (Clark & Nothwehr, 1997), increase adherence to treatment and lower morbidity in adults with asthma (Côte, et.al., 1997; Devine, 1996; Tettersell, 1993). Similarly, asthma education geared towards children and their care-givers has shown an increase in asthma-specific knowledge (Wilson & Starr-Schneidkraut, 1994). Only one published study, was found which examined the asthma specific knowledge of a sample of Australian adolescents (Gibson, Henry, et al., 1995). The results showed adolescents had particularly poor knowledge pertaining to preventative behaviour. In relation to asthma-specific behaviour, although limited, aspects of preventative behaviour (use of medications, peak flow and action plan) and health promoting behaviour have been examined among adolescents with asthma (Forero et. al, 1992; Slack & Brooks, 1995). Although adolescents consider themselves compliant to medication treatments, the results of one study showed less than 50% of adolescents use preventative medications (Forero et al., 1992). Adolescents report difficulty in

remembering to take medications and cite concern about using medication in public and the cost of medications as barriers for using preventative medications. Other aspects of asthma-specific behaviour among adolescents, including precipitant avoidance, communication and symptom intervention have not been reported and require further study. Further exploration of adolescents' concerns and fears in relation to having asthma could reveal other important issues relevant to the promotion of asthma self-care among adolescents.

Chapter 3

Research Methods

The study objectives, research questions, design, and sampling procedures are presented. This is followed by a description of the study procedures, instrumentation and data analysis procedures. Finally, measures taken to address ethical implications of the study are described.

Study Objectives

The objectives of the study were as follows:

1. To assess the asthma-specific knowledge, behaviour, concerns, and fears of a sample of adolescents with asthma.
2. To explore the relationship between the asthma-specific knowledge and behaviour of a sample of adolescents with asthma.
3. To explore the influences of gender and age on asthma-specific knowledge, behaviour, and fears and concerns in a sample of adolescents with asthma.

Research Questions

Objective 1

a) What is the asthma-specific knowledge of adolescents?

b) What is the asthma-specific behaviour?

c) What are the fears and concerns of adolescents?

Objective 2

What is the relationship between asthma-specific knowledge and behaviour?

Objective 3

a) Does asthma-specific knowledge differ by gender?

b) What is the relationship between asthma-specific knowledge and age?

c) Does asthma-specific behaviour differ by gender?

d) What is the relationship between asthma-specific behaviour and age?

e) Do the fears and concerns regarding asthma differ by gender?

f) Do the fears and concerns regarding asthma differ by age?

Research Design

A descriptive design using survey techniques was used to address the objectives and research questions of the study. Three self-reports were sent to eligible subjects by mail to assess: asthma-specific knowledge, asthma-specific behaviour, fears and concerns, of adolescents.

Sample

The target population for the study was adolescents who had been referred to a pulmonary specialist at an outpatient asthma clinic. The criteria for inclusion were: 13 to 18 years of age, diagnosis of asthma. At the time of preliminary planning of the study a total of 177 eligible subjects were identified using a pulmonary physician's data base. Due to the likelihood of a low response rate, all individuals who met the study's inclusion criteria were invited to participate in the study.

Given the nature of the dependent variables (i.e. scores on knowledge and behaviour questionnaires), determining a large effect size was of interest. To capture a large effect ($d = 0.8$), with a power of 0.80, using a two-tailed t-test requires a

minimum of 26 subjects per group. To capture a correlation greater than 0.30 with a power of 0.8 requires a minimum of 28 subjects (Cohen, 1977). Based on a total of 177 potential subjects, it was calculated that a response rate of at least 16% would be needed to yield a sample of 28 subjects. Reported response rates for similar surveys range from 30 - 60% (Dillman, 1978). To maximize response rate, the mail out was repeated two weeks after the first mail out.

Procedures

Ethical approval for the study was obtained from the joint Health Research Ethics Board of the Health Sciences Faculty, University of Alberta and the Capital Health Authority. Administrative approval was obtained from the Caritas Health Group, the site of the patient data base. Once ethical and administrative approval was obtained, a staff member with access to the patient data base was employed and directed by the researcher to mail a research package to all eligible subjects identified through the data base. Each package included: a cover letter explaining the study process to the parent/guardian of the potential participant (Appendix A), a cover letter of support from the physician (Appendix B), an information sheet regarding the study (Appendix C), the Information Survey (Appendix D), a copy of the study questionnaires the Edmonton Asthma Behaviour Scale, (Appendix E) and the Asthma Knowledge Questionnaire (Appendix F), a cover letter explaining the study process to the potential participant (Appendix G) and a stamped, addressed envelope.

Directions included in the cover letter requested participants to mail completed questionnaires to the principle investigator using the stamped, addressed

envelope provided. Return of the questionnaire was viewed as consent to participate in the study. The researcher had no direct access to the patient database. Participants' information returned by mail was anonymous. Thus the identity of either the eligible subjects or the participants was unknown to the researcher.

To maximize response rate, the staff member of the Caritas Health Group sent a second package of questionnaires by mail to all eligible subjects two weeks after the initial mailing. The aim of the cover letter enclosed with the second mail-out was to provide encouragement and direction for potential subjects in terms of how to proceed if they had not yet completed and submitted questionnaires (Appendix H). Alternatively, subjects who had submitted their questionnaires were thanked for their participation and asked to ignore the second set of questionnaires.

Instrumentation

Asthma Knowledge Questionnaire

In order for individuals with asthma to self-manage their asthma they require specific asthma related knowledge. The Asthma Knowledge Questionnaire was developed by FitzClarence and Dr. Henry from Newcastle, Australia (Appendix F). It was originally used to determine the knowledge level of parents of children with asthma. It has subsequently been used to determine the knowledge level of various health care professionals including: pediatric nurses, pharmacists, and general practitioners (Henry, FitzClarence, Henry & Cruickshank, 1993). It has also been used to gauge the acquisition of knowledge by medical students, throughout their medical school years (FitzClarence, & Henry, 1991).

The original version of the AKQ consists of 31 items which require either a true or false response (25 items) or a short answer response (six items)(FitzClarence & Henry, 1991). One point is awarded for each correct response for a possible range in the total score of 0 to31. This tool was validated using a sample of parents of children with asthma, although it has been utilized with several alternative populations including adolescents with asthma, medical students and health care professionals. Two groups were assessed, one deemed as having high knowledge of asthma, while the second groups was determined to have low asthma knowledge (FitzClarence & Henry, 1990). It was discovered that the mean difference between the groups was statistically significant, demonstrating construct validity. Previous published literature was used to verify face and content validity.

Two additional questions were added to the original version of the AKQ to address the use of peak flow meters (using a true false item) and the use of actions plans (using a short answer format). Knowledge of these subject areas are essential to self-monitor and self-manage asthma according to the current Canadian Consensus Guidelines (Ernst, FitzGerald & Spier, 1996). One item (most children with asthma should not eat dairy products) was deleted from the original version of the AKQ as it was very similar to item 5. The scoring procedures were changed to allow for partial points for the seven short answer items. Several questions were modified to allow for up to six marks for one question, depending on the number of possible correct answers. This adjusted the total possible range of total scores on the AKQ (0 to 48). For the purpose of data analysis and discussion of findings, the items in the questionnaire were categorized into four domains: general knowledge, asthma

therapy, asthma symptoms, and precipitants of asthma.

The general knowledge domain includes items that addressed basic pathophysiology, prevalence of asthma, and various miscellaneous items. A total of 11 items (item 2, 4, 9, 15, 16, 24, 26, 27, 29, 31, and 32) were classified into this category which accounted for 12 marks. Asthma therapy includes items that focus on the treatment of asthma (i.e. medications) and issues that surround various asthma therapies. There are11 items (item 10, 11, 12, 13, 14, 17, 18, 19, 20, 23, and 30) in this category, accounting for 16 of the total marks. The third domain focuses on the identification of asthma symptoms. There are five items (item 1, 7, 8, 21, and 28) that address asthma symptoms for a total of seven marks. Precipitants of asthma include anything that may contribute to asthma symptoms. This category includes the identification of possible asthma triggers and methods of coping with them. There are five items (item 3, 5, 6, 22, and 25) in this category, for a total of 12 marks.

Edmonton Asthma Behaviour Scale

The Edmonton Asthma Behaviour Scale (EABS) is a self-administered paper and pencil test aimed at gauging behaviour and behaviour change (Cave, Leong-Sit, Hauptman & Krupa, 1997). A copy of this tool is located in Appendix E. This instrument was developed to be used in measuring the effectiveness of education interventions of individuals with asthma. It aims to determine if a mild to moderate change in behaviour occurs following educational interventions by identifying decreases in problem behaviour and increases in desirable behaviour. The EABS is comprised of six domains: compliance to medical regime, trigger avoidance, health

promotion/prevention, communication and interaction with health care system, symptom intervention, and problem behaviours. Each of the domains is scored and the six domain scores are tallied and divided by 6 to determine the total score. The possible range of scores for the total and the individual domains is 1.0 to 7.0.

The authors have phrased the items in this tool in almost equal thirds of positive, negative and neutral wording to decrease acquiescence bias (Cave, Leong-Sit, Hauptman & Krupa, 1997). Content validity was addressed by requesting health care professionals with expertise in asthma and asthma education to review the instrument and provide comments on the format, content, language and length of the instrument. Test-retest reliability and internal consistency (using Cronbach alpha) was tested by repeating instrument administration to a single sample two weeks following the initial administration on the tool. It is difficult to conclude the reliability and validity based on this testing, as the sample size was limited to 12 participants. The tool did demonstrate stability over time based on overall and separate domain scores.

It is interesting to note that the authors of this tool chose to change the wording of their items from asthma attack to asthma symptoms, which reflects a current trend in recent literature to focus on symptom management as opposed to strict crisis management (Ernst, FitzGerald & Spier, 1996). As well, the instrument addresses monitoring asthma symptoms and peak flows through diary keeping.

Information Survey

The information survey was developed by the researcher to collect basic personal information of the study sample and to solicit additional qualitative data regarding their concerns and fears about having asthma (Appendix D). Demographic and clinical data were collected for the purpose of describing key characteristics of the participants including: age, gender, prescribed asthma medications. Specific questions included to measure adolescents concerns and fears regarding asthma were: what is your biggest concern about having asthma? , and; what is your biggest fear about having asthma?

Data Analysis

Descriptive statistics were used to summarize demographic data and scores on the Asthma Knowledge Questionnaire (AKQ) and on the Edmonton Asthma Behaviour Scale (EABS). Categorical data (gender, medications) was summarized using frequencies. Interval data (age, years having asthma, asthma severity, scores on the AKQ and the EABS) was summarized using frequencies, ranges, means and standard deviations. Correlational procedures was used to explore the relationship between the scores in the AKQ and the scores on the EABS and the relationship between age and the scores on the AKQ and the EABS. The t-test was used to examine gender differences on scores on the AKQ and the EABS. Their responses to open ended questions (fears and concerns) was examined for common themes and summarized using frequencies. Current SPSS software was utilized to conduct the data analysis. The level of significance for statistical analysis was set at 0.05. The concerns and fears of the participants was examined qualitatively to identify common themes among the participants. These themes were also explored in relation to the

gender and the age of the participants.

Protection of Human Subjects

Prior to data collection ethical clearance was obtained from a joint Health Research Ethics Board of the Health Sciences Faculty, University of Alberta and the Capital Health Authority. Also, administrative approval was obtained from the Caritas Health Group, the site of the patient data base.

Potential research participants and their parent(s)/guardian(s) were provided with an information sheet which outlined the purpose of the study, the nature of the participant's role in the study, the risks and benefits to participants and measures taken to assure confidentiality and anonymity. Potential participants were also provided with contact information if they wanted further information about the study.

Return of the questionnaires were considered as consent to participate. Potential participants were advised they could refuse to answer some of the questions even if they chose to enter the study. The participants in this study were subjected to very minimal harm. "A minimal risk is defined as one that is no greater than the risks of everyday life or of routine medical or psychological harm to the participants" (University of Alberta, 1993 p.5). The study was non-invasive and required completion of three self-administered questionnaires only.

Potential participants were informed that the results of the study have the potential to benefit both adolescents with asthma, their parents, educators, and their health care givers. The major anticipated benefit was the potential impact of the results on the provision of optimal asthma care to the adolescent. Greater understanding about the knowledge, behavior, fears and concerns of adolescents with asthma could be used to inform health care professionals how best to meet the needs

of the adolescent population with asthma.

Confidentiality of data was maintained by coding of the questionnaires. Participants did not write their names on the questionnaires, instead a coding number was assigned to each questionnaire received by the principle investigator. The principle investigator did not have access to the names on the database. Participants were informed that raw data will be stored for seven years following the study.

Chapter 4

Findings

The characteristics of the sample and the response rate to the questionnaires are presented. This is followed by a description of study findings pertaining to each of the three study objectives. Findings relevant to the first objective relate to the knowledge, behaviour, fears, and concerns of the participants. Next findings relevant to the second objective deal with the relationship between knowledge and behaviour of the participants. Finally, findings relevant to the third objective include the results of explorations of differences between subjects grouped by gender and age on knowledge, behaviour, concerns and fears.

Sample

At the time of planning the study, the database was comprised of 177 eligible adolescents. However by the time data collection proceeded, the numbers had reduced by 11. Invitations to participate in the study were sent to 166 adolescents. Of the 166 invitations, 34 were returned due to a change in address and one was returned with a note indicating that the adolescent did not have asthma. Of the remaining 131 potential study participants, 27 (21%) completed and returned the questionnaires. The clinical characteristics of the participants and their medication regime are summarized for the total sample and by gender in Table 1 and Table 2 respectively. The mean age of the participants was 15.3 years, with a standard deviation (SD) of 1.4, a median (Mdn) of 15, and a range of 13 to 18 years. The mean age at the time of diagnosis of asthma was 5.6 years, (SD = 4.5;Mdn = 5.0; range, infancy to 15 years). The mean years since the diagnosis of asthma was 9.7, (SD = 4.6; Mdn = 9.0; range, 1.0 to 18.0). On a self-report of severity the mean was 4.3, on

a scale of 1-10, 1 being very mild asthma, and 10 being very severe asthma. Of the 27 subjects, over 80%were prescribed an inhaled steroid and a short-acting bronchodilator. The frequency responses for each of the items describing the participants characteristics are presented in Table 1. The frequency responses for each of the items describing the medications taken by the participants are presented in Table 2.

Table 1

Sample Characteristics

	Male (n = 15)	**Female (n = 12)**	**Total Sample (N = 27)**
	f (%)	**f (%)**	**f (%)**
Age			
13-15	11 (73)	4 (33)	15 (56)
16-18	4 (27)	8 (67)	12 (44)
Years Since Diagnosis			
≤5	3 (21)	2 (18)	5 (20)
6-10	6 (43)	2 (18)	8 (32)
≥11	5 (36)	7 (63)	12 (48)
Self-Reported Severity			
< 5	10 (67)	4 (33)	14 (52)
≥ 5	5 (33)	8 (67)	13 (48)

Table 2

Prescribed Asthma Medications

	Male (n = 15)	Female (n = 12)	Total Sample (N = 27)
	f (%)	f (%)	f (%)
Medications			
Bronchodilators			
Short Acting	13 (87)	10 (83)	23 (85)
Long Acting	2 (13)	2 (17)	4 (15)
Theophylline	0 (0)	2 (17)	2 (7)
Preventors			
Anti-cholinergic	0 (0)	1 (8)	1 (4)
Inhaled steroids	12 (80)	10 (83)	22 (82)
Non-steroidal	0 (0)	1 (8)	1 (4)
Anti-leukotriene	4 (27)	1 (8)	5 (19)
Ketotifen	2 (13)	1 (8)	3 (11)

The participants included 15 males (56%) and 12 females (44%). The mean age of the males in the study was 14.7 years (SD = 1.2; Mdn = 15.0; range, 13.0 to 17.0 years), while the mean age of the females participating in the study was 16.1 years (SD = 1.4; Mdn = 16; range, 14 to 18 years). The mean age at the time of diagnosis of asthma for the males was 6.0 (SD = 4.4; Mdn = 6.0; range, infancy to 13 years), while the mean age at the time of diagnosis of asthma for the females was 5.2 years (SD = 4.8; Mdn = 3.0; range, infancy to 15 years). The mean years since the diagnosis of asthma for males was 8.6 (SD = 4.2; Mdn = 9.0; range, 2 to 15 years), while the mean years since diagnosis of asthma for females was 11.0 (SD = 5.1; Mdn = 12; range, 1.0 to 18.0 years). On average, males reported an asthma severity of 3.8 (SD = 1.8; Mdn = 3.0; range, 1.0 to 8.0) while the females reported an asthma

severity of 4.9 (SD = 2.2; Mdn = 5.0; range, 1.0 to 8.0). Over 80% of the males and females reported they were taking short-acting bronchodilators and inhaled steroids at the time of the survey.

Objective 1

To assess the asthma-related knowledge, behaviour, and fears of a sample of adolescents with asthma.

The descriptive statistics for the total scores, domains and individual item responses for the asthma-specific knowledge and asthma-specific behaviour are presented. In terms of individual item responses, the knowledge and behaviour deficits are highlighted in the presentation. This is followed by a summary of the results of the responses to the open ended questions on concerns and fears.

Asthma-Specific Knowledge

The participants's (N = 27) mean total score for the AKQ was 31.8 (66%) [SD = 4.5; Mdn = 31.0; range, 23.0 -39.0 (48 -81%)]. The results of the analysis of each of the four domains for the AKQ are presented below.

The subjects' mean score on the general knowledge domain was 8.2(68%) [SD = 0.8; Mdn 8.0 (67%); range, 7.0 to 10.0 (58% to 83%)] out of a possible 12 marks. The majority of the participants (82%) were not able to identify one use for an action plan and only one (4%) of the participants was able to indicate two uses for this tool (Item 32). Almost one third of the participants (30%) mistakenly indicated that the best way to measure the severity of asthma is chest auscultation (Item 27).

The subjects' mean score for the asthma therapy domain was 9.9 (62%) [SD =2.1; Mdn = 10 (63%); range, 5.0 to 14.0 (31% to 88%)] with 16 being the maximum possible total score. Only 12 (44%) of the participants could identify more than one

possibility for why a reliever medication might not be effective during an acute exacerbation of asthma (Item 20). Approximately two-thirds of the participants mistakenly believe death from asthma occurs because the attack started too quickly for intervention (Item 14). Over one-half of the participants stated that inhaled medications do not have fewer side effects than oral medications, and that short courses of oral prednisone usually have significant side effects (Item 17, Item 18). Over half of the participants could only identify one preventative medication, and almost two-thirds of the participants could only identify one acute treatment for asthma (Item 10, Item 11).

The subjects' mean score on the asthma symptom domain was 4.5 (64%) [SD =1.3; Mdn = 4.0 (57%); range, 2.0 to 7.0 (29% to 100%)] out of possible maximum of seven. Over one-quarter of the participants was not able to identify two or more of the three main symptoms of asthma (Item 1), while about half of the participants, according to responses, appeared to be unaware that asthma tends to be more of a problem at night (Item 28). A greater proportion of the participants were aware wheeze could be due to muscle spasm (90%) (Item 7) than to swelling of the lining of the airway (67%) (Item 8). Over 40% of the participants indicated they would continue to treat breathlessness with reliever medication every two hours (Item 21).

The subjects' mean score on the precipitants of asthma domain was 8.3 (69%) [SD = 2.5; Mdn = 9.0 (75%); range,3.0 to 12.0 (25% to 100%)] out of a possible maximum of 12. Only 13 (48%) could identify more than one strategy to prevent exercise-induced asthma (Item 22). Only 13 (48%) identified six triggers of asthma (Item 6). A large proportion of the participants (37%) appeared to have the

misconception that cow's milk contributes to mucus production in individuals with asthma (Item 5).

Asthma-Specific Behaviour

Of the sample of 27 subjects, 10 completed all of the items and were eligible to receive a total score. In order to receive a total score on the EABS the participant was required to complete all of the questions and to receive a domain score for all six domains. In some instances participants failed to answer select items, and in others participants did not address items in large sections (i.e. an entire page) of the tool. Previously this tool was used in a facilitated self-administration format where the facilitator was able to ensure all items were addressed. The mean total score on the EABS for the 10 subjects was 4.9 (SD = 0.5; Mdn = 4.6; range, 3.8 to 5.8).

The items included in Domain 1 address compliance to medical regimen. All of the items in this domain were addressed by 24 of the subjects. The subjects' mean score for the compliance to medical regime domain was 5.3 (76%) [SD =1.2; Mdn of 5.5 (79%); range,1.9 to 7.0 (27 to 100%)]. Item response analysis showed > 80% of the participants follow instructions the majority of time (rated 5 to 7 on the 7-point likert scale) (Item 2), while 70% stated they take medications as directed the majority of the time (Item 7). Over one-third of the participants reported difficulty in remembering to take medications the majority of time (Item 11) and over 40% of the participants stated they take less medication than prescribed when they are feeling well a majority of the time (Item 17).

The items included in Domain 2 focus on trigger avoidance. Again, 24 participants successfully completed all of the necessary items to acquire a total domain score. The subjects' mean score the trigger avoidance domain was 3.7 (52%)

[SD = 1.2; Mdn = 3.8 (54%); range, 1.8 to 5.6 (26 to 80%)]. Only 48% of the subjects suggested they avoid things that they know give them asthma the majority of time (Item 4). Over two-thirds of the subjects suggested they remove themselves from an environment which triggers asthma symptoms the majority of time (Item 6).

The items included in Domain 3 address health promotion and prevention activities. All of the 27 participants completed the required items for this domain. The subjects' mean score for the health promotion and prevention domain was 4.7 (67%) [SD = 0.8; Mdn = 4.7(67%); range, 2.7 to 6.1 (39% to 87%)]. Only 5 (19%) of the participants stated they keep an asthma diary (Item 33 a). A majority of the participants (16, 59%) attempted to find out more about asthma from various sources (Item 34 a). Only 1 (4%) of the participants stated they smoked cigarettes (Item 3), while 17 (63%) stated they do not drink alcohol.

The topic of the fourth domain is communication and interaction with the health care system. All of the items in this domain were addressed by 24 participants. The subjects' mean score on the communication and interaction with the health care system was 5.5 (79%) [SD = 1.1; Mdn = 5.9 (84%); range,1.8-6.8 (26 to 97%)]. Only one third of the participants has talked with friends about asthma (Item 25 b), although 25 (93%) stated their friends knew they had asthma.

The eight items in Domain 5 deal with issues surrounding symptom intervention. Only 18 of the participants addressed all of the items for this domain. The subjects' mean score for the symptom intervention domain was 4.3 (61%) [SD = 0.9; Mdn = 4.4 (63%); range,2.5 to 6.3 (36 to 90%)]. Over 25% of the participants stated in the past 3 months they put up with symptoms because they wanted to keep a pet a majority of the time (Item 9 a), because they didn't want asthma to interfere with

something they wanted to do (44%) (Item 9 d), and or because they wanted to continue exercising (48%) (Item 9 e). Ten of the subjects (37%) would ask for help with their asthma when they needed it a majority of the time (Item 15). Over one half of the participants reported they had an action plan (Item 19 a) , while only 11 (40%) indicated that they follow it the majority of time (Item 19 b).

The final domain addresses problem behaviours. Only 16 of the respondents answered all of the items for the domain score. The subjects' mean score for the problem behaviour domain was 5.9 (84%) [SD =1.0; Mdn = 6.2 (87%); range,4.1 to 7.0 (59 - 100%)]. Ten of the subjects (37%) reported in the majority of time they experienced shakiness as a result of either asthma or asthma medications (Item 29 g).

Concerns

Of the sample of 27 adolescents with asthma, 23 responded to the open ended question relevant to their concerns about having asthma. Two categories of concerns emerged from the analysis of the responses to the open ended question about their concerns: impact of having asthma upon activities, and possible breathing problems.

Of the 23 who responded, 14 (61%) stated they were concerned that asthma would impact their ability to take part in activities. Responses that demonstrated their concern about the impact of asthma on activities include: "not being able to do anything"; "not being able to be with friends who smoke and around animals"; "not being as physical"; "it will slow me down in distance running and mountain climbing"; and "not being able to do things".

Of the 23 who responded, 9 (39%) stated they were concerned that they would experience breathing difficulties. Responses that demonstrate concerns categorized as

breathing problems include: "not being able to breath"; "not getting enough air"; and "something could happen and no one would know what to do."

Fears

Of the sample of 27 adolescents with asthma, 20 responded to the open ended question relevant to their fears about having asthma. Three categories of fears emerged from analysis to their responses: fear of dying, fear related to medications and fear of asthma worsening. Fear of dying was identified by 8 (40%) of the participants that responded to the question. Responses that reflected their fear of dying included: "dying in my sleep"; "having a bad attack and dying"; "getting so sick I die"; and "dying."

Of the 20 who responded 4 (20%) indicated that their fears pertained to their asthma medications. Responses that reflected their fears relevant to medications include: "being without my inhalers when I need it"; "overusing my medications and they won't work anymore"; and "side effects of medications".

Another 8 of the 20 (40%) respondents were fearful of the asthma worsening. Included among the responses in this category are: "it will never go away and I will have to go on a respirator"; "afraid it will get worse"; and "hope it doesn't get worse".

Objective 2

To explore the relationship between the asthma related knowledge and behaviour of a sample of adolescents with asthma.

As a result of missing data, total scores on the EABS could only be calculated for 10 subjects who had completed all of the items in each of the domains of the EABS. Therefore, correlational analysis to explore the relationship between total scores on the EABS and the AKQ was not warranted. Analysis of relationships between the

individual domains on the AKQ and the EABS were conducted. Table 3 provides a summary of the comparisons between the four domains of the AKQ and the six domains of the EABS. One significant relationship was found between the general asthma domain of the AKQ and the health promotion/prevention domain of the EABS with a Pearson Correlation of .42, and a p value of .03.

Table 3

Correlations Among the Domains of the Asthma Knowledge Questionnaire and the Edmonton Asthma Behaviour Scale

		AKQ Domains		
EABS Domains	**General Asthma** r (N)	**Asthma Therapy** r (N)	**Asthma Symptoms** r (N)	**Precipitants of Asthma** r (N)
Compliance	.33 (24)	-.09 (24)	.02 (24)	-.18 (24)
Trigger	.09 (24)	-.03 (24)	-.18 (27)	.08 (24)
Health Promotion	.42 (27)**	.25 (27)	.29 (27)	.17 (27)
Communication	.40 (24)	.21 (24)	-.15 (24)	.08 (24)
Symptoms	.12 (18)	.46 (18)	-.39 (18)	.10 (18)
Problems	.16 (16)	-.37 (16)	-.28 (16)	-.33 (16)

Note. ** $p<.05$

Objective 3

To explore the influences of gender and age on asthma related knowledge, behaviour, and fears and concerns in a sample of adolescents with asthma.

Asthma-Specific Knowledge and Gender

The results of analysis using the independent t-test showed there were no statistically significant differences between males and females on the mean total score of the AKQ ($t = -.2$, $p > .05$). Comparisons of males and females showed no statistically significant differences on any of the domain scores ($p > .05$). A summary of the means and SD for the total scores and domain scores on the AKQ by gender is presented in Table 4.

Table 4

Domain Scores on the Asthma Knowledge Questionnaire by Gender

Domain	Male ($n = 15$)		Female ($n = 12$)		Total Possible Score
	Mean	SD	Mean	SD	
General	8.1	0.7	8.3	1.0	13
Asthma therapy	9.9	2.3	9.8	1.9	16
Asthma symptoms	4.7	1.4	4.3	1.1	7
Precipitants	7.9	2.8	8.7	2.1	12
Total Score	31.7	5.0	32.0	4.0	48

Asthma-Specific Knowledge and Age

The results of Pearson correlation procedures showed a statistically significant negative relationship between age and knowledge ($r = -.41$, $p = 0.05$). It would have been of interest to examine possible differences on the AKQ among age categories (i.e., young, middle and older adolescents). However, given the small sample size, further analysis was not appropriate.

Asthma-Specific Behaviour and Gender

There were only 5 males and 5 females for whom total scores on the EABS could be calculated. Given the numbers in each gender group were less than ten, statistical analysis to identify differences on the total EABS were not warranted. Also, there were less than 10 female subjects who had completed three of the six domains (communication, symptom intervention & problem behaviour). Comparisons of males and females were confined to those domains in which there were ten or more subjects in both gender groups. The results of independent t-tests showed no statistically significant differences between males and females on the three remaining domains (compliance, trigger avoidance & health promotion). A summary of the means and standard deviations for the total and domain scores on the EABS by gender is presented in Table 5.

Table 5

Domain Scores on the Edmonton Asthma Behaviour Scale by Gender

Domain	Male			Female		
	n	Mean	SD	n	Mean	SD
Compliance	12	5.2	1.3	12	5.4	1.1
Trigger Avoidance	12	3.5	1.1	12	3.9	1.3
Health Promotion	15	4.6	0.8	12	5.0	0.8
Communication	15	5.5	1.3	9	5.9	0.9
Symptoms	11	4.2	0.8	7	4.6	1.1
Problems	10	5.9	1.1	6	5.9	0.9

Asthma-Specific Behaviour and Age

The correlation between age and scored on the EABS was not statistically significant ($r = .09$, $p = .10$). It would have been of interest to examine differences on the domains of the EABS among adolescents categorized by age (young, middle, old). However, due to the small sample size, further analysis was not justified.

Asthma Concerns and Fears by Gender

A summary of the categories of concerns reported by males and females are presented in Table 6. In Table 7 a summary of the categories of fears reported by males and females is presented. Since one of the cells in Table 6 and all of the cells in Table 7 contain less than five subjects, it was not appropriate to statistically compare the concerns or fears by gender.

Table 6

Asthma Concerns by Gender

Concern	Male (n=12)	Female (n=11)
	f (%)	f (%)
Activity Limitations	8 (67)	6 (55)
Breathing Difficulties	4 (36)	5 (46)

Table 7

Asthma Fears by Gender

Fear	Male (n=9)	Female (n=11)
	f (%)	f (%)
Dying	4 (44)	4 (36)
Asthma Worsening	4 (44)	4 (36)
Medication Complications	1 (11)	3 (27)

Asthma Concerns and Fears by Age

A summary of the categories of concerns reported by participants based on their age is presented in Table 8. In table 9, a summary of the fears of participants reported based on their age is provided. Due to the small number of participants in each age group it was not appropriate to explore possible differences on fears and concerns by category of age (young, middle, old adolescents) using statistical procedures.

Table 8

Concerns of Having Asthma by Age

Age	Impact on Activities f	Breathing Problems f
13	3	0
14	3	1
15	3	3
16	3	3
17	1	2
18	1	0

Table 9

Fears of Having Asthma by Age

Age	Dying f	Medications f	Asthma Worsening f
13	1	0	2
14	3	0	1
15	2	1	1
16	2	2	1
17	0	1	1
18	0	0	1

Chapter 5

Discussion

A discussion of findings relevant to each of the three study objectives is presented. Here the results are first compared to previous studies and where applicable are discussed in relation to the social cognitive theory. The study limitations are presented, and then the implications of this study for nursing practice and research are put forward.

Objective 1

To assess the asthma-related knowledge, behaviour, and fears of a sample of adolescents with asthma.

Asthma - Specific Knowledge

The adolescents in this study correctly responded to two thirds of the questions on a revised version of the AKQ. Compared to the results of Gibson & Henry and their colleagues (1995), using the original version of the AKQ, the participants in this study showed greater knowledge on the total score of the revised version. The differences in level of knowledge may be due to several important factors. Participants were recruited from a pulmonary specialist's database, in Canada, whereas Gibson and his colleagues (1995) recruited their subjects from schools in Australia. The exposure to asthma education may have been greater for the former. Also, in the current study, a revised version of the AKQ was used. Two additional items were added to the AKQ, and the scoring was modified from a total of 31 marks to 48 marks.

General Knowledge

The frequencies of correct responses for the items in the general knowledge domain were > 85% with two exceptions. The first exception concerned identifying the uses for the action plan. This item was added to the original version of the AKQ, and thus was not previously tested The majority of participants were not able to specify one use for an action plan and only one of the participants was able to identify two uses.

The second exception concerned the use of chest auscultation as a means of measuring asthma. Almost one third of participants incorrectly indicated that the best way to measure the severity of asthma is for the doctor to listen to their chest. The lower correct response rate for this item has not been previously reported. The use of chest auscultation as a means of assessing asthma severity is not likely to be included in patient education for asthma self-management. Thus, many adolescents may be guessing the answer to this item and a lower correct response rate would be expected.

Asthma Therapy

Similar to the findings of Moosa & Henley (1996), using the parents of children with asthma, the adolescents in this study obtained their lowest mean score in the asthma therapy domain. Compared to the results of previous studies, the majority of adolescents in this sample have similar misconceptions, particularly in relation to the side effects of asthma medications (Gibson, Henry et al., 1995; Moosa & Henley, 1996). Unlike the findings of Gibson & Henry and their colleagues (1995), the majority of respondents in this study did not believe asthma medications are addictive.

Responses to items in this section also suggested participants had difficulty problem-solving in the context of an acute exacerbation of asthma. Less than one-half of the participants could list more than one reason why a reliever medication might not be helpful during an acute exacerbation of asthma. Congruent with previous findings, a low proportion of the study participants were able to identify more than one preventative treatment for asthma or more than one treatment for acute asthma (Gibson, Henry et.al., 1995). Item responses indicated that two thirds of participants mistakenly believe death from asthma occurs because the attack started too quickly for intervention.

Asthma Symptoms

Similar to findings reported in Australia by Gibson, Henry and their colleagues (1995), a substantial proportion of this sample were unable to identify one or more of the three main symptoms of asthma or that asthma symptoms tend to be more of a problem at night. Item responses suggested a greater proportion of the study participants were aware wheeze could be due to muscle spasm than to swelling of the lining of the airway. Over 40% of participants indicated they would continue to treat breathlessness with reliever medication every two hours.

Precipitants of Asthma

Similar to findings reported by Gibson, Henry and their colleagues (1995), less than one-half of the study participants could identify more than one strategy to prevent exercise induced asthma. All of the study participants were able to identify at least one asthma trigger, although only 13 (48%) identified six.

Asthma Specific Behaviour

The mean overall score on the EABS was 4.9 (70%). This calculation however only includes 10 of the study participants, as the remaining 17 did not complete all of the items required to calculate overall domain scores. Because this instrument has not been used extensively, it is not possible to compare scores of alternative populations. A discussion of the major findings pertaining to each of te domains of the EABS follows.

Compliance to Medical Regime

Overall, the study participants scored high on the compliance to medical regime domain. Of the six domains, the mean scores on the compliance to medical regime was ranked third highest. Item response analysis showed a high proportion of the participants follow instructions the majority of time, and that they take medications as directed the majority of the time. This finding corroborates with that of Slack & Brooks (1995) who concluded adolescents with asthma consider themselves to be compliant to their prescribed medical regime. Also, similar to findings reported by Slack & Brooks (1995), a large proportion of the subjects reported difficulty in remembering to take medications the majority of time. Almost half of the participants stated they take less medication than prescribed when they are feeling well a majority of the time.

Trigger Avoidance

Participants overall scored poorly on the trigger avoidance domain with a mean of 3.7 (52%), the lowest mean domain score. Only 48% of the subjects suggested

they avoid things that they know give them asthma the majority of time. Alternatively, 66% of the subjects suggested they remove themselves from an environment which triggers symptoms the majority of time.

Health Promotion/Prevention

Health promotion/prevention domain was the fourth ranked domain with a mean score of 4.7 (67%). Forero and his colleagues (1996) found more adolescents with asthma smoked cigarettes and consumed more alcohol than those without asthma. By contrast, only one adolescent reported he/she smoked and over 60% of the study participants abstain from using alcohol. The differences found in the reported use of cigarettes and alcohol in this study compared to a previous study conducted in Australia, may be due to differences in the population studied. The sample in this study, as mentioned previously, may have more severe asthma than the community sample used in the previous study conducted by Forero and his colleagues (1992). Adolescents with more severe disease may experience more severe airway reaction to cigarettes rendering them less likely to either begin or continue using cigarettes. Alternatively, adolescents in this study may have under reported their use of cigarettes and alcohol particularly if a parent supervised their completion of the questionnaires. Very few of the participants stated they keep an asthma diary. Over one half of the participants stated they have attempted to find out more about asthma from a variety of sources. This latter finding corroborates with that of Slack and Brooks (1995) who found adolescents wanted access to information about asthma and asthma management.

Communication and Interaction with the Health Care System

The second highest mean domain score was on the communication and interaction with the health care system domain with a mean of 5.5 (79%). Only one third of the participants have talked with friends about asthma. Overall the participants stated they were confident in communicating their health concerns to health care providers.

Asthma Symptoms

The study participants scored a mean of 4.3 (61%) on the symptom intervention domain. This domain ranked fifth out of the six domains. High proportions of the participants suggested in the majority of time in the past 3 months they put up with symptoms because they wanted to keep a pet, because they didn't want asthma to interfere with something they wanted to do and or because they wanted to continue exercising. Over one-third of the participants indicated, in the majority of time, they would ask for help with their asthma when they needed it. Over one half of the participants reported they had an action plan, while less than half of these participants indicated that they follow it the majority of time. Forero and colleagues (1992) found only 9% of adolescents with asthma had an action plan .

Problem Behaviours

Of the six domains on the EABS, the participants demonstrated the highest mean score on the problem behaviours domain (5.9 or 84%). Overall, the participants did not identify any significant problem behaviours related to having asthma. The

asthma or asthma medications with one exception. Over one-third subjects reported they experienced shakiness as a result of either asthma or asthma medications, the majority of the time.

Fears and Concerns

The adolescents in this sample reported concerns about having activity limitations because of their asthma. This is consistent with concerns of parents of children with asthma, who reported a belief that it is necessary to limit the outdoor activities of children with asthma (Spykerboer et al., 1986). This study's sample was also concerned that they may experience breathing difficulties, and a loss of a sense of normalcy. Slack & Brooks (1995) also found that adolescents are concerned with appearing normal, and find that taking medication in a public setting to be embarrassing. Adolescents participating in this study were fearful of dying because of asthma. This theme has not emerged as significant in previous studies with adolescents with asthma. Fears of medication complications also emerged. Moosa & Henley (1996) found that parents of children with asthma had many misconceptions regarding medications similar to those identified by the participants which could contribute to fears related to the complications associated with medications.

Objective 2

To explore the relationship between the asthma related knowledge and behaviour of a sample of adolescents with asthma.

There was no statistically significant relationship found between the total score on the AKQ and the EABS. Analysis of the relationship among the domains of the AKQ an the EABS revealed only the general asthma domain of the AKQ and the health promotion/prevention domain of hte EABS were positively correlated. The lack of findings in this study may have been due to a lack of power to detect differences as a result of the small sample size. Others have reported a weak to moderate relationship between asthma specific knowledge and behaviour (Gibson, Henry et al., 1995; Kolbe, Vamos, Gergusson, Elkink & Garett, 1996). From a theoretical perspective, weak or moderate relationships between knowledge and behaviour would be expected. According to the SCT, knowledge does not directly translate into behaviour. Environmental factors as well as personal factors such as values and beliefs moderate the relationship between knowledge and behaviour.

Objective 3

To explore the influences of gender and age on asthma related knowledge, behaviour, and fears and concerns in a sample of adolescents with asthma.

The results of this study showed no statistically significant differences between gender on asthma-specific knowledge, behaviour, fears or concerns. Nor were there any significant relationships found between asthma specific behaviour, fears and concerns and age. There have been no previous studies in which the effect of gender or the relationship between age and knowledge, behaviour, fears or concerns have been examined. Theoretically, gender and age might be expected to have some

moderating impact on asthma-specific knowledge, behaviour, fears and concerns of adolescents. According to SCT, personal factors play a role in the interaction between knowledge, behaviour and environment. There may be important gender differences in the values and beliefs held in relation to asthma's impact on life. As one ages, life experiences accumulate, which impact on meaning and interpretation of events. Also, as adolescents age, they develop cognitively. Differences in values, beliefs, meaning, and cognitive development in turn would be expected to impact on the extent to which knowledge is translated into self-management behaviour. Also, differences in values, beliefs, meaning and cognitive development would be expected to result in differences in the particular fears and concerns held in relation to having asthma. The sample in this study may have been too small to detect statistically significant differences between gender or relationships between age and knowledge and behaviour. There was insufficient cell sizes to examine gender or age differences or reported fears and concerns.

A negative relationship was found between asthma-specific knowledge and age. This may be an indication of younger adolescents receiving asthma education as children, while older adolescents may not have had this opportunity. The majority of education tends to occur during the time following initial diagnosis. While younger adolescents may have been diagnosed when asthma education was readily available to children, older adolescents may have been diagnosed prior to the surge of asthma education programs.

Study Limitations

There were several limitations of the study related to the sampling technique and the survey method. Because the study participants were identified from a pulmonary specialist's database of patients, it can be assumed that the possible participants did not represent all severity of asthma. In most instances individuals with mild to moderate asthma can be managed quite effectively by a family physician and do not generally require pulmonary specialist's care. Thus, this sample may reflect the knowledge and behaviour of individuals with moderate to severe asthma. Also, individuals recruited from this specialist's practice may have had more access to some formal asthma education compared to the general population of adolescents with asthma. There is no way of knowing the extent to which adolescents completed the questionnaires independently. Adolescents who were supervised during the process of completing the questionnaires would likely be more reluctant to reveal some information (i.e. smoking habits) compared to non-supervised adolescents.

The response rate from the survey was 21%. Caution is advised in generalizing the findings to all adolescents in this physician's practice. The knowledge, behaviour, fears and concerns of the proportion of adolescent patients who did not respond to the questionnaires may be different. This response rate may be a reflection of mail solicitation of participants and the nature of adolescents to participate in research studies. The response rate may have been enhanced by conducting telephone reminders and interviews, however this would have been a costly and time consuming procedure. As the study investigator did not have access to the names of potential participants clinic staff would have to have undertaken this task.

Another limitation of the study was the questionnaires employed. The EABS

utilizes a complex scoring system which requires participants to address all of the items in the tool to receive individual domain and overall scores. As many of the participants chose not to address all of the items, only 10 overall scores were calculated. While the AKQ has been previously used in similar populations in Australia, it has not been used in Canada. Therefore, it was necessary to modify the tool slightly to reflect differences in culture and health care. The scoring of the AKQ was also modified to allow for partial marking and to permit questions with multiple answers to receive more than one mark. Therefore several questions in the tool were worth between two and six marks, depending on the number of possible answers.

Implications for Nursing Research and Practice

There has been limited study of the asthma-specific knowledge, behaviour, concerns and fears of the adolescent. Further study, using larger sample sizes from a variety of settings is required to: determine the generalizability of the findings on knowledge, behaviour, concerns and fears; explore the relationship between knowledge and behaviour; verify the relationship found between asthma-specific knowledge and age among adolescents; establish whether or not there is a relationship between asthma-specific behaviour and age among adolescents and determine whether or not asthma-specific knowledge, behaviour or fears and concerns differ by gender or age.

This is the first study in which an attempt has been made to collect data about adolescents fears and concerns related to asthma using open ended questions. The results indicate that the use of open ended questions are a fruitful method of collecting this information in future research.

The lack of statistically significant relationships between knowledge and behaviour in this study demonstrated that high asthma-specific knowledge does not ensure adolescents will chose to engage in healthy asthma-self management behaviours. Based on Social Cognitive Theory, the adolescents' personal values, beliefs and environmental factors such as peer support would be expected to moderate the relationship between knowledge and behavior. Future research is required to identify the more salient values and beliefs that may be moderating the relationship between knowledge and behavior in adolescents. Also, given the importance of group membership and peer support among adolescents it would be worthwhile to explore the impact of peer relationships on asthma-self management in the future.

The use of questionnaires in the clinical setting appear to be a practical assessment strategy to obtain important information about the adolescent's unique knowledge deficits and misconceptions relating to asthma-specific knowledge and behaviour. This information when pooled together with information about the adolescent's concerns and fears could be incorporated into educational interventions which are more likely to change behaviour in a way that reduces the morbidity and mortality associated with asthma.

The researcher's personal clinical experience, the anecdotal evidence of others and social cognitive theorists support the view that the adolescent asthmatic's beliefs and values are important determinants of the degree to which knowledge translates into behaviour. Unless the adolescent understands the impact of recommended asthma-specific behaviour in relation to asthma-outcomes that are of personal value, it is less likely the adolescent will engage in appropriate asthma self-management behavior. The themes reflected in the adolescents' responses to the open ended

question on concerns and fears about having asthma may mirror some critical valued asthma outcomes. Collaboration between health care professionals and adolescents to formulate goals of asthma education that target their specific fears or concerns are likely to have a greater impact on changing asthma-specific behaviour. For example, many of the adolescents in this study expressed a fear of dying as a result of their asthma. Further, a large percentage of the participants in the study reported the belief that changes in respiratory status that result in asthma deaths occur too quickly for intervention. Although about half of the participants reported they had an action plan, less than one fifth of the participants could identify one use for an action plan. Deaths associated with asthma are largely thought to be preventable if early signs of asthma worsening are acted upon. The action plan is a guide for patients' adjustments of medications in response to early changes in respiratory status.

Many of the adolescents in this study hold misconceptions concerning the side effects of their asthma medications which could well play a role in the extent to which they routinely take them. Thus, for the adolescents in this study, important areas to emphasize in future asthma education are: the role for self-monitoring of symptoms and or peak flow to detect asthma is worsening early; the role of action plans in guiding early treatment of changes in asthma; the role of asthma medications in controlling asthma; the side-effects of asthma medications; and the role of the action plan in reducing mortality through early adjustment of asthma medications.

Similarly, a concern expressed by many adolescents in this study pertained to the extent to which asthma limited valued activities such as physical exercise and sports. Many adolescents indicated they put up with asthma symptoms because they wanted to continue exercising. Also, many adolescents appeared to have limited knowledge

about how to prevent exercise-induced asthma. Future educational emphasis for these adolescents would be on how to control or prevent exercise induced asthma so that the extent to which asthma impacts on this valued activity is minimized. Addressing the misconceptions regarding the side effects of the medications may also increase appropriate asthma- behaviour, particularly when tied to the notion of the role of preventative medications in the control of asthma symptoms and exercise-induced asthma.

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Appendix A

Cover Letter

February 16, 1999

Dear Parent/Guardian,

I am a student in the Master's Program in the Faculty of Nursing, at the University of Alberta. I am doing a study as part of my program. The title of this study is "An Assessment of Knowledge and Behaviour of Adolescents with Asthma." This study is being done to learn more about teenagers with asthma. It may be useful in learning new information about what teens with asthma know, how they act, and their fears and concerns about asthma. The information may be used to develop new programs for teens with asthma.

The study involves your son/daughter with asthma completing the surveys in this package. It would be best if they could complete the surveys in private. The decision to complete the surveys is voluntary. It is your and your son/daughter's choice whether he/she fills out the surveys. If he/she wants, he/she can skip certain questions. If you and your son/daughter decide to take part in this study, please send the completed surveys using the self addressed stamped envelope. This will make sure the envelope gets to the me. I would be very grateful for your and your son/daughters participation in the study.

All of the details you provide will be kept in private, I will not know your or your son/daughter's name. Please read the information sheet provided and keep it in case you have questions later. If you have any questions please contact me by phone at 492-9636 (work), 430-1797 (home), by fax at 492-3608, or by e-mail at hwells@telusplanet.net.

Thank you for your help.

Sincerely,

Heather M. Wells, RN, MN Student, University of Alberta, Faculty of Nursing.

Appendix B

Cover Letter from Physician

Information for: Parents of adolescents with asthma
From: Dr. G.F. MacDonald

I am giving information about a study to all parents of teenagers who I have seen for their asthma. The study is being done by Heather M. Wells, a master in nursing student at the University of Alberta. With your consent, Heather is asking your teen to complete surveys about his/her asthma. This study is important because it will provide us with information about teenagers' knowledge and behaviours related to their asthma. It may also help us to create asthma programs for teens.

You teen does not have to take part in this study, and his/her medical care will not be affected if he/she does not take part. In this package you will find a letter describing the study, three surveys, and a self-addressed stamped envelope. Thank you for your time.

Sincerely,

Dr. G.F. MacDonald, MD, FRCP (C)

Appendix C

Information Sheet

Information Sheet

Title of Project: An Assessment of Knowledge and Behaviour of Adolescents with Asthma
Principal Investigator: Heather M. Wells, RN, MN Student, University of Alberta, Faculty of Nursing
Phone Number: (403) 492-9636 Fax Number: (403) 492-3608
E-mail Address: hwells@telusplanet.net
Supervisor: Carolyn Ross, PhD, Associate Professor, Faculty of Nursing
Phone Number: (403) 492-4894

Purpose: The purpose of this research is to look at the knowledge, behaviours, fears and concerns of teenagers with asthma.
Background: The results of this study will assist in learning more about teenagers with asthma. It may be useful in learning new information about what teens with asthma know, and how they manage their asthma. The information may be used to develop new programs for teens with asthma. The study includes teens who have been told they have asthma by a doctor.

Procedures: Teenagers taking part in the study will be asked to fill out the three forms in this package. It will take about one hour for your teenager to complete the forms. The package provides him/her with the forms and a self-addressed, stamped envelope. Receiving the completed surveys will indicate your consent to your teenager taking part in the study.
Benefits: This study will help us to better understand teenagers with asthma. We also believe that it will be helpful in developing asthma education for teenagers. There will be no direct benefit to you or your son/daughter.
Risks: There are no known risks to teenagers who take part in this study.

Confidentiality: Your name nor your son/daughter's will not appear on any forms. I will not know your name, or your son/daughter's. The forms filled out by your son/daughter will be kept for seven years. You will not be identified in any papers written, or presentations given about this study. Only grouped information will be presented.
Voluntary Participation: Even if you enter the study, your teenager may refuse to answer any of the questions in the surveys. Taking part in the study is totally voluntary. Your teenagers care will not be affected by his/her choice to enter or not enter the study.

Additional Contacts: If you have any concerns about any aspect of this study, you may contact either Heather M. Wells, Dr. Ross, at the numbers above, or the University of Alberta, Faculty of Nursing Research Office at 492-6251. If you would like information about asthma you may contact the Alberta Asthma Centre at 492-9564 or the Centre for Lung Health which has a teen asthma program at 482-8951.

Appendix D

Information Survey

Information Survey

Please complete the following questions.

How old are you? _____ years

I am:

Male _____

Female _____

How old were you when you were diagnosed with asthma?

What medicines do you take (for your asthma, or for other reasons), how did you doctor prescribe them, and how often do you take them? Please include medicine from you doctor, any that you buy, and even vitamins.

Name of medicine	How often did your doctor advise you to take this medicine? (please specify: per day, per week or per month)	How often do you take this medicine? (please specify: per day, per week or per month)

On a scale of 1- 10 (1 being not at all severe, 10 being very severe) how would you rate the current severity of your asthma? _____

6. What is your biggest concern about having asthma?

7. What is your biggest fear about having asthma?

Thank you for completing this survey. Please complete the other surveys and the consent form and post them in the self-addressed stamped envelope.

Appendix E

Edmonton Asthma Behaviour Scale

Edmonton Asthma Behaviour Scale

In this survey we wish to learn more about your behaviours as a person with asthma. Read each question carefully, and try to answer all of the questions. The survey has four kinds of questions:

- If a question is followed by a row or column of numbers, circle a number that best answers the question for you. Please remember there are no right or wrong answers.

	None of the time						*All of the time*
i.e. during the past month how often have you watched television	1	2	3	4	5	6	7

- If a question is followed by two choices, check the box that best answers the question for you.

	Yes	No
i.e. do you have somebody to talk to when you feel sad?	☐	☐

- If a question is followed by a column of boxes, check all that apply

i.e. what do you like to do in your spare time?

(a) listen to music ☐

(b) watch television ☐

(c) go to the movies ☐

(d) read books ☐

- Finally if a question is followed by a blank line, please write in your answer.

i.e. how did you get to school today?

_____

Edmonton Asthma Behaviour Scale

For each of the following numbered questions, circle a number that indicates how often the situation in the question occurs for you. Please answer all questions on all sheets.

	None of the time						*All of the time*
1. Do you understand instructions given to you by health professionals (doctors nurses etc)?	1	2	3	4	5	6	7
2. How often do you follow these instructions?	1	2	3	4	5	6	7

3. How much do you smoke?

-I don't smoke.....1
-one cigarette per day.....2
-2-3 cigarettes per day.....3
-4-6 cigarettes per day.....4
-7-12 cigarettes per day.....5
-13-20 cigarettes per day.....6
-more than 20 cigarettes per day..7

	None of the time						*All of the time*
4. Do you avoid things that you know give you asthma?	1	2	3	4	5	6	7
5. Do you attempt to follow a healthy diet?	1	2	3	4	5	6	7
6. During the last 3 months, how often did you <u>REMOVE</u> yourself from an area when you began to get asthma symptoms?	1	2	3	4	5	6	7
7. How often do you take your medications <u>as directed</u>?	1	2	3	4	5	6	7
8. How often do you get a good night's sleep?	1	2	3	4	5	6	7
9(a) During the last 3 months, did you at times <u>put up with</u> your asthma symptoms because you wanted to keep a pet (dog/cat/bird) in your home?	1	2	3	4	5	6	7
(b)During the last 3 months, did you at times <u>put up with</u> your asthma symptoms because you didn't want to be rude to others?	1	2	3	4	5	6	7

(c) During the last 3 months, did you at times put up with your asthma symptoms because you didn't want to risk losing your job/miss school? 1 2 3 4 5 6 7

(d) During the last 3 months, did you at times put up with your asthma symptoms because you didn't want asthma to interfere with something you wanted to do? 1 2 3 4 5 6 7

(e) During the last 3 months, did you at times continue to exercise even when you began to experience asthma symptoms? 1 2 3 4 5 6 7

10. Which of these best describes your exercise?

-less than once a week for 20 minutes.....1
-once a week for 20 minutes.....2
-twice a week for 20 minutes.....3
-three times a week for 20 minutes.....4
-four times a week for 20 minutes.....5
-five times a week for 20 minutes.....6
-more than five times a week for 20 minutes.....7

11. During the last 3 months, did you at times forget to take your asthma medicine because you felt better? 1 2 3 4 5 6 7

12. Which of these best describes your alcohol drinking?

-I don't drink alcohol.....1
-1-2 drinks per month.....2
-1-2 drinks per week.....3
-3-4 drinks per week.....4
-5-6 drinks per week.....5
-7-8 drinks per week.....6
-9 or more drinks per week.....7

13 (a) Do you change the type of exercise you do to suit your asthma? 1 2 3 4 5 6 7

(b) Do you change the location of exercise you do to suit your asthma? 1 2 3 4 5 6 7

(c) Do you change how hard you exercise to suit your asthma? 1 2 3 4 5 6 7

(d) During the last 3 months, did you at times stop taking your asthma medicine because you felt better? 1 2 3 4 5 6 7

(e) Do you ask for help with your asthma when you need it? 1 2 3 4 5 6 7

16(a) Do you avoid <u>foods</u> that can trigger your asthma symptoms?	1	2	3	4	5	6	7
(b) Do you avoid <u>beverages</u> that can trigger your asthma symptoms?	1	2	3	4	5	6	7
(c) Do you avoid <u>medications</u> that can trigger your asthma symptoms?	1	2	3	4	5	6	7
17. During the last 3 months, did you at times <u>take less</u> of your asthma medicine than the doctor prescribed because you felt <u>better?</u>	1	2	3	4	5	6	7
18. Do you start treatment as soon as you detect your asthma symptoms?	1	2	3	4	5	6	7
19(a) Do you have an action plan to treat your asthma symptoms?				☐ Yes ☐ No Go to question #20			
(b) Do you follow it when the symptoms occur?	1	2	3	4	5	6	7
20. During the last 3 months, did you at times <u>stop</u> taking your asthma medicine because you felt <u>worse</u>?	1	2	3	4	5	6	7
21. Do you feel that you can properly use medication during severe asthma symptoms?	1	2	3	4	5	6	7
22 Do you panic during severe asthma symptoms?	1	2	3	4	5	6	7
23. During the last 3 months, did you at times <u>take more</u> of your asthma medicine than the doctor prescribed because you felt you were having breathing problems?	1	2	3	4	5	6	7
24 Because of your asthma , do you do any of the following?							
(a) Shout, yell, or get upset	1	2	3	4	5	6	7
(b) Use asthma as an excuse to avoid work or school	1	2	3	4	5	6	7
(c) use asthma for personal gain (i.e. sympathy, attention)	1	2	3	4	5	6	7
(d) deny your asthma	1	2	3	4	5	6	7
(e) Preoccupy yourself with the way you look	1	2	3	4	5	6	7

25. (a) Which of these people know that you have asthma?
Please check all the people you have told.

(1) Significant other (boyfriend/girlfriend) ☐
(2) Friends ☐
(3) Relatives ☐
(4) People you work with ☐
(5) Others (teachers, coaches etc) ☐
Please specify_____

(b) have talked to <u>any</u> of the people you chose in (a) about your asthma in general? (other than just saying you have asthma, i.e. how you feel about your asthma, how you cope with asthma etc) ☐ Yes ☐ No

Which people did you talk to?

(1) Significant other (boyfriend/girlfriend) ☐
(2) Friends ☐
(3) Relatives ☐
(4) People you work with ☐
(5) Others (teachers, coaches etc) ☐
Please specify_____

(c) Have you told any of the people in (a) what to do if you have severe asthma symptoms? ☐ Yes ☐ No

Which people did you tell?

(1) Significant other (boyfriend/girlfriend) ☐
(2) Friends ☐
(3) Relatives ☐
(4) People you work with ☐
(5) Others (teachers, coaches etc) ☐
Please specify_____

26 Do you do any of the following because of your asthma?

	None of the time						*All of the time*
(a) Feel inactive	1	2	3	4	5	6	7
(b) Prefer to be by yourself	1	2	3	4	5	6	7
(c) Deliberately avoid others	1	2	3	4	5	6	7
(d) Display a lack of concern for yourself and/or your future	1	2	3	4	5	6	7

27 If you have bad asthma symptoms that are not getting better without treatment, how long do you wait before contacting a doctor?

-less than an hour.....1
-2-3 hours.....2
-several hours.....3
-one day.....4
-a few days.....5
-one week.....6
-wait until my next appointment.....7

28 Do you have one family doctor who looks after your asthma? ☐ Yes ☐ No

29. Do you show any of these changes because of either asthma or asthma medicines?

	None of the time						*All of the time*
(a) Gain in weight	1	2	3	4	5	6	7
(b) Loss of appetite	1	2	3	4	5	6	7
(c) Memory lapses	1	2	3	4	5	6	7
(d) Loss of weight	1	2	3	4	5	6	7
(e) Always tired	1	2	3	4	5	6	7
(f) Trouble sleeping	1	2	3	4	5	6	7
(g) Shakiness	1	2	3	4	5	6	7
(h) Stomach (Digestive) problems	1	2	3	4	5	6	7
(i) Other physical changes Please specify_____	1	2	3	4	5	6	7

30 (a) have you been faced with an asthma emergency away from home or in a new location during the last 3 months? ☐ Yes ☐ No

Go to Question #32

(b) Did you seek help from a doctor? ☐ Yes ☐ No

Go to Question #31

(c) How did you seek help?

_____

_____ Go to Question #32

31For each of the following statements, please indicate how confident you were by circling a number from 1 to 7.

How confident were you in providing the following information to the doctor?

	Not confident at all						*Very confident*
(a) names of your medicines	1	2	3	4	5	6	7
(b) when you take your medicines	1	2	3	4	5	6	7
(c) allergies to medicines	1	2	3	4	5	6	7

32. During the last 3 months, how many times have your asthma symptoms forced you to:

	Number of times				
	zero	one	two	three	four +
(a) Make an urgent telephone call to a doctor?	0	1	2	3	4
(b) make an emergency office visit to a doctor?	0	1	2	3	4
(c) go to an emergency room?	0	1	2	3	4
(d) stay in a hospital?	0	1	2	3	4

33. (a) Do you keep an asthma diary (a daily record of your asthma)? ☐ Yes ☐ No

Go to Question #33 (b) Go to Question #34

33 (b) What do you include in your asthma diary? Please check all that apply.

(1) how often you have symptoms ☐
(2) a reliever medication count ☐
(3) a preventer medication count ☐
(4) peak flow meter readings ☐
(5) other notes ☐
Please specify_____

34 (a) Have you attempted to find out more about your asthma? ☐ Yes ☐ No

(b) Where did you get further information from? Please check all that apply.

(1) family doctor ☐
(2) nurse ☐
(3) hospital doctor ☐
(4) asthma clinic ☐
(5) family ☐
(6) friends ☐
(7) support group ☐
(8) books and magazines ☐
(9) other ☐
please specify_____

Asthma Checklist

For each question below, please check the box that best answers the question for you.

i.e. During the past two weeks have you watched any television? ☐ Yes ☐ No

1. During the past two weeks, have you attempted to find out more about your asthma? (for example by reading pamphlets /books, watching television, or getting information about asthma?) ☐ Yes ☐ No
2. During the past two weeks, have you had any formal education about asthma? (for example, getting advice and/or information from doctors, nurses, pharmacists, health educators?) ☐ Yes ☐ No
3. During the past two weeks, have you had asthma symptoms that made you telephone a doctor? ☐ Yes ☐ No
4. During the past two weeks, have you had asthma symptoms that made you visit a doctors office? ☐ Yes ☐ No
5. During the past two weeks, have you had asthma symptoms that made you visit an emergency room? ☐ Yes ☐ No
6. During the past two weeks, have you stayed in a hospital because of your asthma? ☐ Yes ☐ No
7. During the past two weeks, has your asthma been the cause of any crisis to you or your family? ☐ Yes ☐ No
8. During the past two weeks, have you been distressed about something in your life that might have affected your asthma? ☐ Yes ☐ No

Appendix F

Asthma Knowledge Questionnaire

Asthma Knowledge Questionnaire

Please answer the following questions. This is not a test, you are not being graded on your answers. Several of the items are true/false questions, please circle the best answer.

1. What are the three main symptoms of asthma?

1.

2.

3.

2. More than one in 10 teenagers will have asthma at some time.

   True False

3. People with asthma have abnormally sensitive air passages in their lungs.

   True False

4. If one person in a family has asthma then all his/her brothers and sisters are almost certain to have asthma as well.

   True False

5. Most children with asthma have an increase in mucus when they drink cow's milk.

   True False

6. Write down all the things you know that cause asthma (sometimes called trigger factors).

1.

2.

3.

4.

5.

6.

7. During an attack of asthma the wheeze may be due to muscle tightening in the wall of the air passages in the lungs.

   True False

8. During an attack of asthma, the wheeze may be due to swelling in the lining of the air passages in the lungs.

   True False

9. Asthma damages the heart.

   True False

10. Write down two asthma treatments (medicines) which are taken everyday on a regular basis to prevent attacks of asthma from occurring.

1.

2.

11. What are three asthma treatments (medicines) which are useful during an attack of asthma?

1.

2.

3.

12 Antibiotics are an important part of treatment for most people with asthma.

   True False

13 Allergy injections cure asthma.

   True False

14 If a person dies from an asthma attack, this usually means that the final attack must have begun so quickly there was no time to start any treatment.

   True False

15 People with asthma usually have "nervous problems."

   True False

16 You can catch it from another person

True False

17 Inhaled medications for asthma (i.e. puffers, inhalers) have fewer side effects than tablets.

True False

18 Short courses of oral steroids (such as prednisone) usually cause significant side effects.

True False

19 Some asthma treatments (such as Ventolin) damage the heart.

True False

20 A person has an attack of asthma and takes two puffs of Ventolin (or other reliever medicine) from a puffer (metered dose inhaler). After 5 minutes he is no better. Give some reasons why this may have happened.

1.

2.

3.

21 During an attack of asthma which you are managing at home you require Ventolin (or other reliever medicine) every two hours. You are gaining benefit but you are very breathless after two hours. Provided that you do not get any worse, it is fine to continue with two hourly treatment.

True False

22 Write down ways of helping to prevent attacks of asthma during exercise.

1.

2.

3.

23 People with asthma become addicted to their asthma drugs.

True False

24 Swimming is the only suitable exercise for people with asthma.

True False

25 Other people smoking may make your asthma worse.

True False

26 With appropriate treatment most people with asthma should lead a normal life with no restriction on activity.

True False

27 The best way to measure the severity of a person's asthma is for the doctor to listen to his/her chest.

True False

28 Asthma is usually more of a problem at night than during the day.

True False

29 Most people with asthma have stunted growth.

True False

30 People with frequent asthma should have preventative drugs.

True False

31 A peak flow meter is a good way to monitor asthma.

True False

32 List three uses of an action plan.

1.

2.

3.

Appendix G

Cover Letter to Potential Participant

Information Sheet for Teens

Title of Project: An Assessment of Knowledge and Behaviour of Adolescents with Asthma

Principal Investigator: Heather M. Wells, RN, MN Student, University of Alberta, Faculty of Nursing
Phone Number: (403) 492-9636
Fax Number: (403) 492-3608
E-mail Address: hwells@telusplanet.net
Supervisor: Carolyn Ross, PhD, Associate Professor, Faculty of Nursing
Phone Number: (403) 492-4894

Purpose: The purpose of this research is to look at the knowledge, behaviours, fears and concerns of teenagers with asthma.

Background: The results of this study will assist in learning more about teenagers with asthma. It may help us learn new information about what teens with asthma know, and how they manage their asthma. The information may be used to develop new programs for teens with asthma. The study includes teens who have been told they have asthma by a doctor.

Procedures: You are being asked to take part in a study. Teens taking part in the study will be asked to fill out the three forms in this package. It will take about one hour for you to complete the forms. The package provides you with the forms and a self-addressed, stamped envelope. Receiving the completed surveys will indicate you and your parents consent to taking part in the study.

Benefits: This study will help us to better understand teens with asthma. We also believe that it will be helpful in developing asthma education for teens. There will be no direct benefit to you or your parents.

Risks: There are no known risks to you taking part in this study.

Confidentiality: Your name will not appear on any forms. I will not know your name. The forms you filled out will be kept for seven years. You will not be identified in any papers written, or presentations given about this study. Only grouped information will be presented.

Voluntary Participation: Even if you enter the study, you may refuse to answer any of the questions in the surveys. Taking part in the study is totally voluntary. Your care will not be affected by your to enter or not enter the study.

Additional Contacts: If you have any concerns about any aspect of this study, you may contact either Heather M. Wells, Dr. Ross, at the numbers above, or the University of Alberta, Faculty of Nursing Research Office at 492-6251. If you would like information about asthma you may contact the Alberta Asthma Centre at 492-9564 or the Centre for Lung Health which has a teen asthma program at 482-8951.

Appendix H

Follow-Up Cover Letter

August 19, 1999

Dear Parent/Guardian,

As you may be aware, I am a student in the Master's Program in the Faculty of Nursing, at the University of Alberta. I am doing a study as part of my program. The title of this study is "An Assessment of Knowledge and Behaviour of Adolescents with Asthma." If your teenager has already completed the questionnaires for this study, thank you very much, and please disregard this package. If your teenager has not participated in this study I would like to again invite him/her to take part.

This study is being done to learn more about teenagers with asthma. It may be useful in learning new information about what teens with asthma know, how they act, and their fears and concerns about asthma. The information may be used to develop new programs for teens with asthma.

The study involves your son/daughter with asthma completing the surveys in this package. It would be best if they could complete the surveys in private. The decision to complete the surveys is voluntary. It is your and your son/daughter's choice whether he/she fills out the surveys. If he/she wants, he/she can skip certain questions. If you and your son/daughter decide to take part in this study, please send the completed surveys using the self addressed stamped envelope. This will make sure the envelope gets to the me. I would be very grateful for your and your son/daughters participation in the study.

All of the details you provide will be kept in private, I will not know your or your son/daughter's name. Please read the information sheet provided and keep it in case you have questions later. If you have any questions please contact me by phone at 492-9636 (work), 430-1797 (home), by fax at 492-3608, or by e-mail at hwells@telusplanet.net. Again, if your teenager has already completed these surveys, please do not ask them to do so again, and I would like to thank you for taking part in this study.

Thank you for your help.

Sincerely,

Heather M. Wells, RN, MN Student
University of Alberta, Faculty of Nursing