

**Management of a Preschool Child's Asthma:  
The Parents' Perspective**

**By**

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**A Thesis  
Submitted to the Faculty of Graduate Studies  
in Partial Fulfilment of the Requirements  
for the Degree of**

**Master of Nursing**

**Faculty of Nursing  
University of Manitoba  
Winnipeg, Manitoba**

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**MANAGEMENT OF A PRESCHOOL CHILD'S ASTHMA:  
THE PARENTS' PERSPECTIVE**

**BY**

**BEV CLARK**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
of Manitoba in partial fulfillment of the requirements of the degree  
of  
MASTER OF NURSING**

**Bev Clark      1997 (c)**

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## ABSTRACT

The goal of this study was to explore and describe the process of managing the preschool child's asthma from the parent's perspective. An exploratory, descriptive study was conducted using semistructured tape-recorded interviews as the primary data collection method. Seventeen parents of fifteen preschool children with asthma formed the sample. Data were analyzed using qualitative data analysis procedures. Parents' descriptions of their experiences revealed that their process of "Integrating Asthma into Daily Life" involved three phases: Ascribing Meaning, Learning to Manage, and Incorporating the Disease. The phases, including properties, strategies used, the primary condition and outcomes are described in detail.

## ACKNOWLEDGMENTS

I would like to extend a thank you to:

- the participants of the study for allowing me into a portion of their lives.
- my thesis committee: Dr. Karen Chalmers, Dr. David Gregory, and Dr. Wad Watson for their timely constructive comments and ongoing support.
- my husband Wes and children Kevin and Krista for their love and support and giving up more than I know while I finished my thesis
- my extended family and friends for being there for me throughout the thesis process, and
- MARN (Manitoba Association of Registered Nurses) for funding this thesis work.

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## **CHAPTER ONE**

### **STATEMENT OF THE PROBLEM**

#### **Introduction**

Asthma is a significant health problem for all childhood age groups. Asthma is increasing in prevalence with resultant augmented costs to the health care system and costs of morbidity and mortality for the children. Other costs of the disease include the financial costs to families and the burden of illness for children and their families. Young children affected by the disease are dependent upon their parents for decisions about their treatment, care at home and visits to health care professionals. Intervention studies have focused on the education of patients about the disease and appropriate home management. The studies have not addressed the area of parents of young children and their management of their child at home. This chapter discusses the epidemiology of asthma, the impact of chronic illness, asthma as a disease and the treatment goals, families and intervention studies, ending with the purpose of this study.

#### **Epidemiology**

Asthma is the most common chronic disease of childhood, affecting up to 5-10% of children (Gergen & Weiss, 1990; Pedersen, 1992). Respiratory disease is the leading cause for hospitalizations in Canada for children of all ages. Despite the decreases in overall admissions for respiratory disease, the number of admissions for asthma has increased for infants and preschool children between 1980-1990. Every year 67,000 admissions to hospital in the 1 to 4 year age group are for respiratory disease. Asthma is the leading cause of hospitalization, accounting for 25 percent of these admissions. The

proportion of admissions for girls and boys remains constant with boys admitted to hospital for respiratory disease at a rate of 1.6 times that of girls (Canadian Institute of Child Health, 1994).

A similar pattern is seen provincially. Asthma is the second leading cause of admissions to Children's Hospital in Winnipeg. The admissions to hospital for children with asthma has consistently increased since 1982 with a dramatic increase in 1991. In 1992, 5.3 percent of childhood hospitalizations in Manitoba were attributed to asthma (Manitoba Health, 1995). The average hospital stay is 2 to 3 days, which converts to an approximate cost of \$810.10 per hospital visit. Asthma children are also cared for in Emergency departments. Asthma accounts for 3,500 visits per year at Children's Hospital which is 11 percent of the entire utilization of Children's emergency department. In addition, in 1992, 28,839 physician visits in Manitoba were for children with asthma (Manitoba Health, 1995). The total cost to Manitobans for asthma care is estimated to be approximately \$3,700,000 per year (Health Sciences Centre, 1995).

Asthma deaths have also increased over the last decade (Whitelaw, 1991). Mortality in children with asthma in the U.S. between 1979 and 1987 increased substantially (Weiss & Wagener, 1990). Elements that may be driving this trend are possibly an increase in prevalence rates, an increase in severity of asthma, and changing patterns of medical care (Weiss & Wagener, 1990). Across Canada, mortality rates in the 5-34 year old age group have doubled from 0.2 percent per 100,000 in 1974 to 0.5 percent per 100,000 in 1984. (Barnes, Roger & Thomson, 1992, p.120). For the past two decades the risk of dying from asthma in Canada, has been greatest for young children

living in the prairies (Wilkins & Mao, 1993, p. 190). A link between risk of death from asthma, and grain growing areas, where certain molds are prevalent, has been hypothesized, but not substantiated (Wilkins & Mao, 1993). Four main categories of risk factors that contribute to death from asthma include: 1) delays in appropriate care; 2) misuse of medication (over or under); 3) improper care; 4) risk factors, such as nocturnal symptoms and infection (Hindi-Alexander, 1987, p.493).

### **Impact of Chronic Illness**

Families caring for children with chronic illnesses have been found to experience many complications as a result of the effects of the disease on the normal family functioning. Chronic illness is a nonnormative event in the life cycle of the family. Families that deal with chronic illnesses have been found to experience some financial difficulties because of treatment demands and costs of medications. The disease course may be unpredictable, causing uncertainty. Family relationships may be affected, including parental and sibling relationships. The family may experience social isolation. Access, co-ordination and continuity of care may be difficult, causing strained health care provider relationships (Thomas, 1987; Yoos, 1987).

Chronic illnesses such as asthma, with an early onset, have the potential to complicate the physical and emotional development and psychological adjustment of children (Ryan-Wenger & Walsh, 1994). Dependency behaviors, low self-confidence, anxiety and depression have been reported in asthmatic children (Khampalikit, 1983). A child's lack of physical strength, and restriction of physical activity may affect the child's social adjustment and activities with friends. Other effects of asthma include loss of time

at school and work, with asthma as the leading cause of school absenteeism (Weiss, Gergen & Hodgson, 1992).

### Asthma

Asthma is characterized by episodic, variable airflow obstruction and increased responsiveness of the airways to a variety of stimuli (Drazen, et al, 1987). Irritants such as cigarette smoke, odors and outdoor pollutants; specific allergens such as dust mites, animal proteins, mold spores, pollens; and, reactive chemicals, can all elicit an asthmatic reaction. Precipitants such as viral infections or exercise are also evident in some patients (Bechler-Karsch, 1994; Sexton, 1981). Children may have asymptomatic periods without bronchospasm for months or years (Sexton, 1981). The variable clinical pattern and natural history of asthma impose the need to individualize treatment with regard to avoidance of allergenic and nonallergenic triggers, choice of medication, and immunotherapy, when adequate avoidance is not possible (Spector & Nicklas, 1995).

One of the most important outcome goals of asthma therapy is prevention of the long-term effects of airway inflammation. Prevention includes two major components: 1) eliminating exposure or minimizing the effects of exposure to allergens and irritants and 2) a prophylactic therapeutic plan. Because of the need for individuality of treatment, outcome goals might include the following:

1) reduction in emergency care, 2) reduction in hospitalization, 3) prevention of nocturnal symptoms, 4) tolerance of physical activity appropriate for the patient's age, 5) improvement in pulmonary function 6) minimization of time lost from work, school, and daily activities, 7) improved self-image based on a full understanding of the disease and confidence in approaches to treatment, 8) optimal control of asthma with use of the least medication possible, administered in a manner that permits the most normal lifestyle and is associated with minimal side effects, and/or 9) general improvement in the quality of life of the patient (Spector & Nicklas, 1995, p.712).

Environmental controls are extremely important in the management of young asthmatics. Repeated exposure to indoor allergens is a risk factor for the development of chronic asthma and for triggering acute symptoms. For young children who spend most of their time in a limited environment, there is an important opportunity to decrease and possibly prevent the chronicity and severity of asthma. (Spector & Nicklas, 1995, p.864). Effective use of therapeutic regimens by the patient or family member at home provides earlier intervention, and earlier intervention during an acute exacerbation increases the likelihood that emergency medical requirements will be unnecessary (Hurd & Lenfant, 1992). These treatment and intervention expectations on parents with young children present some challenges.

#### Infants and young children with asthma

When asthma presents in infants and preschool children, often coughing is the only symptom noted by parents. Coughing children have been shown to have markedly decreased air flow. Wheezing is also a common symptom in children. These symptoms may appear intermittently with exposure to specific allergens or during certain seasons and may not cause symptoms severe enough for parents to recognize the degree of obstruction (Drazen, et al, 1987). The children are often described as having frequent colds. The parents seek assistance for these colds in walk-in clinics and emergency departments where the child may not be properly assessed for a chronic illness.

The home management of asthma in young children also presents unique challenges. The administration of medications to young children is more difficult than for

school age children. Inhaled steroids and bronchodilators are usually given using compressors and this means that parents must carry the compressor and have access to a power source. Pulmonary function tests and use of peak flow meters at home to monitor the effectiveness of treatment regimens are difficult to administer in young children. It is also difficult to limit the activity level of preschool children and they are often more tolerant of low levels of oxygen for longer periods of time, therefore, children do not limit their own activity until very late in the progression of the acute asthma episode. Young children are also unable to describe their symptoms clearly to adults, leaving the adults responsible for assessment of their symptoms. Therapeutic aims for asthma management have different implications for the parent of the patient, when parents are unable to experience the symptoms themselves. Asthma as a chronic disease, which has a varied trajectory with unpredictable remission and exacerbation (Hobbs, Perrin & Ireys, 1985) frequently requiring parents to make decisions about the care of their child's asthma at home.

### Families

One of the main functions of families is to socialize their members. Health promotion and health maintenance are learned in the family where beliefs, values and health patterns are established (Hanson & Boyd, 1996). The family is recognized as a potent influence on health and illness. Within the family context, children learn the meaning of illness, the acceptability of routine medication use, and use of the health care system. Health promoting behaviors such as level of activity, eating habits, and cleanliness of the home are often family specific. Wilson-Pessano and Mellins (1987)

identify the need for future research that provides "clear specification of the health behaviors requisite for parents of preschool-aged children with asthma" (p. 487). Young children depend on their parents to care for them and to make decisions about their care and are therefore a vulnerable group (Danielson, Hamel-Bissell & Winstead-Fry, 1993; Friedman, 1986).

### Intervention

Intervention studies in the treatment of asthma have focused primarily on educational strategies. It has been assumed that medical management is only as successful as the ability of patients' or families' ability to manage the asthma on a day-to-day basis. Education is one way to improve avoidance of triggers and improve compliance with medication regimens. Asthma education programs are based on social learning and behavioral therapies (Hindi-Alexander, 1987). Most educational programs have focused on increasing the knowledge of asthma, avoidance of triggers, treatment and management skills.

Most programs on asthma management are directed toward school-age children and their parents. Many settings have been used to deliver programs including hospitals, medical offices, outpatient departments, camps and schools. Providing education that improves children's and parent's skills and confidence in managing acute asthma episodes has shown to result in a decrease in emergency room visits (Colland, 1993; Taggart, et al, 1991; Rachelefsky, 1987; Weiss, Gergen, & Hodgson, 1992). Despite many educational programs, however, parents and children often admit not using the knowledge that they have gained (Bernard-Bonnin, Stachenko, Bonin, Charette, &

Rousseau, 1995; Kolbe, Garrett, Vamos, & Rea, 1994; Taggart, et al, 1991). Participants reported lacking confidence in the treatment efficacy or in their ability to either make judgements about when to perform recommended actions or how to perform them correctly (Taggart, et al, 1991, p.45).

### Conclusion

One of the functions of families is to care for their young children and model healthy patterns of behavior. In families with a chronically ill preschool child, many of the treatment decisions and home management is dependent upon parents. Asthma home management programs have been geared to the school age children and their parents. High hospital admissions rates in the preschool age group indicates a lack of control of the asthma. Much of the ongoing treatment of asthma needs to focus on the avoidance of triggers in the home, and the regular use of medications. Health care support for the preschool parent group has not been effective in reducing the present morbidity and mortality of the disease in the preschool age group. Educational strategies are only found to be effective if provided in a manner that is helpful to the target population. Education, however, does not always mean a change in behavior. To improve the management of a preschool child's asthma, the health care system needs to respond to parent concerns, which have not been clearly identified.

## **Purpose of the Study**

### **Goal:**

**Understanding the process of managing the preschool child's asthma from the parent's perspective is the overall goal of this study. Questions that were used to guide the study included:**

- 1) What are the experiences of a parent caring for a preschool child with asthma?;**
- 2) What factors facilitate a parent's management of a preschool child with asthma?; and**
- 3)What factors hinder the parent's management of a preschool child with asthma?**

## **CHAPTER TWO**

### **REVIEW OF THE LITERATURE**

#### **Introduction**

Topics addressed in the review of the literature include epidemiology of asthma, the impact of asthma on the child, families with a chronically ill child, and asthma intervention studies. The epidemiology is examined over the last three decades. The morbidity and mortality statistics have implications for the treatment of asthma and the cost effectiveness of these treatments to the health care system, families and individual children. The actual treatment goals and research about asthma have improved over the last two decades. The goals of treatment for asthma, or intervention studies, have focused on self-care strategies. The treatment goals for asthma involving self-care have different implications for preschool children, who are not capable of managing their own care. Family literature as applicable to the management of childhood chronic disease is examined.

#### **Epidemiology**

There have been some disparities reported in the literature examining the prevalence of asthma world wide. These disparities have arisen out of a difficulty in clearly defining asthma. The degree of variability of airway obstruction and measuring this has led to a variety of other diagnoses that could be made, creating confusion about the actual numbers of children with asthma. In the 1970's there was a change made in the standard diagnostic definition of asthma from a disease known mainly as smooth muscle constriction to a chronic disease with ongoing inflammation. This lead some researchers to believe that more children were being labeled differently rather than the prevalence of

asthma actually increasing. Therefore, many of the numbers of asthma cases have been in question in the last three decades. Most studies use the information compiled by the national or local health care systems. Depending upon the sophistication of the system being used, the numbers could be misleading. This is especially true in some of the developing countries. Most studies conclude though, that the incidence of asthma has risen and that even with these inherent inaccuracies, the disease is of importance.

#### World Wide

Prevalence rates of asthma in developing countries were compared with those in Europe and North America (Cookson, 1987). Thirty-two studies were compiled and secondary analysis performed. This analysis showed an increasing prevalence, especially in urban areas, during the 1980's. In Patna, India, Japan, South Africa and Papua New Guinea the prevalence of asthma was less than one percent, as compared to 5-20 percent in more Westernized countries. The most common allergen was the household dust mite. In the developing countries, parasites present in the children increased the IgE levels and may have influenced the expression of the disease.

Data from seven countries in Latin America were used to describe the prevalence of asthma and the impact on the health care system (Carrasco, 1987). Asthma in Latin America was found to be most prevalent in children. Chile had a childhood rate of 2.7 percent and Uruguay had the highest rate with 7.5 percent. A clear linkage was established with other atopic disorders (e.g. allergic rhinitis). Eighty six percent of people studied with asthma had an atopic background. House dust mites were found to be a common allergen. The prevalence of asthma or the clinical expression of the disease was not affected by the variation in climate.

### The United States

A retrospective descriptive study described the prevalence, hospitalizations and death rates of asthma over two decades from 1965 to 1984 (Evans et. al, 1987). A marked increase in hospitalization rates for asthma was found. There was also a moderate increase in death and a smaller increase in overall prevalence of the disease in the United States (US). In 1979 to 1981, 22 percent of children had seen a physician for asthma that year. There were 459,000 hospitalizations in the U.S. for asthma in the two decades, a 200 percent increase. There were 3,400 deaths with asthma listed as the underlying cause. Asthma was generally found to be most prevalent among males, those living below the poverty line and persons living in the South and West. No increase in the severity of asthma was found.

Among U.S. children and young adults in a small geographic area, a secondary analysis of statistics from 1979 to 1987 was used to describe the rates of change in asthma mortality (Weiss & Wagener, 1990). The hospitalization rates increased most dramatically among children from 0 to 4 years of age. The nonwhite, urban poor were disproportionately affected. An annual average of 295/100,000 deaths was reported in the under 34 year old age group. This increase in mortality was demonstrated most rapidly in the 5 to 14 year old age group.

Using this same time frame 1979 to 1987, another study used secondary analysis to describe changing patterns of hospitalization among children less than 17 years of age (Gergen & Weiss, 1990). The number and characteristic of hospital admissions increased. In 1979 there were 110,000 asthma hospital admissions among the 1 to 17 year old age group. In 1987 there were 163,000 admissions for this same group. The average

length of stay in hospital deceased and was possibly related to better medical treatment. Hospitalization rates for any other reason decreased by 4.6 percent annually during this time period, while the rate for respiratory disease remained constant or increased. The majority of the increases came in the 0 to 4 year old age group. Non-white children were again found to be affected more. Poverty was linked to the increased rate of hospitalizations; it was hypothesized that these risk factors could be related to smoking and the indoor environment.

An estimate of the costs related to asthma in the United States was developed using a retrospective comparative analysis of 410 hospital statistics (Weiss, Gerger & Hodgson, 1992). Medical costs included hospital inpatient care, emergency room services, outpatient care, inpatient services of physicians, visits to physicians' offices and medications. There were 463,500 hospitalizations for asthma, 34.6 percent were for patients under 18 years of age. The length of stay was an average of five days, for 2.3 million days and a cost of one billion dollars. Forty-eight percent of 1.81 million emergency visits were for children under 18 years of age at a cost of \$200.3 million. One and one half million outpatient visits cost \$129.2 million. Physician visits accounted for \$93.9 million dollars, with one third for the under 18 year old age group. Asthma accounted for 1 percent of the U.S. health care costs. Indirect costs were calculated using loss of school days, loss of work days and mortality. A link was made between poverty and the high rates of hospitalization.

There was a change, since the 1970's, in the use of more steroids in the management of asthma which increased the costs of medications in the treatment regimen. However, Weiss, Gerger and Hodgson (1992) suggested that with an increased

use of steroids, there would be a resultant decrease in the overall cost of the disease. With regular use of medications, better control of the asthma would be achieved. When asthma is well controlled, the disease rarely leads to hospitalization. It is concluded that to reduce the overall costs of asthma, the health care system needs to direct their attention to the primary care efforts for the treatment of asthma (Weiss, Gerger & Hodgson, 1992).

#### Canada

A descriptive study of Canadian statistics (Bates & Baker-Anderson, 1987) demonstrated similar trends to the U.S. studies. In 1974 there were 8,903 male hospital admissions and 5,440 female admissions for asthma. In 1982/83 there were 18,410 male admissions and 10,218 female admissions for asthma. For males this is a rate of 286/100,000 in 1974 and 659/100,000 in 1982/83. Asthma admissions rose in Ontario despite an overall decrease in respiratory admissions. British Columbia had a lower rate than Ontario and it was suggested that this could be related to lower air pollution levels.

Another study also demonstrated an increase in the rates of admission to hospital and death from asthma in children across Canada during the 1980's (Wilkins & Mao, 1993). The greatest increase was seen in New Brunswick and Prince Edward Island with a 90 percent increase, in the under 15 year old age group. The lowest increase in hospitalization occurred in Manitoba and British Columbia. There was a 50 percent greater increase in the admission of boys over girls. While rates of asthma deaths also increased, especially in Saskatchewan and Alberta, the rates of death from other respiratory diseases decreased. There was also a decrease in length of hospital stay, as was seen in the U.S. The severity of the admissions was not considered in this study. The

number of hospital beds available for admission may now be interfering with the discussion of hospital admission rates. The increase in rate of deaths that occurred in Saskatchewan and Alberta has been hypothesized to be related to the presence of Alternaria, a grain mold common on the prairies and found to be a common allergen in children on the prairies.

### Manitoba

In Manitoba, for the period from April 1994 to March 1995, children under 5 years of age used 9.5 percent of services for asthma care. There were 976 cases of children under 12 admitted to Manitoba hospitals for asthma, accounting for 2.9 percent of admissions for asthma in the province. Leading causes of hospitalization in 1992 were chronic diseases of the tonsils, followed by asthma with 1,260 admissions. These asthma admissions accounted for 5.3% of all hospital admissions for children. Physician visits for asthma numbered 28,839 (Manitoba Health, 1995).

Environmental factors that are known to affect Manitoba's children include stubble burning and second hand smoke. The report on the Health of Manitoba's Children (1995) suggest three strategies to help control the increase in asthma. These include restrictions on stubble burning, restriction on smoking in public places and asthma education provided by nurses to support and enhance educational opportunities of professionals.

### **Asthma - The Disease and Physical Impacts**

Changes in the knowledge of the disease process of asthma in the last few years has led to new definitions of asthma. Previously considered to be primarily a bronchospastic disorder, asthma is now recognized as a chronic respiratory disease characterized by

paroxysmal or persistent symptoms, with variable airflow limitation and airway hyperresponsiveness to a variety of stimuli. Airway inflammation or its consequences are important in the pathogenesis and persistence of asthma (Ernst, Fitzgerald & Spier, 1996).

Fatal asthma has been associated with airway inflammation, but bronchoscopic techniques have shown that the same inflammatory changes are present in airways of mild asthmatic patients who may be asymptomatic at the time of examination. Asthma is frequently misdiagnosed or underdiagnosed, especially in children. Asthma may be difficult to diagnose because of the variable clinical presentation. In children, the only presenting symptom may be a cough, which is often associated with other childhood diseases such as bronchitis or pneumonia. In children, as in adults, the diagnosis depends on the history and response to treatment (Padavich & Marshall, 1994). For young children, the history is dependent on observers. Observers, such as day care workers may only see the child for certain parts of the day. If the child coughs with excessive activity at the day care, the parents may not note this at home. Observers may not be cognizant of the importance of symptoms such as a cough at night. The disease is episodic in nature and therefore the child may not exhibit symptoms when they see the physician. Induced deep breathing may produce wheezing symptoms not normally seen.

The most common symptoms include coughing, wheezing, shortness of breath, prolonged expiration, chest tightness and sputum production. Conditions known to be associated with asthma include rhinitis, sinusitis and nasal polyposis. Chest tightness may present as a stomach ache in a child. The pattern of symptoms is important to diagnosis. Often children present with seasonal, perennial, nocturnal, episodic or continuous

symptoms. Frequently the children have distended, overfilled lungs from improperly filled alveoli. The history of precipitating or aggravating factors can also aid in the diagnosis of asthma. A history of atopy in children or in their parents supports the diagnosis.

Spirometry is usually considered an important diagnostic tool. Spirometry measures the severity of airflow obstruction and response to inhaled bronchoconstrictors. This test can be difficult to conduct in children under five years of age. Peak flow monitoring is also considered valuable in the diagnosis and monitoring of the disease. Peak flow primarily measures large airway obstruction. Accurate measurements of airway obstruction rely on the child's willingness and ability to exhale as hard as possible. Therefore, peak flow is also difficult to measure in children under five years of age, although some accuracy has been accomplished with some children, 3 to 4 years of age (Galant, 1993).

Asthma is often classified as mild, moderate or severe. The classification is usually based on the symptoms presented, the frequency of the symptoms, the exercise tolerance of the child and lung function, based on spirometry and peak flow rates. Because this may not be accurate in young children, some practitioners classify the disease according to control. Control is based on the number of severe incidents in a given time frame in response to prescribed treatment.

Asthma treatment is based on the three characteristics of the disease. The pharmacological therapy of the disease is designed to reverse and /or control inflammation and to treat the airway obstruction and airway hyperresponsiveness associated with asthma. Most medications are given using inhaled devices. For young

children, the most effective is usually a nebulized treatment in the home. Metered dose inhalers with spacers are often effective by the age of three to five years.

Interventions aimed at the atopic patients include environmental control and immunotherapy. Environmental control would be aimed at common allergens for the individual child. Pollens and molds are common allergens in the outdoors as well as outside irritants such as stubble burning. Indoor allergens include the house-dust mite as one of the most common. Indoor irritants also include tobacco smoke, wood smoke, household chemicals, strong odors or sprays. Animal dander is often another severe allergen for many children.

Immunotherapy is not used consistently and is assessed on an individual basis. The child's response to the immunotherapy needs to be assessed by the parent's as being effective enough to warrant the treatment. The overall goal of therapy is to allow children with asthma to achieve a normal level of daily activity with minimal side effects from the treatments (Rachelefsky, Fitzgerald, Page & Santamaria, 1993; Spector & Nicklas, 1995).

Studies on the dyspnea and symptoms of asthma in relation to the amount of airway obstruction have been designed mainly for adults (Janson-Bjerklie, Ruma, Stulberg & Kohlman Carrieti, 1987; Kikuchi et al, 1994; Rodrigo & Rodrigo, 1993 ). The inability to investigate children's lung function using traditional devices has limited the amount of randomized testing done on children. Some experiments being conducted at Winnipeg Children's Hospital are measuring obstruction using computerized sound waves. These studies may improve the ability to detect changes in lung function in

children earlier and less invasively in the future (Wodicka, Kraman, Zenk, & Pasterkamp, 1994).

### Families with a Chronically Ill Child

Since the 1980's there have been many studies about families with chronically ill members. Most have focused on the impact that the chronic illness has had on the functioning of the family (Davis, 1980; Hodges & Parker, 1987; McCubbin, 1989; Thorne & Robinson, 1988a; White, Richter & Fry, 1992; Gallo, 1991; & Whyte, 1992). One exploratory study (Davis, 1980) of 30 families of children with a variety of disabilities examined the care of the disabled children in the home and the caretaking roles of parents. Developmental and exchange theories were used as the conceptual framework. Analysis of the interview data indicated that normal organization and structure of the families was maintained through adherence to norms and the right to apply sanctions to members who deviate. The study concluded that a disabled child's role and function within the family can be conceived as an exaggeration of his/her normal dependent position within the family (Davis, 1980).

### Concerns and psychological effects

Hodges and Parker (1987) attended group support meetings of parents of school-age children with diabetes. The participants were 14 adults, 10 females and 4 males. The discussion was led with open ended questions. The purpose was to identify major concerns facing parents and identify the psychological effects the concerns had on parents. The identified concerns were classified into four groups. These included managing the diabetic regimen with knowledge and understanding, coping with the

restraints imposed by diabetes on a daily basis, dealing with school problems and working with the health care team. The psychological impact was described by a variety of emotions expressed by the parents in dealing with their child's disease.

#### Relationships with health care workers

Thorne and Robinson (1988a) reported two previous qualitative studies of 17 cancer patients and their 9 family members and 6 families with a chronically ill child. Multiple in-depth interviews were reviewed to evaluate the relationships with health care workers. The evolving relationships were described as having three stages (a) naive trusting, (b) disenchantment and c) guarded alliance. This framework provided an explanation of observable behaviors and ways to arrive at appropriate objectives of care.

#### Family stressors, resources, parental coping patterns

A study of 54 families, compared a group of single-parent and two-parent families who had a child with cerebral palsy (McCubbin, 1989). The differences in family stressors, resources, family types, parental coping patterns and child health indices were examined. The families were matched for severity of the child's handicap, and age and gender of the parent. The typology model of adjustment and adaptation was used to explain the anticipated results. There were several scales used to measure the concepts. Family Inventory of Life Events (FILE) measured family stressors and demands, family resources were measured using Family Inventory for Parents (CHIP) and family types were described using The Family Adaptability and Cohesion Evaluation Scale (FACES I). The child's impairment was graded by health care professionals using a scale devised for the study. The child's overall health was rated as well as their health improvement,

related to the Cerebral Palsy management. The findings indicated that single-parent families were not experiencing higher stress levels than the two-parent families with a handicapped child. Approximately half of each single-parent and two-parent groups represented the balanced family type that was hypothesized to be more functional over the life cycle. One significant difference was that the single-parent families were more adaptable and flexible with an ability to change the power structure, negotiation styles, role relationships, and relationship rules in response to normative and situational stress. The single-parent family did show two areas of vulnerability. These included lower financial well-being and this included a diminished ability to meet financial demands and lower optimism about the family's financial future. Single-parent families also scored significantly lower on the mother's coping behaviors related to maintaining family integration, co-operation and an optimistic definition of the situation.

### Adaptation

Studies using terms such as adaptation and coping were often labelled family coping but were usually parent report of how they were coping. All studies were descriptive. Many studied adaptation to Cystic Fibrosis (Stullenbarger, Norris, Edgil & Prosser, 1987; McCubbin, 1984; & Whyte, 1992). These studies described the types of adaptation families experienced and described some nursing assessments that would assist families in coping. Stullenbarger et al.(1987) did not find maladaptive behaviors displayed by cystic fibrosis children or parents, using parental report with a convenience sample of 38 mothers.

Galo (1991) used a descriptive study approach to examine how families adapt to diabetes. McCubbin and Patterson's ABCX Family Crises Adaptation model was used. Nursing implications were discussed focusing on three areas of concern: a) pile up of demands, b) family perceptions and c) family resources.

#### Coping mechanisms

Another descriptive correlational study of coping mechanisms used by parents and children with chronic illness examined 90 children with epilepsy and 88 with asthma using several standard measures of social, psychological and family variables (Austin, 1990). Families were compared after children were assessed as displaying adaptive or maladaptive behaviors. Poor adaptation was found in 28 percent of the children with epilepsy and 11 percent of the children with asthma. The families of poorly adapted children tended to have increased demands on them or more stressful events during the previous year; low family esteem and poor communication; poor sense of control over the child's medical condition; less financial stability; and negative parental attitudes toward the affected child (Austin, 1990, p. 101). Strategies to guide nursing interventions in facilitating coping were suggested and included (a) guiding strategies to decrease stressors, (b) maintaining or increasing family resources, and c) changing negative attitudes by encouraging new beliefs (Austin, 1990). Austin was also involved in a previous study of parental attitude and adjustment to epilepsy (Austin, McBride & Davis, 1984). Fifty parents of children aged 6 to 14 with epilepsy were expected to show that parents with negative attitudes toward epilepsy would result in children with poor psychosocial adjustment. It was concluded that parents whose children have regular

seizures are confronted with adjusting to them; fewer seizures would allow families to deny them. Perceived seizure control was positively related to seizure control and parental adjustment. Fishbein Expectancy Value model of attitude was used in both studies.

### Normalization

Normalization, as a coping strategy, was explored in several studies. Normalization was called "social meaning," in a study of four families with chronic illness. This small sample included children with diabetes and leukemia (Anderson, 1981). This study concludes that the social reality for the sick child must, of necessity, be different from that of the well child. The family may semantically define the child as "normal," but the restrictions placed on the child by the disease limits the extent to which the person can be normal in the everyday sense. The study reports that family interventions would be more useful than individual interventions, but these require understanding of the family's explanatory model of health and illness.

A study of families of 15 children with osteogenesis imperfecta described how these children normalized aspects of their actual care. Activities of daily living, relationships, and family activity adaptations were described from the qualitative data (Deatrick, Knafl & Walsh, 1988). Five principles of normalization were described through interviews, with 20 mothers (Krulik, 1980). These families had children with cystic fibrosis or leukemia and were compared to 20 families without chronic illness. The normalizing efforts used by the families were targeted at two areas: to strengthen the

resources and coping abilities of the child and alter the environment to compensate and accept the child.

#### Health beliefs and perceptions

Previous studies also cited by Clark et al. (1988) have shown that health beliefs reported by children differed from their parents' beliefs, and from the parent's accounts of their children's beliefs. Rosenberg (1989) cites literature that describes family health beliefs as predictors of health behavior. Only one study indicated that a child's health and illness behaviors were correlated with beliefs. The modeling of health behaviors in families and the relationship with the child's health behaviors indicates that parental behavior is a much better predictor of the child's behavior than beliefs. Studies also tried to predict parental styles and family environment in relation to compliance with therapeutic regimens. Children from families where parents informed them and gave them a lot of autonomy, engaged in health promotion practices. This was not true in families where parents used a disciplinary approach. Health behavior has also been associated with family cohesiveness (Clark, et al., 1988).

Khampalikit (1983) studied the interrelationships between the asthmatic child's dependency behavior, the child's perception of their illness and the mother's perception of the child's illness. The exploratory study compared 57 asthmatic children, aged 8 to 13 and their mothers, and 54 healthy children. Dependency behaviors of the two groups were compared. The more severe asthmatic children were found to display more: a) dependency behaviors, b) help seeking with problem solving and c) need for emotional support. Perceptions of the impact of asthma on the life of the child was perceived very

similarly by the child and the mother. However, some asthma symptom interpretation showed little or no relationship between mother's perceptions and the child's perceptions.

#### Personality traits and family structure

In a study of 34 asthmatic children between the ages of 10 and 15, personality traits and attitudes and the family structure were compared (Baron, Veilleux & Lamarre, 1992). The children were classified using clinical scores of anxiety. The criteria to measure the anxiety were developed by the investigators and reliability of the criteria established. During the interview of the children and their families, the interviews were observed by two others for cross-verification. Families were classified as disengaged - very low cohesion; separated - low to moderate cohesion; connected - moderate to high cohesion to enmeshed - very high cohesion. The results showed that the highly anxious children came from enmeshed families in which all decisions regarding occupations and family leisure activities are made by the parents. The children considered to have normal anxiety, came from homes where there was medium cohesion. The adaptability score of families is a measure of discipline roles and rules in the family and the capacity of family members to negotiate. Most of the well-adapted children were from structured families and connected families. A strong association was also found between the acceptance of the illness by the mother and a well-adapted child. Socio-economic factors were not found to explain the differences between the three groups of children. The final conclusion of the study is that overanxious children, who are poorly adapted to their asthma and life in general come from rigid, overprotective and enmeshed families. The

children are over dependent on adults for treatment and receive more medication. The child's asthmatic symptoms were seen to be aggravated when the parents were in conflict. The severity of the asthma in this study was defined as the number of episodes in a year. An episode was defined as a period of three or more consecutive days during which the child was symptomatic. The authors discuss that this study identifies why children in the third or overanxious group can be helped easily, with a remarkable decrease in medication after psychological treatment. The authors suggest a future study should examine whether the ability to adapt precedes the illness or whether it develops with the child's chronic illness. It is identified as crucial to pay attention to the families of asthmatic children, in particular to the amounts of cohesion and support the child receives (Baron, Veilleux & Lamarre, 1992).

#### Family hardiness, stressors and functioning

Another study looking at the asthmatic child's family used a descriptive correlational design to examine relationships among family hardiness, family stressors, and family functioning (Donnelly, 1994). The convenience sample of 27 parents included parents of children aged 1 to 5 years with a medical diagnosis of asthma, prescribed medication and a clinic visit to the health centre within the past year (Donnelly, 1994). The Resiliency Model of Family Stress, Adjustment and Adaptation was used as a theoretical framework. Family hardiness was defined as the family's internal strengths and durability characterized by an ability to work together to solve problems and difficulties, a view of change as beneficial and growth producing rather than threatening, an active versus passive orientation in adjusting to and managing stressful situations, and

a sense of control over the outcomes of life events and hardships. Family stressors were described as feelings as fear, guilt, anxiety and helplessness related to the unpredictable periods of exacerbation that characterize chronic illnesses. Family functioning was measured using the family adaptation and cohesion evaluation scales (FACES II). The study results suggested that the added variable of a child's asthmatic condition did not significantly alter the family hardness level. The high risk groups at the one end of the scale were the young families who may need intervention. Parents appeared to have low levels of stressors, but these were defined by the interpretation given to the experience by the parents. One stressor identified by the parents was employment issues. Parents of asthmatic children did not all identify that they had a child with a chronic illness, but 12 did indicate that they had a family member that became seriously ill. The results indicated a positive relationship between family hardness and family type. The researcher suggests that families scoring at the lower end of the family-type scale were more at risk of dysfunction. Having the families themselves identify what is stressful was important, rather than using stress scales.

In summary, families with chronically ill children have been studied fairly extensively. Most of the studies have focused on the functioning of the family as a result of having a chronically ill child. The efforts the family has made to normalize the experience has been delineated. Few differences have been found in the single or two parent families and their ability to manage a child with a handicap. The families of asthmatic children are reported to make a difference in the outcomes for the child (Baron, Veilleux & Lamarre, 1992; Donnelly, 1994 & Khampalikit, 1983). The literature does not address the actual process of managing a preschool child with asthma.

### Asthma Intervention

The treatment of asthma has been aimed at long-term improvement with avoidance of trigger factors, early use of anti-inflammatory therapy, and prevention of exacerbation by early treatment (Boulet, Chapman, Green & Fitzgerald, 1994). "All consensus documents have stressed the importance of patient education... These strong and uniform recommendations arise from the belief among asthma specialists that for treatment to be effective, patients must become effective partners in their own care" (Boulet, et al., 1994, p. 185s).

Education about asthma has included limited pieces of information at a time. One important part of management is inhaler use. The technique is practiced with the patient and parents using simulated inhalers. The repetition of the information is considered important for retention and behavioral change (Shields, 1990). The literature suggests that correct inhaler use is not well retained and is important in the maintenance of symptoms in asthma (Bernard-Bonnin, Stachenko, Bonin, Charette & Rousseau, 1995; Boulet, et al., 1994; Colland, 1993).

Use of multiple teaching strategies is a positive way to improve the outcomes of educational endeavors (Benard-Bonnin, et al., 1995; Capen, Dedlow, Robillard, Fuller & Fuller, 1994). The Manitoba Lung Association offers small group sessions, lectures by health care professionals and pamphlets. Asthma camps are also available where nurses participate in the education. (Alaniz, 1995).

Written information for patients and their family to take home from the physician visits is another strategy used as part of educational endeavors. The instructions usually include what medications to take, and future management decisions such as the use of

inhalers in response to symptoms. The use of written instructions for patients to take home has been a practice proven to be beneficial in educational literature (Becker, McGhan, Dolovich, Proudlock & Mitchell, 1994; Kolbe, Garrett, Vamos & Rea, 1994).

Studies examining the effectiveness of asthma education projects have indicated that comprehensive teaching interventions do not necessarily translate into a significant change of behavior (Bernard-Bonnin, et al., 1995; Taggart, et al., 1991). Change in behavior as a result of education, has been linked to the educational content. Content needs to be pertinent to the individual and continuously adapted to the patients' social, economic, psychologic, and cultural circumstances (Kolbe, et al., 1994). The actual content of the education may not be as important as relating it in some way to the child's life experiences. Colland (1993) reports an educational training program for children with asthma that included self-management training and cognitive behavior therapy in a group. The program used games and learning materials specifically designed for the 8 to 13 year old age group. The study included 112 children with identified inadequate self-management abilities. An experimental and two control groups were randomly selected. The findings indicated that children who took part in the training program were more able to deal with their illness. They know what they can do themselves, in order to minimize the effect of their asthma in daily life. Knowledge about asthma improved significantly in the experimental group but had decreased in six months. Coping continued to increase, but knowledge decreased (Colland, 1993). This implies that regular rehearsal is an important teaching strategy.

The literature suggests that children with asthma which is out of control require more education. To improve problem solving is thought to improve control. By teaching

the use of a peak flow meter, children and parents could objectively measure the increasing bronchoconstriction before symptoms are more pronounced. The family could use the information to make treatment decisions. The use of a diary to record medication use and daily symptoms is recommended. The medical team would gain information about the child's disease trajectory and the families' interpretation of it. The literature supports reinforcement and behavioral efforts to increase compliance with medical regimens (Bernard-Bonnin, et al., 1995; Boulet, et al., 1994; Kolbe, et al., 1994; Perrault & Malo, 1989; Rachelefsky, et al., 1993). Behavioral methods are aimed at providing patients with better control through facilitation of the decision-making process (Perrault & Malo, 1989). In coping theory, problem solving is described as one of the most effective coping strategies for use in chronic illness (Green & Frankish, 1994).

One study by Clark, et al. (1988) reported that self-efficacy, participation in health education and experiencing a hospitalization appear to be predictors of self-management behavior in the chronically ill child. The children in this study ranged in age from 7 to 17 years old. Their findings infer that educational programs frequently try to increase children's perceptions of the seriousness of their illness and the value they place on self-management. Clark, et al. (1988) suggest that these perceptions and values are not major influences on a child's behavior. Bolstering a child's feelings of self-efficacy may be a more effective educational strategy, especially for those who have experienced hospitalization.

Green and Frankish (1994) describe theories and principles of health education as applied to asthma. Self-efficacy is a key component in the social learning theory, and refers to the person's perceived ability to cope with a given situation. Four ways to

influence self-efficacy in self-management of asthma are outlined. They include: a) previous successful performance of asthma management, b) observation of a credible role model c) encouragement and exhortation and d) moderate levels of emotional arousal.

One recent study by Mesters, Nunen, Crebolder and Meertens (1995) addressed the lack of information for parents of preschool children. One flaw in the study, was that education was provided with two to eight contacts with the parents. The number of contacts and the content was based on what the general practitioner felt was sufficient to cover the material.

Literature about educational programs to address self-management of asthma has concluded that these programs have some success in improving the outcomes for asthmatics. The programs have supplied information about asthma, how to avoid triggers, improving decision-making, and compliance with medical regimens. The programs have been geared to the school-age child and their parents. Educational strategies have not been developed to address the parental management of the preschool child's asthma.

### Summary

Asthma is an increasingly prevalent chronic illness in children with severe implications for the child's future health. The disease is costly to the health care system. The care of asthma must focus of self-management on a day-to-day basis. For the preschool child the asthma must be managed by the parents. Educational programs have been found to be effective in improving control over the disease in target populations.

The education has not been geared to parents caring for a preschool child with asthma. The literature about families with chronic illnesses includes many diseases but has included little about asthma. Studies have focused on the psychosocial adjustment or adaptation of the family as a whole or of individual family members. Few studies have used the outcome of the child's disease or use of the health care system in relation to the family's coping.

Current literature about asthma identifies the importance of education about triggers and the use of the prescribed medication regimen to control the disease and its possible physiologic effects on the child. The fact that admissions and emergency visits have increased despite an increased scientific knowledge about asthma indicates that parents have not been well informed or are unable to use the information. This study will improve nursing's understanding about how families manage their child's asthma in the home and how this could be creating an impact on their child's health.

### Conceptual Framework

The conceptual framework for this study includes concepts from family systems theory and symbolic interaction theory. Symbolic interaction theory often used with grounded theory, is an approach to the study of human behavior which emphasizes human interactions and the way that these interactions shape both the individual and society (Blumer, 1969; Chenitz & Swanson, 1986; Edwards & Saunders, 1990; Glaser & Strauss, 1967; Manis & Meltzer, 1967). Family systems theory also includes the importance of interactions within the family unit. Interactions between family members influence the behavior of that member and resultantly all members of the system. It is

also assumed that the interactions between the family and larger systems, such as the health care system, have an impact on the behavior within the family (Bomar, 1996; Dugas & Knor, 1995; Friedman, 1992; Hanson & Boyd, 1996.

### Symbolic Interactionism

Symbolic interactionism is a theory about human behavior and focuses on the meaning of events to people in natural or everyday settings. Meaning guides behavior and a stage of deliberation or definition of the situation precedes action. The reality or the meaning of the situation is created by people and leads to action and the consequences of action. Symbolic interactionist thought engenders that humans are capable of developing a concept of self, which is learned during childhood and through social interaction. Situations are handled in, and modified through, an interpretative process used by the person in dealing with the things he/she encounters. Communication and a common language for communication provides the mechanisms for meaning to be shared. A process of consensus about definitions explains group behavior. Families are based on consensus and shared meanings of events. The individual as part of the collective aligns his/her definition with those of others and acts according to shared meanings (Blumer, 1969; Chenitz & Swanson, 1986; Edwards & Saunders, 1990; Glaser & Strauss, 1967; Manis & Meltzer, 1967).

### Family Systems Theory

Families provide environments which encourage healthy or unhealthy behaviors that may persist throughout life. Each family has characteristic values, roles and power structures as well as unique communication patterns. Parenting styles are found to

influence many future behavioral patterns. Families fulfill affective, socialization, health care and coping functions in varying ways (Pender, 1996).

Families' daily routines influence their children's physical, mental and social health, as well as the health of the family unit. It is important to recognize that families are a major determinant of children's well-being. Everyday parenting activities nurture and socialize children to be healthy, responsible adults. Because parents' understanding of their roles and child development are clearly varied, it is important for nurses to explore how parents understand their roles in order to tailor health promotion and education so that they are meaningful to families (Bomar, 1996; Danielson, Hamel-Bissell & Winstead-Fry, 1993; Friedman, 1992; Hanson & Boyd, 1996; Wright & Leahey, 1994).

Nursing is changing perspectives to expand conceptions of the unit of care, from individuals to families as the unit of care. In the primary, secondary and tertiary levels of prevention framework, families are seen as being important in all levels. In primary prevention the family can influence life-style choices that may prevent illness. In secondary prevention, the meaning the family attaches to symptoms can influence the decision to seek health care. In tertiary prevention, families influence how members comply with treatment regimens (Danielson, Hamel-Bissell & Winstead-Fry, 1993). These areas of prevention are evident in the treatment of asthma in children. The family is important in all levels of management of the disease.

Families must be understood within their own context. This is why the management of asthma is more or less effective by different families. Family process is the ongoing interaction between family members through which they accomplish their instrumental and expressive tasks. This is what makes families unique. The family

structure and function may be similar for several families, but how they react to situations in their lives may differ tremendously. By viewing families in this way, the family systems theory best suits this conceptualization (Hanson & Boyd, 1996).

The family systems theory views families as a social system in constant interplay with other systems in the community at large (Bomar, 1996). A system is both a part and a whole, as is a family. This concept of systems theory emphasizes that the family's wholeness is more than simply the addition of each family member. It emphasizes that each individual is best understood within the larger context of the family.

A family system is part of a larger suprasystem and is also composed of many subsystems. A suprasystem is considered the community they live in and society in general. Subsystems could be composed of two parents, or a parent-child dyad. Systems are arbitrarily defined by their boundaries. Boundaries aid in specifying what is inside or outside the system. In family systems, the boundary must be both permeable and limiting. In extremes of either, too closed or too open, the family is not allowed to use their own resources effectively (Wright & Leahey, 1994). Boundaries filter the flow of inputs and outputs from the environment. Input refers to the energy, information and resources that the system receives and then processes in order to achieve its goals or outputs. Output refers to the energy, information and resources that are released back to the environment.

A change in one family member affects all family members. This concept assists in the recognition that any significant event or change in one family member will affect all family members in varying degrees, as would occur in a family with a chronically ill child. Change in a family members behavior would best be understood from a circular causality rather than a linear causality perspective.

The family is able to create a balance between change and stability. After a disturbance, the family needs to find a balance, which is often a shift to a new position of balance. The family reorganizes in a way that is different from any previous organization of the family. This could be evident after the diagnosis of a chronic illness, such as asthma. In healthy functioning families, this is an ongoing process (Dugas & Knor, 1995).

### Summary

This study will incorporate principles from both frameworks. The symbolic interactionism theory defines human behavior through experience and groups experience definitions of behavior through shared meaning. The group being considered in this study is the family. Family systems theory also advocates that constant interaction among individuals influences behavior. The parents making decisions about their child will impact on others within the family. The meaning attached to the asthma will influence the family meaning that is adopted and the behavior of individuals regarding management, within that family. Families can be studied using the family systems framework. Because the framework considers the family as a whole, it provides a holistic approach to nursing. When the family is viewed as a whole, the processes active within that system are dependent upon one another.

As parents work through the complex process of caring for a child with a chronic illness, such as asthma, they develop a sense of social self. This may be within the system of the family or the larger systems, such as the health care system. The interactions that people engage in provides feedback for the development of roles. In symbolic interactionism, role is conceptualized as an integrated set of social norms that are

understood to be societal expectations about how one should or should not behave. Roles are subject to change. Roles within families change as needed to fulfill the societal expectations of parenting. The caregiving role will be a new role for parents with a chronically ill child.

In this study, the parent-child dyad, consisting of the parent caring for the asthmatic preschool child will be considered within the larger context of the whole family. The family as a social system will be influenced by larger systems such as the health care system. The process of managing their child's asthma will be considered from the parent's perspective. The decisions that parents make about the care of the child impact on the way the child acts and are interdependent. The boundaries may be more or less permeable and may impact on how the family finds stability in managing a child's chronic illness. All interactions between the parents and the child impact on the management of the child's asthma.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **Introduction**

The research design and decisions related to the methodology are directed by the purpose and nature of the study. In this chapter, the methodology selected for this study are delineated. The method of grounded theory is discussed and then the methodological decisions for this study are presented. Data collection and data analysis methods for grounded theory and the methods used for this study are presented. The measures of rigor for a qualitative study are discussed and techniques used to address rigor in this study are delineated. The final section identifies ethical considerations.

#### **Research Design**

##### **Qualitative Methodology**

Qualitative research is undertaken to document and interpret as fully as possible a phenomena under study. The participant's viewpoint is of interest and the relationship between researcher and respondent are the key to gaining access to the data (Leninger, 1985). The subjective realities of the investigator and his or her respondent are recognized as an integral part of the environment and the data set (Ramos, 1989). Verbatim statements and behavior patterns are studied critically to detect patterns and themes within natural settings. The qualitative researcher does not control or manipulate individuals or groups of people. The naturalistic data are valued and sought as a way of knowing (Leninger, 1985).

### Methodological Decisions

Qualitative approaches include ethnography, phenomenology and grounded theory. These three methods were considered for this study. The properties of the grounded theory approach appeared to fit best with the research question. Grounded theory, like other qualitative approaches is interested in the participants' views. This research approach reveals a basic psychosocial process, a central concept in the research question for this study. The method moves beyond the description of a phenomenon to generate theory, which could be important in future nursing endeavors with families with an asthmatic child. Grounded theory is a systematic approach to the collection and analysis of qualitative data for the purpose of generating an explanatory theory that assists in the understanding of a social phenomena (Chenitz & Swanson, 1986). Grounded theory is characterized by using field research, being linked directly with symbolic interactionism and combining both inductive and deductive research methods (Glaser & Strauss, 1967; Streubert & Carpenter, 1995). From an inductive perspective, theory emerges from specific observations and generated data. The theory can then be tested using further data collection, using the deductive research method. Grounded theory is considered more inductive in nature, moving from the analysis of a specific social phenomena to a general theory.

Symbolic interactionism is a theory about human behavior. It is believed that humans develop a sense of self through a social process of interaction with others. Humans constantly react to social situations based on their understanding of the situation (Chenitz & Swanson, 1986; Glaser & Strauss, 1967; Lincoln & Guba, 1985). In order to understand the person, it is important to understand the meaning of events or objects to

them. The meaning of all events and objects is learned through social processes. This links the grounded theory method with the symbolic interactionism perspective.

The grounded theory methodology is applicable to nursing research. Nursing occurs in a natural setting and the nursing process depends upon the collection of data about patients or clients. The nursing care delivered should be based on the data collected about that individual and the current literature. Nursing is concerned with individuals and their experiences. In this study, the interest was in the parental perspectives of managing a preschool child's asthma at home. The grounded theory approach facilitated the development of a beginning substantive theory to advance the understanding of the parental perspective. The design chosen for this study was qualitative, exploratory and descriptive using the grounded theory methodology.

### Research Design

#### Sampling

A convenience sample of parents who visited one of two pediatricians in one clinic were recruited. This provided a sample of parents from one area of the province. Parents were recruited into the study who met the following criteria:

1. Parents of preschool children (defined as 1-6 years of age) diagnosed with asthma by a physician.
2. Parents able to speak and read English.
3. Parents who had their children treated for asthma by one of two pediatricians in the participating medical clinic.
4. Both parents or the parent most involved in the care of the asthmatic child.

The severity of the asthma in the child may affect the response required from parents in management of the asthma. Therefore, purposive sampling was used to interview parents of children from the full spectrum of severity of their child's asthma. Purposive sampling is congruent with the grounded theory methodology, recruiting participants as directed by the needs of the research (Morse, 1986). The participants were selected based on the inclusion criteria and severity of the child's asthma (Burns & Grove, 1993).

Severity has different definitions, but may also be considered level of control instead of severity by some physicians. The criteria for the definition of asthma severity for this study were defined as follows:

#### Mild Asthma

Uses a bronchodilator less than three times per week.  
No prophylactic medications required.  
Minimal symptoms of cough or wheeze with vigorous activity.  
No night-time awakening.

#### Moderate Asthma

Usually requires prophylactic medications, e.g. Intal or inhaled corticosteroids.  
If symptoms are well-controlled on regular Intal would be less severe than patient on regular inhaled corticosteroids.  
If not using any prophylactic medications, or if using them inadequately, requires bronchodilators more than three times per week, but usually less than three times per day.  
Has night-time awakenings, at least two times per week and symptoms with activities.  
If oral prednisone required, would be less than four courses per year.

### **Severe Asthma**

**Requires high dose, regular inhaled steroids or, if on no regular medications, requires bronchodilator more than three to four times per day.**

**Experiences symptoms at rest.**

**Experiences regular night-time symptoms**

**Usually requires more than four courses of steroids in the last year.**

(Ernst, Fitzgerald & Spier, 1996; W. Watson, personal communication, September 5, 1996).

The severity was determined by criteria addressed in the interview of parents using the asthma history of the child (Appendix A). Requests were made to the pediatricians for recruitment of participants, based on the severity of the child's asthma, that was under-represented during the data collection. Moderate to severe asthmatic children's parents were recruited near the end of the study to confirm applicable hypotheses.

Sample size in grounded theory methodology is not predetermined, instead data are collected until there is no new information. The number of participants required in order to gather sufficient data to saturate categories varies, but the literature suggests the number is small (Glaser & Strauss, 1967). The predicted maximum number of participants for this study was 30. The study was completed using 15 interviews, when it was decided that there was no new information being received from participants.

The sampling approach ensured that participants included parents of children on a continuum of severity of asthma. A variety of age groups within the preschool age group and the length of time from diagnosis provided a sample with a variety of experience in the management of their child's asthma.

### **Recruitment**

A convenience sample of parents visiting the medical clinic to see their child's pediatrician was accessed. The physicians or their staff provided a letter of explanation to parents who met the above inclusion criteria (see Appendix B). At the end of the study to facilitate the purposive sampling, letters were mailed to potential participants, rather than waiting for severe asthmatic children and their parents to visit the clinic. The recruitment continued until saturation of the core category occurred. The clinic released, to the researcher, the names and phone numbers of potential participants willing to hear more about the study. The researcher contacted the potential participants and provided further explanation using the information from the written script (see Appendix C). Arrangements were then made for an interview with willing participants.

### **Setting**

The interviews took place at a location convenient for the participants. In the majority of cases, this was the participant's home. Three interviews took place in the researcher's office, as this was requested by the participants. One interview took place in a rural setting, although more participants came from rural homes. The rest of the homes were in a variety of socioeconomic areas in the urban setting.

The settings provided privacy for the parents to express themselves about their experiences in managing their child's asthma. The setting was at times very noisy, with preschool children being present at most interviews. Interruptions occurred frequently from the children, but the researcher tried to make the parents feel comfortable and bring the interview back to the topic at hand.

### Data Collection

Grounded theory uses participant observation, interviews, and field observation as common methods of data collection. Interviews were selected as the main data collection approach for this study. Field observation can be used to document social interaction within the phenomenon of interest. Field observation in many homes would not be easily accomplished to see the parental management of a child with asthma, as this is an ongoing activity with daily living. Interviewing is a technique which is flexible and allows the researcher to explore greater depth of meaning (Burns & Grove, 1993). This approach was used to obtain the perceptions of the participants. A semi-structured interview guide was used to initially guide the interviews (Appendix D). The semi-structured interview guide provided some structure, but allowed participants the opportunity to reveal relevant information in a naturalistic way. Some have described this method as a focused interview to elicit as much information as possible about specific topics (Polit & Hungler, 1987). The interview allowed the respondent to stress what they saw as important and relevant (Lincoln & Guba, 1985). The interview was used to construct records of action-in-process from a variety of people who have likely performed these actions time and time again (Lofland, 1976 as cited in Chenitz & Swanson, 1986).

The questions of the interview guide were general in nature to allow the participants to share their experiences and feelings. It was meant to allow the participants to describe the process that unfolded as the parents learned to manage their child's asthma on a day-to-day basis. Five general questions were used to guide the initial interviews (Appendix D). Topics included the time period surrounding diagnosis, how

parents learned to manage the asthma, factors that were helpful and those that hindered the parent's management of their child's asthma, as well as roles of the health care providers that parents identified.

The interview format included a "warming up" time and collection of demographic data and the child's asthmatic history (Appendix E and A). Data were also collected by using field notes following the interviews about interactions, or observations noted during the interview with the parents. The demographic tool and asthma history of the child, completed during the interview, was used to describe the sample, using several characteristics of the families.

Fifteen interviews lasted on average one hour, but ranged from 30 minutes to one and one half hours, and were completed over a 10 month period. The demographic data and asthma history of the child were collected first. The semi-structured interview guide provided initial structure to each interview. Other questions were developed to further probe experiences of the parents to substantiate categories as they developed in the data analysis. This practice of the interview guide evolving during data collection was consistent with the theoretical sampling principle and the constant comparative method of grounded theory. Each subsequent interview was guided by the data collected at the previous interview.

#### Data Analysis

Data collection and data analysis occurred concurrently. As the tapes were transcribed and analyzed, further data collection continued. Data analysis techniques that were used included: 1) transcription procedures, 2) analytical procedures, 3) organization procedures, and 4) a concurrent review of the literature.

### Transcription procedures

Transcription followed as soon as possible after the interview. This was dependent, however, on the availability of the transcriber. Audio tapes were transcribed verbatim onto a computer using the Microsoft Word or Word Perfect programs. The data were then transferred into Nudist (Qualitative Solutions & Research Pty. Ltd., 1994), a qualitative software program. The researcher listened to the tapes to assist in the analysis and check for errors in transcription. This method was consistent with the constant comparative data analysis technique described for grounded theory. The constant comparative method recommends the early transcription of interviews in full to enable the researcher to develop relevant categories and guide future data collection. The field notes were typed by the researcher following the interview and included with the transcript of the interview.

### Analytic procedures

The constant comparative method was used as described by Glaser and Strauss (1967). The constant comparative method involved four steps: 1) open coding and developing categories; 2) integrating categories; 3) delimiting the theory 4) writing the theory. The first step, open coding included the researcher coding each incident in the data with as many labels or names for the concepts as possible. The process of open coding was assisted by using the Nudist (Qualitative Solutions & Research Pty. Ltd., 1994) qualitative data computer program. The Nudist program allowed the researcher the computer ease of organizing data, defining the codes and moving the data when further information was gathered. The codes were identified by blocking sections of the raw data and then gathering together for comparison of the fit with other pieces of data which

received the same coding. All of the categories were considered tentative. Theoretical properties of the codes and categories became evident, as the similarities and differences were compared to the other categories. The categories were also compared to similar categories previously noted in the literature. While going through the coding processes, the researcher wrote memos, identifying the thoughts developing about possible larger categories or formulation of the theory, in theoretical notes. The main themes were identified and then traced throughout the data analysis process from the memos.

The next step in the constant comparative method was integrating categories. Concurrent collection of the data and analyzing the data was important to allow the categories to be further substantiated or refuted by the emerging data. This step is also called axial coding ( Strauss & Corbin, 1990). In axial coding, subcategories and categories were linked by a set of relationships. This developed the researcher's thinking to the model level. This level of thinking provided information about properties, strategies used, intervening conditions, and the consequences of the process delineated.

The third step of the constant comparative method was delimiting the theory (Glaser & Strauss, 1967). The major modifications that occurred to the categories became less and less as the new data were compared with the unfolding categories. Integration of more categories occurred. Strauss and Corbin (1990) call this selective coding. The reduction of the number of categories promoted the development of a beginning substantive theory. The process was considered complete when the main category became theoretically saturated or no new data were added to the categories with new interview data.

The final step of the constant comparative method was the writing of the beginning substantive theory. The coded data, lists of categories and the memos provided the basis of the theory. The memos were used to guide the summary of the categories. The organizing framework of the beginning substantive theory was divided into three phases or main categories. In each section the properties, strategies, conditions and outcomes of each category are described. Properties refer to the attributes or characteristics pertaining to a category. Strategies are the ways in which action took place or the way that the phenomenon was handled in the category. The conditions are what gives rise to the phenomenon or facilitate or constrain the strategies taken within a specific category. Outcomes are a description of the consequences of the category or a consequence of the strategies used during that phase of the theory (Strauss & Corbin, 1990). When writing, the researcher returned to the coded data, when necessary, to provide support for the theory and to provide illustrations.

#### Organization of the data

Data were organized into categories found in each interview and identified after reading the transcripts and listening to the tapes. The demographics were charted and a summary written for each interview to allow easy visualization of the data. The Nudist (Qualitative Solutions & Research Pty. Ltd., 1994) program facilitated organization of data into categories and themes as they developed. A list of the categories developed are in Appendix F.

#### Review of the literature

As new concepts emerged as being important to the parents, the literature was reviewed. In grounded theory research, the literature is useful to stimulate theoretical

sensitivity, by recognizing concepts that appear repetitively in the literature. The literature can stimulate questions and guide initial observations. Finally literature can be used to supplement the validation found from the data as it emerges (Strauss & Corbin, 1990).

### **Measures to Enhance Rigor**

When qualitative research is viewed as an entity of its own, there are different views of the criteria of rigor associated with scientific inquiry. Sandelowski (1986) used Guba and Lincoln's four criteria: 1) truth value, 2) applicability, 3) consistency, and 4)confirmability. These four criteria are discussed in relation to the scientific rigor of this study. These criteria are parallel to 1) internal validity; 2) generalizability; 3) reliability; and 4) neutrality used to assess rigor in quantitative research.

#### **Truth value**

The truth value of a qualitative study is embedded in the discovery of human experience as the experience is lived or perceived by participants. Truth is participant-oriented as opposed to researcher-defined. A qualitative study is considered credible when faithful descriptions of the human experience are provided. The descriptions must be thorough and complete. Member checks are important. Emerging categories and hypotheses can be confirmed with future participants to add credibility. When investigators become too enmeshed with subjects, this becomes a threat to the truth value. The researcher has difficulty distinguishing her own experience from those of the participant. Lincoln and Guba (1985) label this "going native." The researcher must be aware that qualitative interviews are sometimes exhausting experiences. Researchers have discussed that they become too involved in the data and the "cause" being

expressed by the participants (Dunn, 1991). Actions to protect against this threat included using normal stress reducing techniques, such as walking daily, scheduling only one interview per week or as reasonable time allowed, and discussing thoughts and feelings about the process of the research with the thesis chair.

Peer debriefing with one colleague provided a good outlet as well as conversing with the thesis committee chair. Peer debriefing provides the researcher feedback about the credibility of the process that is being undertaken, probing the researcher's biases, keeping them honest. The second role of peer debriefing was to act as a sounding board for hypotheses that developed. The third role was to assist in the methodological steps in the research process, pushing the researcher further in data analysis. Finally, debriefing sessions provided the emotional release to allow the researcher to attend to the data with a clear mind (Lincoln & Guba, 1985).

### Applicability

Applicability refers to the fittingness of the findings and the representativeness of participants, tests and testing situations. The more tightly controlled the study, the more difficult it is to say that the conditions of the study are real-life conditions. In qualitative research, the study of phenomena in their natural settings is important. Each situation is different, with a particular researcher in interaction with a particular subject in a specific context. Therefore, generalizability is not a goal.

Samples in qualitative research are often not representative in the quantitative sense, but are considered to represent the group being studied. Sample sizes in qualitative studies are typically smaller than in quantitative research. The volume of data is large and the participants are chosen because of their ability to describe the phenomenon being

studied. The continued selection of participants was related to the data that emerged as the data collection and analysis occurred. Sample size was therefore not predetermined (Chenitz & Swanson, 1986; Lincoln & Guba, 1985).

Representativeness is based on the data produced, not on the particular participants who have been interviewed. It is a possible threat, that the participants were probably those who were most enthusiastic to share their stories. In this study a variety of groups were represented by the patients and their families who visited the medical clinic. The two pediatricians attract a wide variety of families because of their geographical location. The participants were from a variety of socioeconomic groups as well as from urban and rural settings.

Fittingness of a qualitative study refers to the fit of the explanation or beginning theory produced from the data. Only with thick data descriptions, can other researchers make any transferability judgments (Lincoln & Guba, 1985). The researcher in this study had the thesis committee read and confer with the data excerpts provided as evidence of the fit of categories during data collection and analysis. The thesis committee also reviewed the writing of the findings to recommend the fittingness of the data to the beginning theory developed. The data were compared to the literature throughout the data collection and analysis stage to confirm the categories and check for further explanations, descriptions or theories related to the categories produced from the data. The researcher deliberately tried to find negative cases to discount or disprove a category developed from initial data analysis.

### Consistency

Sandelowski (1986) compares the third criterion, consistency, with the category of reliability of quantitative research. There are many measures of reliability in quantitative research, such as internal consistency, inter-rater and intra-rater reliability. The value of repeatability is inherent in this criterion of consistency. Qualitative research emphasizes the unique experiences of the subjects and these are not necessarily repeatable by other participants, but auditability can be addressed. Auditability in qualitative research, refers to the consistency of the qualitative findings. A study and its findings are auditable when another researcher can read the data, categories and category definitions and come to the same or comparable conclusions, given the researcher's perspective and situation. In this study, raw data were read by one other experienced researcher to validate the categories. The data analysis procedures were outlined previously in this chapter, including methods of coding of data and the development of categories (Appendix F) to allow another researcher to follow the path of the decisions made during the study. The memos written, following the researcher's thought patterns, and process notes about methodological decisions would allow another researcher to complete the same study with different participants.

### Confirmability

Neutrality, used in quantitative studies, refers to the freedom from bias in the research process and findings. Confirmability in qualitative research is achieved when auditability, truth value and applicability have been achieved. The confirmability of qualitative research refers to the findings themselves. It is the subjective reality of the

participants and the interpretation placed on the data by the researcher that constitutes confirmability of the data.

### **Ethical Considerations**

In this section the values or assumptions held by the researcher are reviewed. The participant and researcher relationship is discussed. The risks and benefits of the study will be reviewed. Confidentiality of the data through the data collection, analysis and dissemination of the study results are discussed.

#### **Researcher values**

In grounded theory, the values of the researcher must be considered as part of the methodology and during the establishment of the problem statement. In this study, the researcher assumed that the value of health is important to all. The researcher assumed that the care of a child is important to parents and that there is some social conscience to care for their child to the best of their ability to prevent the severity of the impacts of a chronic illness.

#### **Risks and benefits**

Predicting the significance of a study, as part of calculating the risk-benefit ratio is difficult in grounded theory. The qualitative researcher develops and modifies the focus of the research throughout the study. This is a strength of qualitative research, but is a problem in predicting the benefits of a research study. The likely benefits of this study were to define the process of management of a preschool child's asthma from the parent's perspective. This provides health care providers a view of the disease from the parents' perspective. This new outlook could influence the education being provided and programs being developed to better meet the needs of the preschool child with asthma.

and their parents. This research could also improve the current management of the disease by parents, improving the children's outcomes and decreasing the health care costs.

The costs to the participants was their time and some inconvenience. This required at least one to one and one half hours of their time, allowing for time to get into the home and out of the home during the interview. The participants arranged for a time and had to make some changes in their scheduling to keep the appointment, causing them some inconvenience. There were possible psychological issues related to parental guilt if they felt that they had not provided appropriate management of their child's asthma, but there was no evidence that this became an issue for parents in this study.

#### Informed Consent

Consent must be obtained from participants and documented. The researcher must ensure that the rights of participants are protected during the study. Consents must contain four elements: 1) disclosure of essential information, 2) comprehension, 3) competency, 4) voluntarism (Burns & Grove, 1993). Participants in this study were asked to sign a consent form (Appendix G) which contained the recommended information (Burns & Grove, 1993; Polit & Hungler, 1987).

#### Confidentiality

Confidentiality of any disclosed information is required to protect participants' rights (Burns & Groves, 1993). The participants were made aware that the physicians or staff who recruited them would not have access to the data. Their responses during the interview were kept strictly confidential. They were informed of the people who had access to the data. The thesis committee and transcriber had access to the raw data, but

no identifying information was stored with the data. Their participation in this study would not affect their care within the health care setting. The researcher was not in a position of power with the participants, as the researcher was not involved with direct patient care.

The transcribers was made aware of the need for confidentiality of the information. The transcribers were chosen carefully with regard to this matter. Transcribers signed an understanding of their confidentiality pledge. Transcribed data was only viewed by the researcher and the thesis committee. Tapes from the interviews and the transcripts were stored separately from the lists of participants and data identifying the participants. The raw data and code numbers will be stored in locked cupboards, for 7 to 10 years, consistent with the Medical Research Council's policy.

#### Protection of Participant's Rights

For this study, the interviews elicited some negative feelings from participants about their previous interactions with health care providers. Participants were clearly told that their anonymity would be maintained and their identity not revealed to any health care providers, including the physician's office. Some participants may have experienced guilt feelings, if they felt that they had not acted appropriately in the management of their child's asthma. This would have been an unanticipated effect of the research and affect the care the parents later provide to their child. The researcher was prepared to provide a referral to other health care professionals who could assist in resolving some of these feelings, but the need never arose. Social workers from the hospital in the urban setting were accustomed to dealing with parents and concerns about the conflicts of caring for their children. The parents could have been referred to these professionals for a private

consultation. There are also several private psychologists in the area who would have been available for consultation, but would have required private payment. For participants from outside of the urban setting, the mental health workers were available to them, without cost, usually without referral from a physician.

The other information that was possible to uncover during interviews with parents was one of child neglect or child abuse. The laws require health care professionals to report any child abuse, even if the information is obtained during their professional duties. The researcher would have been required to report any information which led the researcher to believe that a child was in need of protection. If this information surfaced during the interview, the interview would have been suspended. The researcher would have discussed with the parents the seriousness of what was revealed. The researcher would have then notified the parents that the families' name would be given to the local child protection agency to speak to the family. It is not up to a researcher to label the situation as abuse, but to pass onto the authorities the information that was revealed. If the researcher had feared for her personal safety, the information about the referral would have been given over the phone.

Some intervention was necessary during some interview interactions. A need for information about asthma surfaced during some interviews. Pamphlets from the Manitoba Lung Association were occasionally given out and some education was provided at the end of several interviews. The researcher would have been willing to provide future education to these parents in the management of their child's asthma, if they had requested, but it was not required at this time. The data from the interviews

where some intervention took place, were used, as the intervention took place after the interview data were obtained.

A summary of the study will be made available to participants at the conclusion of the study. Any published data will be presented without any identifying information about the participants. Only a summary of the study will be provided to the physicians who recruited the participants and no identifying information will be available to them.

#### Conclusion

This chapter has presented a review of qualitative research, in particular the grounded theory methodology and how it was followed in this study. The specific data collection and analysis procedures conforming to the grounded theory methodology have been presented. The chapter has elaborated on ethical considerations and measures to enhance rigor.

## **CHAPTER FOUR**

### **FINDINGS**

#### **Introduction**

**In this chapter, the findings of the qualitative study investigating the parents' perspectives of managing a preschool child's asthma are presented. In the first section the sample is described. The findings of the qualitative data analysis are detailed in the second section.**

#### **Description of the Sample**

**Seventeen parents, fifteen mothers and two fathers, participated in the study, representing fifteen preschool asthmatic children. Families had from one to four asthmatic children in their families. All but one family had a history of asthma. Mothers ranged in age from 21 years to 41 years of age and fathers ranged in age from 21 to 45 years. There were five single mothers interviewed, all others were two parent families, but most fathers did not participate in the actual interviews. Sixty-six percent of mothers held less than a University education. The families had an average of one other child, with numbers ranging from zero to three. At the time of interviews, nine mothers were homemakers, one was going to school full time, three worked outside the home full time, and two worked out of the home part time. Sixty-six percent of family incomes were under \$40,000 per year. Demographic data is shown in more detail in Table 1.**

**The asthmatic child ranged in age from one to six years. The average age was 2.9 years. The children had been diagnosed with asthma at the age of 3 months to 4 years of age. Parents had been managing a child with asthma for an average of 1.8 years. Time**

since diagnosis varied from 3 weeks to 5 years. Ninety three percent of families had a previous family history of asthma. There were six families with another child with asthma. Within these six families there were from two to four children with asthma. Within the sample of preschool children with asthma there were nine males and five females. The sample contained four children with mild asthma, six with moderate and five with severe. The asthmatic information is contained in Table 2.

**TABLE 1****Demographic Characteristics**

<b>Mother Characteristics:</b>	<b>Father Characteristics:</b>
<b>Current Age</b>	<b>Current Age</b>
Mean: 32.5 years	Mean: 36.5 years
Range: 21-41 years	Range: 21-45 years
<b>Education</b>	<b>Education</b>
Less than high school 2	2
High school diploma 1	1
Community College 7	1
Undergraduate	
Degree 3	3
Graduate Degree 2	2
<b>Family Income Range</b>	<b>Number of Other Children</b>
10,000-19,999 4	Median: 1
20,000-29,999 1	Range: 0-3
30,000-39,999 3	
40,000-49,999 2	<b>Ages of Other Children</b>
50,000+ 2	Mean: 6.8 years
	Range: 3 months - 18 years
<b>Number of Single Parent Families</b>	<b>Primary care parent</b>
<b>n = 5</b>	<b>Mothers</b>

**TABLE 2****Asthmatic Child's Characteristics****Number of children - 15**

<b>Current Age</b>	<b>Age at Diagnosis</b>
Mean: 2.9 years	Mean: 1.35 years
Range: 1-6 years	Range: 3 months - 4 years
<b>Sex</b>	<b>Duration of Asthma</b>
Male: n=9	Mean: 1.8 years
Female: n=5	Range: 3 weeks - 5 years
<b>Severity of Asthma</b>	<b>Siblings with asthma</b>
Mild: n=4	Number of families: 6
Moderate: n=6	Number per family:
Severe: n=5	Range: 1-3 siblings
<b>Family history of asthma</b>	
number of families: n=14/15	

### **Findings: Integrating the Asthma Experience into Daily Family Life**

**Qualitative data analysis led to the development of a beginning process theory titled “Integrating the Asthma Experience into Daily Family Life.” This beginning theory describes the processes through which parents learn to manage a preschool child’s asthma. “Integrating” is accomplished through three phases: “Ascribing meaning,” “Learning to Manage,” and “Incorporating.” These phases describe the process that parents go through to develop satisfactory control of the asthma while incorporating the disease requirements into their own unique family situations. This section provides a detailed description of the three phases. The description will include the properties or characteristics of each phase, the strategies used by parents to progress through the phase and the primary condition that enables successful progression through the phase. The outcomes of each phase will also be described. Throughout the chapter excerpts from the data are used as illustrations of the analysis.**

**Figure 1**

### **Integrating the Asthma Experience into Daily Family Life**

**Phase I**

**Phase II**

**Phase III**

**Ascribing Meaning**

**Learning to Manage**

**Incorporating**

#### **Ascribing Meaning**

Prior to the diagnosis of asthma parents have been faced with an ill child with an unknown disease. The length of time that parents have faced this uncertainty varied. The

diagnosis of asthma creates a variety of reactions from parents and plays a part in ascribing meaning by the family. Ascribing Meaning refers to the meaning that is attached to the diagnosis and the action that parents feel will be required on their part to respond to the diagnosis. The properties, the strategies used and the primary condition and outcomes of the Ascribing Meaning phase are illustrated.

#### Properties of Ascribing Meaning

Ascribing Meaning was characterized by three main properties: acknowledging the diagnosis of asthma; drawing on previous experience; and recognizing impacts of the disease. (see Figure 2) Each of these properties described the efforts that parents made to respond to the diagnosis of asthma in their preschool child and come to some conclusion about the impact of the disease on their family.

#### Acknowledging the diagnosis

To acknowledge the diagnosis parents proceeded through two phases: reacting to the diagnosis; and supporting the diagnosis of asthma. The progression through the phases was not a linear process and parents fluctuated between the phases. Progression through the phases was complete or incomplete.

##### 1) reacting to the diagnosis

At diagnosis, parents expressed a variety of emotions and reactions to the label of asthma. Many parents expressed a substantial emotional reaction. The types of reactions included: "It was intense," "It was terror, just sheer terror." (1) One mother related the initial emergency department experience:

I remember when we brought him into emergency, and when we, had one mask and it wasn't enough, they had to mask him right away again, and he was, he was really in distress. And I remember the fear, just being terrified." (12)

Some parents' reactions were more relaxed and unemotional. These tended to form parents of children who had demonstrated a less extreme physical response prior to the diagnosis of asthma. These children were usually the mild asthmatic cases. Two parents expressed the idea that "it's no big deal to have asthma." (4, 6).

## 2) supporting the diagnosis of asthma

When parents heard the diagnosis, they compared the diagnosis with what they saw in their child. Parents expressed belief or disbelief in the medical diagnosis. Parents accepted or supported the idea that the disease that they saw in their child was in fact asthma, the diagnosis presented by the physician. The experience surrounding the onset of the illness became a part of what parents relied on to come to the conclusion of the correctness of the diagnosis. One parent related "...you bring a limp baby. I knew before he even was limp by the wheezing and the rattling in his chest that it was asthma." (1) Another parent expressed the diagnostic phase this way: "She was on Ventolin constantly, like they would finish one and start another, for hours, she scared us. It became life threatening."(12)

One parent outlined how she came to believe that her child had asthma:

Well actually I wasn't convinced that they knew that he had asthma because at the time that he took ill I had a girlfriend die of meningitis. And I was terrified that, that's what he had but, the first problem we had was the peanut butter allergy, then after that the asthma came out. (2)

Some parents did not accept the diagnosis, "I don't really think he has asthma. It only happens with colds. We give him the medications and it goes away." (4).

In summary, one characteristic of Ascribing Meaning is acknowledging the diagnosis. This included two phases: reacting to the diagnosis, and supporting the diagnosis. The time that this took varied with parents and the movement through the phases was individualized. The acknowledgement of the disease was enhanced by an emotional reaction, and support for the diagnosis within the family that this disease was a diagnosis that the family would need to deal with.

#### Drawing on prior experience

In addition to acknowledging the diagnosis of the disease for their child, the parents also had more or less prior knowledge of asthma that created an impact on the meaning ascribed to the disease and their experience with their child. This property contained two phases: developing an awareness and making the link.

##### 1) developing awareness

Parents' prior experience with asthma affected the impression that the diagnosis left with them. Many parents had family histories of members who had been diagnosed with asthma. The severity of the disease in that person, and the knowledge of the disease during the time of that relative's experience influenced the impression that the disease had on the parents. Parents took the prior knowledge of the disease and actually defined what asthma was from their understanding of the relative's experience. Many told of relatives with asthma: "...my grandfather, he in fact died from complications with his

asthma" (7); "his father had some wicked attacks"(1); "his dad had severe asthma as a child and I have asthma"(2); "my sister has asthma and my grandmother"(6); "his father had it and my mother-in-law thought it was before it was diagnosed" (10); "I'd heard of asthma, because I had it." (12) There was only one family in this study with no prior experience with asthma.

Some parents had prior experience with older children with asthma. One mother of two boys said:

My middle one we have had to go, oh he has had to have IV's quite often, we were in the hospital probably every four months with him ... I knew before they diagnosed (this child) because it was all so similar. (7)

## 2) making the link

Parents had to take their prior experience and come to some conclusions about that experience and the relationship between the prior knowledge and the knowledge they had of their child's diagnosis of asthma. "I didn't realize at the time that that was my grandfather's problem" (7); "It wasn't really scary for me because my dad has it, so I grew up with it and my husband had it, so he grew up with it" (11).. Some parents felt that the disease seen in their relatives was not the same as their child's "...compared to our son's, our asthma is nothing" (2); "my sister's asthma, she was in and out of the hospital, ... he's not like that, I don't believe he has asthma" (6).

Some parent's lack of prior intimate experience influenced the meaning that they attached to asthma. One mother envisioned something quite extreme:

So, it was scary, I thought oh no not my kid. You know, and all I could picture before me was these emergency trips to the hospital. Some are with oxygen tanks, it looks like, you know, but it hasn't been like that. (8)

One mother of four described the differences in her fourth child with asthma:

Hers was really scary to me, because it comes up so quickly, ... it became life threatening,... and it never had before then. Even when she was young, like she's seen her brothers on the compressor, so it wasn't a big deal, she'd sit with the compressor and mask, it wasn't a big deal.(11)

One mother described the idea of not knowing exactly what asthma was:

Well, I had no idea really what asthma was. I had never, nobody in my family ever had asthma, I didn't know, you know, that your tubes were inflamed and you couldn't breathe and cough, I don't know, I just didn't think that's what asthma was, I don't know. I never thought of it before, why would I need to? (10)

In summary, the property of drawing on prior experience included two phases:

developing awareness and making the link. The parents explained their prior experiences and the understandings that they had of asthma from that experience, then they related this to their own experience with their child's illness. This assisted parents to put the diagnosis into perspective considering their prior experience with the disease.

#### Recognizing the impact of the disease

The impact that the disease asthma was having on their child needed to be recognized to be acknowledged. This property then had two phases: labelling the symptoms; and secondly connecting the symptoms. The ability of parents to label and actually connect those symptoms to the diagnosis of asthma was important to the meaning that would be ascribed to the disease.

### 1) labelling the symptoms.

The parents had to be able to recognize the symptoms that were being presented by the disease in their child. Asthma has a widely variable pattern to the disease and the diagnosis is made based on the unique symptoms presented by that child. For some children there was one significant event that led the parents to seek emergency care:

There's the two different kinds, our eight year old and the one year old, both have a little bit chronic..., but mostly viral, and our oldest one is very much exercise-induced, and the third boy has had viruses kicking it off, but it has simmered down right now. The one year old often isn't actually wheezing, but...it's heavy. (11)

The parents related a variety of symptoms that they recognized in their child. "Wheezing, when his chest is so tight, it hurts. He starts running around, and he starts to choke, he starts to gasp." (12); "The coughing gets so bad, she can't get off of the couch." (5); "The wheezing, the phlegm, just the sound he makes, you know. He looks grey, almost like a little old man, as opposed to a very vibrant young boy."(1); "The indrawing and ... the no color in his mouth, he is always pale though."(12)

I can usually tell if it's an asthma cough, or a normal kind of cough... The asthma cough is kind of a drier cough... and his breathing gets heavier, like you can sense that there's a tightness way down, like he's not getting air through. (8)

For other children with less severe disease the diagnosis was made based on a series of reoccurring symptoms. There may have been many doctor's office visits with complaints about night-time coughing, reoccurring episodes previously labelled as colds or a history of skin problems and other allergy episodes with allergic rhinitis and cold-like coughing. Some parents described the less obvious symptoms: "Dark circles under

his eyes, sneezing, coughing as soon as they lie down" (12); "Runny nose all the time". (10)

## 2) connecting the symptoms

Parents needed to recognize that the symptoms that the child displayed were actually connected to the diagnosis of asthma. Because the symptoms have often been misdiagnosed several times before the diagnosis of asthma was made, the parents sometimes had trouble associating certain symptoms with the diagnosis. One mother described her dependency on her husband to notice changes in her son's symptoms:

My husband is the one that,... I depended on him, like because being with the kids all day, I didn't notice things like he would notice, like J would need to be masked where as I had, being with him all day outside or something, I would just ugh, attribute it to hard play or something. (12)

Some parents described the episodes prior to diagnosis and looked back and realized that they were probably also asthma. "The runny nose is definitely a first sign. I just thought it was the start of a cold." (10) One mother described the pattern of symptoms in her first son's diagnostic episode: "...we thought it was just colds or pneumonia, like we didn't think this could just be a breathing problem. Probably if we got on and treated it sooner..." (7)

In one case the mother described her child as having "breathing problems" and demonstrated retractions, talked about the coughing without a wheeze, the constant runny nose and taking the child with a "cold" to the emergency department for Ventolin treatments. She did not relate these episodes to the diagnosis of asthma.

In summary, the third characteristic of Ascribing Meaning involved the parental recognition that there were symptoms that they could see in their child that were associated with asthma. In order to do this they first had to be able to label the actual symptoms and then be able to connect them to the diagnosis of asthma. This allowed parents to make some sense of what was taking place within their child.

### Strategies in Ascribing Meaning

Parents used one of three strategies to work through the phase of ascribing meaning. These strategies were evident in parents' reactions to the diagnosis and future actions with their child. The three strategies included denial, avoidance and confronting. Parents who used a positive strategy that encouraged action were successful at working through the phase of Ascribing Meaning.

#### Denial.

Some parents used denial as their primary strategy. They were unable to acknowledge the diagnosis. They had a flat emotional or no emotional reaction to the asthma label. This led to a disbelief in the medical diagnosis applied to their child. These parents were unable to label symptoms that their child experienced or relate them to asthma. The parent's prior experience with the disease often supported their belief that their child did not have asthma. One mother denied ever being told of the diagnosis, did not relate the symptoms she described to asthma and related how her son's illness was different from her sister's, and therefore could not be asthma.(6)

**Avoidance.**

Avoidance is defined as an acknowledgement of the diagnostic label of asthma by the parents, but they tended to avoid carrying out any further evaluation about the impact of the disease. Parents may or may not have had prior experience to support their actions. They may ignore symptoms that they have been told were associated with asthma. Parents who were able to recognize some aspects of the disease, but were unable to act on the recognition tended to use the avoidance strategies.

Parents of one child described having asthma as “no big deal.” They talked about how the inhalers helped the colds their child repetitively developed. The father stated he also had asthma. The child reportedly coughed at night and had a runny nose frequently without fever. The parents acknowledged that their child had been diagnosed with asthma, but were reluctant to face any of the accompanying symptoms that their child displayed as being attributable to the disease asthma.(4)

**Confronting.**

Confronting is defined as taking a realistic look at the diagnosis and the impact that the disease had on their child and the rest of the family. This facilitated successful movement through phase one Ascribing Meaning. Parents tended to have an emotional reaction to the diagnosis, but then quickly realized that this was a disease with symptoms that they recognized their child had experienced, often for some time. Parents may have experienced an event with their child that they considered to be a crisis. The parents were reflective about the symptoms that their child displayed. They were able to ascribe

some meaning to the disease and were able to move into the second phase. The meaning that they ascribed to their child's asthma meant that they were required to take some action. One mother described her thoughts about the diagnosis and what it meant to her:

"It meant restriction, my heart kind of sank a little bit because I thought he might not have the same kinds of opportunities at that moment [limp in emergency] that other kids might have....it's something you just have to control." (1)

#### Conditions for Ascribing Meaning

The primary influencing condition in ascribing meaning was the parent's perception of severity of the asthma. Health care providers define severity based on the symptoms that the child displays, and the amount of medication required to decrease the symptoms present in the child. The severity rating of a child's asthma made by a health care provider is often not the same as the parent's perception. The severity perceived by the parents influenced all properties of ascribing meaning.

If a severe episode preceded the diagnosis of asthma, this experience influenced the parental reaction. The severe episode gave rise to some specific parental belief in the diagnosis. If parents thought they had reason to accept the diagnosis of asthma for their child, they were able to accept the symptomatology displayed by their child. The severity of the disease in the person in their previous experience influenced the thinking of parents in relation to their own child. If the person whom they knew previously, had asthma "bad," the parents would also be willing to accept severe disease in their child as being truly part of the asthma label.

If the parents' previous experience was with someone with more severe disease the parents would judge the symptoms in their child against their previous experience. If

it was the parent's belief that people with mild asthma were not really sick, they either did not believe the diagnosis or ignored the symptoms that they were told were associated with asthma in their child. The parent's perception of the severity of the asthma influenced the passage through the phase of ascribing meaning. This was the primary condition that led parents to the next phase of the process of "Integrating the Asthma Experience into Daily Family Life." One mother compared her child's more severe asthma to others in the neighbourhood:

Like I don't understand....I've got a puffer, I've got asthma and I look at the kid, ...I've never known him to be sick except with colds and I sit there and think, are they being handed out too freely and diagnosed too freely saying that they do have asthma and it makes the public think that asthma is no big thing, it's like a cold or a flu.(2)

In conclusion, Ascribing Meaning was characterized by three properties: acknowledging the diagnosis of asthma; drawing on prior experience and recognizing the impact of the disease. In the first property of acknowledging the diagnosis of asthma, some parents proceeded through two phases: reacting to the diagnosis, and supporting the diagnosis. This was the acceptance of the diagnosis or decision that family members made about the correctness of the diagnostic label of asthma for their child. The second property, drawing on prior experience involved two steps: developing an awareness, and making the link. Parents saw their own child's disease within their own reality, taking into consideration their prior experience with asthma. The third property, recognizing the impact of the disease involved the parents' ability to label the symptoms that their child was experiencing and then secondly actually relate the symptoms to the diagnosis of asthma.

Parents followed through this phase using one strategy of either denial; avoidance; or confronting. The perception of the severity of the disease was the primary condition that influenced the passage through the phase of Ascribing Meaning.

**Figure 2**

## **ASCRIBING MEANING**

### **PROPERTIES**

#### **Acknowledging the diagnosis**

- 1) reacting to the diagnosis
- 2) supporting the diagnosis of asthma

#### **Drawing on prior experience**

- 1) developing awareness
- 2) making the link

#### **Recognizing the impact of the disease**

- 1) labelling the symptoms
- 2) connecting the symptoms

### **STRATEGIES**

#### **Denial**

#### **Avoidance**

#### **Confronting**

### **CONDITION**

#### **Perception of Severity**

### **Outcomes of Ascribing Meaning**

The outcomes of the phase of Ascribing Meaning were a result of the way that parents reacted to the diagnosis, acknowledged and integrated their prior knowledge and the meaning that they attached to the diagnosis. The outcomes varied for parents depending upon the severity of the disease in their child and the reality this created for

them. Parents who felt that the disease was a threat to their child's well being and was severe enough to impact on their lives progressed to phase two, Learning to Manage.

Some parents who had used the denial or avoidance strategies in response to the diagnosis, ascribed a different meaning to the disease. These parents either did not believe that their child had the disease at all or felt that the disease was not impacting on their child enough to threaten the child's health. They appeared to be stuck in phase one and did not go on to learn any more about the disease, and did not make any changes in their environment. They continued to seek medical attention for their child when the child acutely appeared ill. They may or may not have continued the medications the length of time prescribed by the physician. If they felt the child was still benefiting by using the medications, to get through the "cold" they would use the inhalers for that length of time.

In summary, outcomes of the initial phase of ascribing meaning were based on the meaning that parents had developed, based on their prior experience, the threat they saw at diagnosis and the symptoms that they saw in their child that they attributed to asthma. Their perception of the severity of the disease was the primary condition that impacted on the successful progression through the stage. The next phase of Learning to Manage was not engaged in by parents who did not successfully complete the first phase.

### Learning to Manage

The second major phase parents progressed through in their efforts to "Integrate the Asthma Experience into Daily Family Life" was "Learning to Manage." The action that parents took as a result of the meaning ascribed to the diagnosis and disease of

asthma is described by the Learning to Manage phase. This section describes the properties of this phase, strategies that parents used and the primary condition of passage through the phase. (see Figure 3) The outcomes of the passage through the phase is also described.

#### Properties of Learning to Manage

Learning to Manage has four properties that were evident during this phase: Observation; Monitoring; Participation and Prevention. This section describes each of these properties. These properties represent interrelated processes that parents pursued in their search for knowledge and ability to manage the asthma.

##### **Observation.**

Observation is the property that refers to the parents' ability to watch their children in a more knowing way than the way they had watched their child prior to the diagnosis of asthma. Parents observed other children with asthma and how their parents treated them. Parents observed the way that physicians and others treated their child in response to the diagnosis. Parents observed their child's behavior with the knowledge that the diagnosis of asthma had been applied to their child. The observations took place in a variety of settings.

Parents described the way that they observed the look of their child when he/she was having an asthma attack. They often described them as looking different than other children. One mother said that "he looked like an old man instead of a child."(1) Each parent could identify the ways that their particular child reacted; coughing as soon as they lie down at night was a common example that they related to the asthma; wheezing, the

sound you never forget; "I listen to his chest, a friend that is a nurse gave me a stethoscope and taught me how to listen to his chest" (12). Other less obvious symptoms included:

not sleeping properly, things like that, ... if she has a bad night, if she's been up a few times, then there's probably a problem and nonverbal things like they get very agitated, the preschoolers, that I didn't know.(11)

Parents described watching their children in a variety of settings. They were watching for the reactions of their child to that environment. Parents talked about their own home; they lived on farms, in new and old homes, and apartments. Parents often expressed concern as their preschoolers expanded their environments to the outside play areas and friend's homes: "Then I was also paranoid about what somebody was going to feed him."(2)

In summary, Learning to Manage included parents watching their children differently than they had before the diagnosis of asthma was made. Parents began to recognize the initial symptoms of an asthma episode, rather than attributing the symptoms to just colds. Parents observed their children in a variety of settings.

#### **Monitoring.**

As parents were given medical prescriptions and recommendations from a variety of places and people, they needed to begin monitoring. Monitoring refers to the need to watch the effect of the medications and other treatments on the symptoms that they associated with the asthma in their child.

Parents had to first learn what to monitor in their child. They needed to know what effect different medications had on their child. They needed to know how to give the correct dosage of the medication and how the child reacted. Parents learned that there were side effects of the medications, and how to monitor for these. Parents often easily related the routine of medications that were required:

He gets the Ventolin and Pulmicort mixed ... three times a day. And the Ventolin I use if needed up to every 4 hours but I haven't had to since we increased it (the dosage). (7)

We seem to know if she starts coughing, we start her on her blue inhaler, and she's on the brown inhaler all the time anyway, once a day... so right now, I bumped her to two brown puffs a day, like one in the morning, and one at night and I've been giving her blue inhaler...., before her brown inhaler,... and that seems to help her some. (10)

Medication side effects concerned most parents about asthma medications. The word steroid held a certain concern:

I know that all this medication is no good, because a lot of it is steroids. It seems every time we try and reduce them it flares up so we're back to the routine again. (2)

I still question [the use of the medication all the time] every time I see my Doctor, but they tell me I'm under using it, so I've been using it and keeping it at three times a day, but... do I need to use that much all the time, they say there is no side effect, but there might be some. (7)

When she was on the oral steroids we never really got over the coughing, she was on it for 2 weeks, she was still coughing at the end of the 2 weeks but not nearly as bad. But she started attacking like she would bite and kick and she doesn't do those things. The side effects were really bad with her. (5)

The other complaints about side effects came mainly from the use of Ventolin: "I know since we increased it he breathes better and he sleeps better, but he just doesn't sit still. What do you do?" (7) The symptoms that parents associated with their child's asthma and the associated triggers had to be monitored. Parents recognized the types of triggers that were often described by the literature or their doctors. "I even noticed actually since the snow has started to melt that the mold is coming... that he is getting worse."(7)

They had to monitor their children to see if these triggers applied to them in particular:

I usually don't have to give him a fourth treatment [in the afternoon]... as long as I can control his activities and he is not running around and getting too hyper, he is OK.(2)

We actually just noticed that [symptoms with activity] more last year when he was playing ball, he hit the ground and asked his dad for help because he couldn't breathe. (12)

In summary, parents described the type of monitoring that had to take place to Learn to Manage their child's asthma. They monitored their child's symptoms in response to specific triggers and to medications. The medications also had side effects which they had to monitor.

#### Participation.

Parents became participants in their child's asthma care. The level of involvement varied tremendously among parents. The relationships between the health care workers

impacted on the involvement parents felt that they needed to have. Some parents trusted the physician's prescriptions and recommendations:

"Sometimes I'll wonder if I should really have to be bringing him in every time it starts, and I guess I've never really asked the doctor that, I've just assumed that I should get him in."(8)

Other parents lacked trust in the physician and the health care providers' abilities to assist them:

I don't really think they know a lot. I was at Wal-Mart one day and they had an asthma clinic set up there and my interest was, whether there were new medications out that could reduce some of his other medications. And she didn't even know what I was talking about. I knew more than the nurse there and the pharmacist knew. (2)

One nurse told me that, that was my job to stay up there [in the hospital] with him and I felt just awful because I got three kids at home. ....We would go up in the afternoon and evening but when you get somebody that tells you that's your job... I got upset and said look 'that's your job to do this, my child's sick, that's your job to take care of him'(2)

Parents made choices about the part that they felt they needed to play in their child's asthma care. Some described a sense of total responsibility to one or passively asking the physician every time there were any symptoms. One mother explained why she attended each time she felt the child was ill:

I don't know why it happens like that, but sometimes it's worse than others, or whatever, but I found that it's not necessarily the same dosage all the time... and I don't want to be giving him the dosage that he was on the last time if it's going to be..., if it's not right this time.(8)

Another mother was more assertive in her approach to the medical treatment that her child was receiving:

He was getting worse and worse, so I went in there mad, and I took my team of sisters with me, and I said I wanted something done, and then that's when we got the compressor and he started to get better. (9)

In summary, the parents began participating in the care of their child's asthma. The level of involvement varied between parents. They had to participate in treatments and decision making about the treatments that were appropriate for their child. Some parents participated more actively than others.

### Prevention

Parents had to learn the steps to prevent an asthma attack in their child. The prevention of asthmatic attacks included appropriate routine medication administration as well as making environmental changes in the home and the places where the child may encounter triggers.

Parents had to learn what triggers were most prevalent in their child's environment and the frequency of their child's exposure. Other environmental events influencing their child's health were also considered, such as exposure to smoking, cold air, activity and colds. Parents described environmental changes that they had made in their own homes: "We have this new home, we have no carpet, I don't use downy or pretty smelling things with clothes, I sometimes even have to double rinse the clothing."(7)

I started changing things. I got rid of plants. I ripped the carpet out of his room. I took out most of his stuffed animals. I did everything that the doctor recommended I could do to help. Like he couldn't go outside cause he couldn't go in the sun, he would get swollen, he would get these awful blisters. It just seemed to be that these allergies came and then the asthma came, the asthma seemed to get worse because

of all these allergies. He couldn't go outside on a windy day it had to be a calm day. (2)

In summary, the parents had to learn as part of managing, the preventive practices required to benefit their child. They had to come to the realization that each child is unique and what affected their child may not have been the same for other children with asthma.

In conclusion, Learning to Manage was characterized by four interdependent properties: observation, monitoring, participation and prevention. Meaning ascribed in the first phase had an impact on the decisions that parents made about the actions required. This was evident in the properties that have been described in the Learning to Manage phase. Most parents felt comfortable in the role that they had chosen through these properties of Learning to Manage.

#### Strategies in Learning to Manage

The strategies that parents used to learn to manage their child's asthma included information seeking; using the knowledge; and balancing. Each strategy is discussed in the following section.

##### **Information seeking.**

Information seeking referred to the need to gain knowledge. This strategy was used early in the illness as a way of coping with the diagnosis of asthma and the illness that the parents had watched develop in their child. Parents saw this as an ongoing need in some cases; others were satisfied with initial discussions and felt no further need for

information. Parents learned the management of their child's asthma and their role expectations through the use of these information seeking behaviors. The actual topics included symptoms, triggers (including environmental changes that may be required), and medication use.

An early form of information seeking was about the disease itself. Parents obtained information from reading pamphlets, from health care professionals in one-on-one situations either in the doctors office or in the hospital, as well as from the occasional group session.

Most parents received verbal information from their doctor at the initial diagnosis, especially if this was in the office setting. Many parents also identified a lack of information after the visit. They did not understand the disease and the symptoms or treatment and its purpose. Many parents relied heavily on the physician to explain treatments on an ongoing basis, as the child displayed new symptoms, or became more ill.

Numerous parents sought out information on their own. Many turned to the Lung Association and found the information that they wanted and needed. Some watched television shows to get as much information as they thought they required. One parent identified the public health nurse in her area as being helpful in providing information and feedback. One mother identified magazine articles, newspaper articles and drug stores as sources that provided her with up-to-date information on an ongoing basis. A couple of parents also identified their pharmacist as an ongoing source of information about the prescribed medications.

Formal settings, such as hospital teaching and groups organized through the Lung Association, were used by a small number of parents. Some parents were given information in the hospital if the initial diagnosis was made during an episode which necessitated hospitalization. Few parents talked about any further information provided in hospital. Another formal setting included the Lung Association sponsored clinics. Few people accessed these because of the time commitment required or not being interested in group learning.

In summary, information seeking was a strategy that parents used to learn to understand the disease asthma, the effects on their child and the how they would be required to be involved in prevention and treatment. The information seeking was carried out either on initial diagnosis only or in an ongoing pattern. Some parents were satisfied that they had enough information, others were not.

#### Putting the knowledge to use.

Parents soon realized the amount of information that they thought was sufficient to put the treatment into action. Action that was required by parents in their home management of their child varied because of the severity of the disease and the variable course displayed by the disease in each child. Topics were similar though, and included: symptom recognition, treatments, and some environmental changes or adaptations to accommodate the removal of obvious triggers. As parents gained knowledge from their information seeking behaviors, their actions followed. Parents most often described a trial and error method of learning and acting to accommodate their child. Trial and error

was required because of the variable nature of the disease in each child and the individual environments that each person is exposed to in their daily life.

Symptom recognition was one of the first challenges that parents had to deal with. Depending upon the meaning ascribed during the first phase, parents displayed varying degrees of recognition of symptoms that could be attributed to asthma. Parents who denied the diagnosis were reluctant to relate the symptoms that their child displayed as related to asthma. Other parents watched their children with new knowledge and understanding about the impact of the disease on their child. This was an ongoing effort on the part of the parents and often needed confirmation from their physician about what they were observing in their child.

Some treatment knowledge was required to administer their child's medications at home. For preschoolers, the mode is often a compressor with a face mask. Some parents had to go to an emergency department to receive a face mask medication when the use of inhalers at home did not work. This was often time consuming and inconvenient. Parents described the ways that they administered the medications, the frustrations with the actual use of the mask, as well as knowing when to give it:

It was always me that had to take him and grab hold of him and get his arm right behind my back, cross my legs and hold on to him while he would scream like hell when I had the mask on his face. I also learned, let him scream. If he is screaming he is taking deep breaths, if he is taking deep breaths the medication is getting way down in there where I want it to be.(1)

This use of the knowledge required parental decision making based on the symptom recognition and knowledge of the medication's action:

I try everything I can at home and if I don't see, like I put him on oral steroids at the most four at home and like if I don't see a change within 48 hours I know that this is not going to work and so I end up taking him in. I try to do whatever I can at home, I don't run him up every time he starts to wheeze where probably some parents do that. I don't do it because there is more I can do at home because my doctor feels comfortable that I know what I'm doing.(2)

Parents were not given information about the medications side effects and had to learn about the side effects in a trial and error method. They saw their child react in different and often frightening ways to the medications. Parents soon developed opinions about the use of certain medications. They developed trust or distrust in certain health care professional's decisions about prescribing, based on the effects that they saw from the medications given to their child:

The side effects of the prednisone for her were awful,... he suggested (the prednisone) a few times and I keep reminding him and he goes 'oh, maybe not'....Really I don't think he knows what he is doing anymore. I know he doesn't know what he is doing! You know we try this it doesn't work, oh well, we will just try something else.... I said I don't think she should be taking this much.(5)

Environmental changes were suggested in the literature about asthma, as important in controlling the disease. These environmental changes were acted upon in a large variety of ways by families. Ways that families chose to respond to environmental changes varied from moving, building new homes, to making very few changes. Again the variable course of the disease and the severity of the illness influenced the decisions that parents made about the use of the knowledge that they had gained.

Lifestyle choices that may be required were learned about during parental information seeking. Smoking is an irritant to many asthmatic children and exposure

often triggers an asthmatic attack. The fact that smoking was an irritant or trigger influenced the behavior of some family members. Parents often smoked, extended family smoked, many public places such as restaurants allowed smoking. Parents needed to make choices about exposing their child to an environment that may endanger their health. Some parents tended to deny their smoking affected their child:

When he was small, I used to think why? Why my son? Why can't he breathe right? I blamed myself cause I smoke and I thought I did this to my baby but I really didn't. I'm sure smoking doesn't help.... The smoking doesn't bother him....He doesn't like the smell of it but then neither do I and if I could quit I would you know, ..I just, I can't do'er. I am weak. You know, I know quitting for him would probably be the best gift I could give him. I just can't seem to get there, you know. I changed a lot of other habits, you know, but maybe someday. (1)

Other parents recognized the smoking threat and were very serious about limiting their child's exposure to it, "There is no smoking in the house, there is no smoking in the car, we don't even enter restaurants where there is smoking." (5)

In summary, putting the knowledge to use involved carrying out the recommended treatment regimen of the asthma. This included transferring knowledge to unique actions that their child required. This was a difficult task for many parents because of the variable pattern presented by the asthma. Parents had to learn by trial and error. The decisions parents made about how to act were often based on the meaning that had been ascribed during the first phase. When parents considered the disease a threat to their child, they were realistic about the severity of the disease for their child and acted accordingly. They implemented things that would assist their child to deal with the asthma.

**Balancing.**

Balancing is a strategy that involved taking the information that the parents had learned about asthma and its treatment and applying the information to the management of their child within their lives. Parents developed an understanding about the symptoms they thought were relevant in their child and the use of treatment that was recommended by their physician. Treatments had been tried and were judged by the parents as being effective or not in treating their child's illness. Parents then began making choices about which treatment that they wanted to use for their child. Some parents began the use of inhalers on their own when they recognized that symptoms were present in their child. Some parents were learning to prevent symptoms by removing exposure to the environmental stimuli that was discussed in using the knowledge. Lifestyle choices that the parents made often had an impact on the entire family and possibly the extended family as well. Parents had now begun to make decisions about the way that they wanted to manage the asthma.

Parents weighed the risk benefit ratio of the treatments, environmental changes and lifestyle choices with how they perceived their child's health. This meant that parents made choices that were not always what had been recommended by the literature or information that they received from health care professionals. Parents often said, "I tried it and it didn't seem to make enough of a difference, so I decided to go back to what I was doing before."

I don't need to be criticized for what I did do or didn't do. I quit smoking, it didn't change his asthma.....[now smoking again] There were so many things I did, maybe it did help, maybe it didn't. to me I did it hoping that it did help. But for the first three years it didn't seem to matter what I did... (2)

We had a cat before we had the kids, and they're very attached to her, and I didn't, I don't think that's fair that they have to do without her. Our 8 year old can't pick up the cat because it really bugs him, so we let him have a hamster... We catch a lot of flack for that, like having a cat and the hamster and things, but I don't think it's fair to kids to not have a pet. If she [the cat] dies we won't get another one. (11)

We got a dog this year and he was in the house this winter, and S did have a rough winter and I'm sure it was because of the dog, but he won't be in this winter, so I said to my husband, no more. (12)

In summary, balancing was about fitting the knowledge gained in information seeking with the trying out of this new knowledge and then making choices. Parents did what they felt was best for the entire family. Some of the decisions were based on a negative impact on other family members that did not seem to be benefiting the ill child enough to warrant the change.

In conclusion, the strategies used by parents in 'Learning to Manage' involved information seeking; putting the knowledge to use; and finally balancing. The choices made throughout this phase were influenced by the primary condition.

#### Conditions for Learning to Manage

The primary condition influencing the movement through the phase of Learning to Manage was the 'perception of support.' This is defined as the perception of support that parents sensed from informal or formal structures. The parent's perception of support influenced the entire phase and the outcomes. Parental needs for support were influenced by several factors, including being single parents, the severity of the disease, and the

presence of complicating illnesses. Support came from a variety of places, including immediate and extended family; the health care system; the family's immediate social system and larger social systems. Support is discussed using the above headings.

#### Needs for support.

Parental support needs varied based on a variety of factors. As identified in the description of the sample, many care givers were single parents. These parents had to make more individual decisions about the care of their child, especially if the father was not involved. Some of the single parents tended to seek medical knowledge and psychological support that they needed, from their physician. Some of these parents thought highly of their physician and were not interested in seeking support from anywhere else: "I always feel better once I've gone to the doctor's with her." (10)

I guess if something different arose I would go to the doctor and say how do I handle this. You know that there is some different pattern in the way his attacks come on or what to do with them. (1)

Asthma compounded the symptoms from other illnesses, such as depression or lung infections. Parents were then required to deal with an illness that was complicating other health care needs of their child. The rest of the family was affected more when the health of the asthmatic child was more complicated. Often other children had their activity restricted because of the asthmatic sibling: "Like even the other kids, have said 'Oh well I guess we won't do anything today cause S is sick,' our whole life hinges on how S is feeling today."(5) These conflicts created unique situations in which greater support was required for parents.

The severity of the disease that the parents were learning to manage also had an impact on support needs of parents. Some parents of severe asthmatics were unable to continue to work. One mother quit work to stay home to care for her highly allergic child. She developed a business in her home to attempt to support herself. Other parents also had difficulty with time loss from work. If employers were supportive though, they were better able to fulfil their obligations without guilt.

#### Family support.

Many parents also identified informal supports that were important to their learning to manage their asthmatic child. Some families identified relatives with previous experience as helpful in providing information or support in the environmental changes:

My mother-in-law brought all that,... the pillow case cover and the mattress cover and a special quilt blanket for her bed....She brought it because she knew about it, but, would I have done that?.. I don't know.(10)

Another way that family members were supportive included accompanying the parent on visits to health care providers. This may have been on visits to the doctor's office or the emergency department. The physical presence of the family members seemed important to the parents to feel that they were doing the right thing in seeking medical attention for their child:

He was getting worse and worse... so I went in there mad, and I took my team of sisters with me [laughter], and I said I wanted something done and then that's when we got the compressor (9)

Some families felt that their relatives lacked enough information to actually 'help' them manage their child's asthma. The parents said that if someone has not actually cared for a child with asthma they would not understand. Parents therefore felt very alone in learning to manage the disease. "I was just by myself...Everybody thought I was always exaggerating about it (crying). (2) One mom said: "they can't make me feel better when she's having an asthma attack...they don't know about it." (10).

#### **The Family's Immediate Social System.**

The young age of the child and the need to provide medications on a regular basis meant that child care was a concern. Parents must consider the usual child care issues, but also have the burden of trying to provide enough information to the caregivers to make decisions about the care of their child's asthma in the parent's absence. Environmental risks were often present in the day care; carpet, smoking, and perfumes. These triggers had to be identified and, if not dealt with, parents often had to seek child care elsewhere. Day care workers often did not understand the impact of things as simple as placing a well dressed child outside, on a very cold day. Mothers explained:

With day care it was hard... I never even knew if they would be giving him his mask if he needed it, and they'd say that he wouldn't need it at all and I'd pick him up and his voice would be hoarse from coughing and I knew that he needed it. (9)

I would never leave my children with a sitter, when they're needing their medication unless they're experienced 'cause I mean, that's a lot of responsibility for someone else. (12)

#### **Health Care System Support.**

The support that was initially required was the provision of some education about the disease, asthma. This was often done by health care professionals first met during

illness episodes. Their physician was usually the first person that they encountered. Education that was provided to the parents and how the parents felt when they left the appointment often influenced other information seeking behaviors:

He (the doctor) gave me a lot of pamphlets and a lot of compassion. He is a very understanding doctor. He is the kind of doctor who genuinely cares about his kids, like every patient he has is like one of his kids, they're not just a number on a file and that makes a big difference.... Because of his attitude I guess he made me want to learn as much as I possibly could about it, so I could help S.(1)

If the parents perceived a lack of support they felt more animosity towards the physician and resultantly, also some of the recommended treatments. If the parents believed that the physician had not attended to the symptoms that the parents were concerned about, they sought care elsewhere or became more assertive in their approach to the physician:

There was one time I wasn't getting through to the doctor, our eight year old has really bad coughing asthma, when his is acting up, and we'd go into the office and his lungs would be clear, there'd be no wheezing, no nothing. He'd walk out of the office, and he's coughing his lungs out, to the point where he pulled groin muscles. He burst vessels in his eyes, until then we got no where.... That was frustrating because I knew he needed prednisone, and I was really ticked off that they thought there was nothing wrong with him. It was difficult to explain how severe the coughing was. ....We ended up in emergency with a different doctor and we got it that way. (11)

Other support which was important to parents was the quality of the encounter with health care providers. "All I understood is that she has to take these inhalers, and when to go back to his office again, that's all he told me." (3) Not only was accurate information important, but also attention to the actual symptoms that were a concern to the parents. Parents identified the need to be reassured that they were making the right decisions

about the management of their child. This reassurance was sometimes supplied by health care professionals such as their physician, a nurse, or their pharmacist.

#### The Larger Social System Support.

Supports for families were also needed from the larger society. Children with asthma often had an associated atopy, which involved food allergies. Many foods on the market today include ingredients that are not well labelled. Parents encountered problems in feeding their child safely. Parents had to read labels extremely carefully and then often found out that a notification came out in a news item, that a certain brand did contain a substance that their child was allergic to. This was especially true for nuts:

I can't remember which brand of Fruit Loops I bought him but for some reason I looked at the label, 'possible traces of nuts,' and I sat there and I thought oh great, now I how am I going to tell this kid that he can't eat these, ...you find one thing that he does like and that you know he can eat, but then you can't always get it at the store so it is just always a battle. (2)

Many products may contain oils or are in contact with nuts while processing, without consumers being aware. The products can have a devastating effect on a child's health and could be life threatening.

There were also some uniquely rural issues raised. Some of the issues included field burning, exposure to large hog barns, and the lack of available health care. One mother talked about the lack of a consistent doctor:

In the rural area...there is not always a doctor,...it he comes down with an attack I either have to go to (next nearest bigger town) and his history is not as available to them... You rely on this family doctor and he is all of a sudden gone. (7)

There were also advantages to living in a small town, "And they get to know you, especially in a small town, the nurses would recognize you and if you came in they knew that he needed some oxygen....and get it quickly."(7)

Financial burdens of the treatment of asthma created support needs for parents. Medications were often very costly. Social systems were not helpful to parents who struggled with this added financial burden. Many parents were living within restricted incomes. If parents wanted financial assistance they often had to give up their work. If a mother was working and able to meet obligations for rent and her living expenses, she could not receive assistance for medications unless she quit her job. Two jobs were sometimes required to provide enough financial resources to meet the asthmatic medication costs, if the parent did not want to go on Social Assistance. One mother explains how she dealt with some of the expensive treatments of her son's allergies:

I said well, I can't afford it, I said I can't cut anymore corners I was already going in the hole with bills,...I just started finding different ways to deal with it.. I just bath him twice a week, the bath salts cost way too much.(2)

In summary, the perception of support was required for parents to learn to successfully manage their child's asthma. The support could come from formal or informal systems. The support that was required varied with each families' unique circumstances. The type of support could come from a close circle within the family and be suffice to meet their needs, or from the health care provider's relationship with the parents, or from large societal systems such as financial support for the medications or in prevention such as in the case of food package labels. If parents felt supported, they were

better able to successfully go through the processes involved in phase two, Learning to Manage.

**Figure 3**

## **LEARNING TO MANAGE**

### **PROPERTIES**

Observation

Monitoring

Participation

Prevention

### **STRATEGIES**

Information Seeking

Putting the knowledge to use

Balancing

### **CONDITION**

Perception of Support

### **Outcomes of Learning to Manage**

The outcomes of successful passage through the Learning to Manage phase were that the child's asthma appeared to be under control and the child's asthma was not representing a major disruption in the family's life. Parents were satisfied with the care that they were providing to their asthmatic child. Parents expressed an ability to recognize symptoms that their child displayed, when to give appropriate dosages of medications, and when to seek medical attention. The child was reportedly able to participate in most activities and was not being slowed in their development by the disease. Parents were able to work successfully and had supports systems in place that

they thought were sufficient to allow them a lifestyle that they considered normal. Parents who felt unsupported in their efforts to learn to manage the asthma were less able to proceed successfully through this phase. The child's asthma was often reportedly out of control, or the child continued to display symptoms attributable to the asthma. Parents were often unhappy with the treatment of the asthma and felt that their life was being unnecessarily disrupted by the disease.

Some parents described symptoms which should have been considered part of the asthma experience, but they were unable to or had never had accurate information to allow them to associate the symptoms with the disease. Part of this problem appeared to be related to an unsuccessful passage through the first phase of Ascribing Meaning. Parents had not been convinced of the suitability of the diagnosis, or they were unaware of the symptoms considered a part of asthma. Their prior experience had frequently influenced these opinions.

Parents described treatment that did not seem to fit the symptoms that they were depicting in the child. This usually involved incorrect usage of inhaled steroids. There were several possible reasons for this mismanagement. The parents may have misinterpreted the instructions or the prescription may have been lacking the required dosage or never prescribed at all. The method of administering the medications was not checked by a health care professional. If the medications were not being given properly or in a therapeutic dosage range, the asthma would be less likely to be controlled effectively.

In some homes there were obvious environmental triggers present that may have been affecting the child's health. Many parents smoked. Some smoked outside, but the presence of the irritant could still have been affecting the child. In other homes, there were problems with cleanliness and carpeting in the bedrooms. The parents often mentioned environmental changes that they had made and often stated that they knew it would have been better for their child to have not been exposed to the irritants, but that it was a difficult choice. One mother talked about a family pet, a cat. The mother admitted that all four of her children had asthma, but that she felt the psychological damage of removing the cat from the home would be greater than the physical effect of having the cat.

Parents who had made alternate choices from those prescribed or recommended about the management of their child's asthma, could have been affecting their child's health. But, if parents felt they had made the best choice for their family, they were satisfied with the care the child was receiving. These parents often described ongoing symptoms in their child that they had come to accept as being part of the disease.

In conclusion, the outcomes of the Learning to Manage phase were most obvious in the actual health of the child. If the child was being adequately controlled there were no ongoing symptoms which were not being treated. In families which had not successfully passed through this phase, parents expressed feelings of inadequate support. The children were having ongoing symptoms that concerned the parents and the families' progression through the Learning to Manage phase was incomplete.

### Incorporating the Disease

The third phase of the beginning theory “Integrating the Asthma Experience into Daily Family Life,” was ‘Incorporating the Disease.’ Incorporating the Disease implied that parents had gained some control of the disease, but had now progressed in their thinking from the present to more future oriented. Parents were able to maintain lifestyle choices that they had made regarding the care of their child’s asthma. They had also begun to take a look at the larger picture of their life, and anticipate changes that may be required while the child grows and the environmental exposures changed. This section describes the properties or characteristics, strategies, primary condition and outcome of this phase. (see Figure 4)

#### Properties of Incorporating the disease

The two properties of this phase include: maintaining and anticipating. These two properties describe an advance in the thinking about the parental roles in managing their child’s asthma. The two properties are expanded upon in this section.

##### **Maintaining.**

In the “Learning to Manage” phase, parents had to make some lifestyle choices that had an impact on their entire family. These have included issues such as: having pets in the home, smoking or allowing smoking in their child’s immediate environment, the cleanliness of their home, or where they live, going out of the home to work and the way that they are available to their child, as well as the larger environmental exposures in the public. Parents explained the ongoing work:

It's easier now, it's second nature. It was hard to learn it, the what to do and how to do it but once I've learnt it, it's just do what you have to do not, it's not that panic situation any more.... You have to control asthma, you can't cure it, you have to maintain and control it. I control it by not giving him foods that are going to set off an allergic reaction., by not having animals, and by trying to keep the dust bunnies down. (1)

Many of their decisions have been difficult ones that have created either tension or relief in the relationships within the family. The decisions also had an impact on other groups or systems in the families' environment. The decision may have been to not allow smoking in the house or anywhere that they take their child. There may have been a financial burden placed on the family because of the need to be home with an asthmatic child rather than at a job.

The need to maintain the lifestyle choices is ongoing. As preschoolers get older, their environments become less controlled by the parents. The children want to be out to parks with friends and play at friend's homes, without the supervision of their own parents. One severely asthmatic child's mother found this especially difficult because of the number of allergies that the child had and the severity of the reactions.

#### Anticipating.

The need to anticipate the triggers was learned by parents during the "Learning to Manage" phase. The next phase again represents advanced thinking on the part of parents and their ability to anticipate the possible changes that may trigger their child, as the child's growth and development stage changed. This is the anticipating process as part of the third phase of Incorporating the Disease.

Anticipating needs of a child is a part of normal parenting responsibilities of preschool children. Children are unable to anticipate the consequences of their actions.

**As a child's environment changes, he or she is often not able to anticipate the consequences of exposure to certain allergens or triggers. Parents began to think more proactively about how to anticipate the kinds of things that their child may react to. They were able to identify social situations to avoid. One mother spoke of family events that she refused to attend because many of the family members smoked.**

**As preschoolers approached school age and were exposed to school-type environments, parents needed to become aware of the types of triggers in these new situations that their child may encounter. The parent's ability to react to these possible triggers, would have implications for the safety of the new environment for their child. One mother explained, "The room [kindergarten] is fully carpeted. The sand tables are a problem, there is a lot of dust." (5)**

**Relationships that the parent was able to develop with other parents of asthmatic children, teachers, friends and family influenced the type of experience that they had. One mother felt other's perceptions were not the same as her own:**

**I know a teenager that is much worse than F. Then again there is a little boy in her class that his mum is just positive that he is almost just going to expire in the next little while, and meanwhile, F is sitting there coughing and coughing and she is being sent home with no one thinking that she is that bad. ... She [the teacher] tries but she doesn't know enough about it to worry about it. Sure her kids don't have it so she doesn't have to worry about it. (5)**

**The parents may have felt reassured or very anxious, when their child was not with them, depending upon their perceptions of how their child's needs were being met. For people seeking day care arrangements, the parents needed to feel secure that the care providers understood the effects of wearing perfume on their asthmatic child. One**

mother identified this to a worker after recently consulting a pediatrician and the day care worker immediately stopped wearing any perfume. The mother felt reassured and pleased with the day care worker's response.

The need to look at their larger environments and begin to anticipate the changes that might be required helped their child as well as others. It seemed that some parents developed a social conscience for all asthmatics in their area. Parents were able to identify things such as stubble burning, the labelling of foods, and the number of hogs to be brought into an area as possible irritants or allergens that may impact on their child or other asthmatic children. One mother was doing research about the hog barns started in a US state to understand what research had been done about allergens produced by the hog barns. There were public hearings held to discuss allowing them to be opened in their municipality.

The physical changes that occur as children grow may make parents think that their child is growing out of the disease. As the airways grow, they may see fewer symptoms with the same intensity that they saw during the child's early development. The need to anticipate growth and less control over the disease affected how parents treat their child and the freedom that they allowed them. Several mothers identified that they had probably been overprotective of their asthmatic child. They felt they had to sometimes do other things for their other children to make up for the attention that they had given their asthmatic child.

### **Strategies for Incorporating the Disease**

Parents used three strategies to carry out "Incorporating the Disease." The three strategies: Mobilizing, Sustaining and Adjusting were used to try to maintain the choices made to deal with the disease during the second phase, Learning to Manage. As the child aged, new strategies were needed to move beyond just learning, to being able to incorporate the disease into their life as they progressed further into their family's developmental stages.

#### **Mobilizing.**

The first strategy, mobilizing was the need for parents to be able to anticipate the triggers and be proactive about trying to meet the needs of their child. Because a child's needs change as the environment is less controlled by the parents and the child gains independence, the parent had to feel satisfied that they were still protecting their child from harm. The child could meet many new triggers and parents must have been able to mobilize other resources to feel comfortable. Several approaches were used to meet the need to mobilize all resources that they knew they had developed during the learning to manage phase. These approaches included: teaching, researching and negotiating.

##### **1) teaching**

Parents identified that the knowledge base of others who had not been faced with an asthmatic child or differed from their own child's experience required them to do some teaching. Parents were able to distinguish between those that had knowledge about their child's asthma and those that did not. Parents taught the people who would be with

their children and tried to educate them about their child's symptoms, medications and needs regarding avoidance of triggers:

My family's the only family in town and I mean they have no idea what asthma is, none of them will smoke around her, or if we go to their house, everybody will smoke outside, so it's just not my house that they have to smoke outside, they have all started to do that. They don't know about it, it just what's happened with us, is all that they know. (10)

## 2) researching

Parents began to realize the type of triggers that may have precipitated an asthmatic attack. These parents then had to research actual environments that their child may be exposed to and the possible triggers found there. They had to be able to know where to go for more information about how to deal with the new triggers.

## 3) negotiating

Parents had to learn to negotiate the management of their child's asthma. Negotiations had to take place with a child who was gaining more independence. "He's going to miss out on a lot of things until he can make his own choices, but right now I make his choices, so I feel like a mean parent." (12) Their children often wanted more control over their own medications and their ability to decide about exposure to triggers such as other people's pets and activity. "Now he knows how it works, he knows the machine, how to put the machine on and how to put the medicine in it." (1) As children developed wider interests, parents needed to develop a relationship with their child to negotiate how much the child could take over and how much control the parent needed to maintain:

I tend to be a little paranoid. If I send him outside and it is summer and he is not at his friend's house and they decide to go somewhere else, yeah, I do panic.. because then I don't know where he is and he disobeyed me and he went to the park.... Like nobody cares about his health or anything, it is just me.... Now we have an agreement, he has to have his medications all done before he goes outside (2)

**The parents began to understand the need for the child to develop his/her own ability to regulate the asthma:**

We have puffers stashed all over the house, they're in their backpacks, they're in their jackets in zipper pockets, so they're never without one. It's ingrained in our kids heads, that you don't leave without a puffer. (11)

**The parents were often relieved when the child could recognize themselves, the symptoms and anticipate the needed treatment:**

...Now, if he's feeling crummy, he'll come and ask for it [medication], the first day that that happened, I thought this is wonderful. It just takes all the guessing out of all your wondering. (12)

**Negotiations also had to take place with authority figures, in places where their child would be spending a larger part of his/her day. This was a skill that parents needed to learn to cope with the anxieties of having less control over their child's environment than when they were preschoolers. As children move to the next growth and development stage of school-age, parents always feel some anxiety about the transition. This is more pronounced for parents of asthmatic children:**

I have to fight on a regular basis... about going outside. We don't want him having an asthma attack outside on the playground an somebody out there supervising not knowing what's going on, thinking he is making a snow angel, when in actual fact he is basically dying. (1)

They (the school) told me that they didn't want children carrying their inhalers to and from school. I said none of that. So, she carries it with her in her pouch.... I had to finally get a note from the doctor to say that she needs to carry it on her person at all times, to convince them. (5)

He was in day-care in the last year full time, when I was away working full time. He was in there from eight in the morning until five at night....I took him out of there because it,...I wasn't,... a lot of things there bothered me, I guess maybe I was so used to having him at home. (9)

### Sustaining

The second strategy was sustaining. Sustaining referred to changes in environmental controls or lifestyle choices that had been made by the parents and the need to continue them. This was work for many parents to continuously keep up the modifications that they had made in their own lives to accommodate their child with asthma. The parents needed to make decisions about their child's needs and the reorganization that had taken place within their family:

People have said to us, well you shouldn't keep him from going to these family dances. Well, are they going to be smoking?...Can people not just leave their cigarettes at home for one night? For three hours? (12)

It was not only the changes made to their home environment but the personal lifestyle choices that needed to be maintained. Other children may have entered the family, other activities or needs of family members may have conflicted with the needs

of the child. Parents were trying to make the best choices about their child's health and the needs of the family:

I couldn't find anybody that would come into the home and felt comfortable enough to give him medication and then when I did finally find somebody it was through child and family services, a respite program. But, then one lady they sent me, well you can forget it because I couldn't get any sleep because I was wondering if she was doing everything and she didn't really know what she was supposed to do, even though I told her. I ended up getting S's godmother to come in once a week to give me a break. (2)

Some parents had learned that to think positively about the changes they had made: "They [the family] have all been pretty good... [parent quit job to be home with asthmatic child] if anybody needed a baby-sitter for an asthmatic child or child with allergies, I would fit just great." (2)

Parents who quit smoking needed reinforcement that that was required to create an impression on the incorporation of the disease into their families' life.

I think it would be good to have [support group] cause some people would find help,...but I probably wouldn't use it because I've dealt with it for six years already and I've done it on my own and I don't want to go somewhere and have somebody tell me maybe I did something wrong or you shouldn't do this or should do this and you should do that. That isn't what I need to hear. I don't need to be criticized for what I did and what I didn't do. I quit smoking, it didn't change his asthma. It was good for me to quit smoking but there were so many things I did that didn't change his asthma, I got rid of the stuffed toys, I scrubbed his room down, I got rid of the carpet, I changed my cleaning supplies, there were so many different things I did, I stripped the bed three times a week instead of once a week. I vacuumed the mattress, like there were so many things that I did, maybe it helped maybe it didn't. [so started smoking again] (2)

### Adjusting.

The third strategy was adjusting. The parents had a certain amount of knowledge not only about the environmental triggers of their child's asthma, but also the medication regime. The parents were able to adjust the dosages of the medications to a level to sustain their child's health regardless of the situations encountered. "It just kind of routine, ...you know that there's going to be bad times of the year, so you start using Pulmicort." (12) With the second one the learning was quite different....you catch the symptoms and you know there is something up so you get on it faster.... You have to think ahead. (7)

I keep a calendar, with us to keep a history of what she has been taking and the symptoms, then if we get into trouble, and have to go to hospital or something, we get the right treatment because they know what I've been giving her. (10)

This strategy was accomplished as a final part of being able to manage their child's asthma successfully. They no longer had to think as carefully about each decision they were making. They felt they had come to a point that they could adjust the medications enough to maintain the child's health at an acceptable level. The adjustment may have required consultation with a physician, but parents felt that normally they could interpret the symptoms that their children were displaying and understand the course that needed to be taken:

When he starts getting better, I switch him from the Pulmicort to the Intal. I make those decisions on my own, but often still get them checked, just pop into the doctors office and have it confirmed. I pretty much have a handle on it now. (9)

I'll ask her,... are you wheezy, she knows if she's wheezing, or, I'll tell her to take a deep breath so I can listen,... but she won't say I think I need my inhaler yet. (10)

In summary, strategies that parents used to incorporate the disease into their ongoing situations included mobilizing, sustaining and adjusting. The use of the strategies was evident in their ongoing work with the asthma, the needs of the child that they could anticipate, the requirements of the disease and the accommodations that needed to be made.

#### Conditions for Incorporating the Disease

The primary condition operating to influence the passage through the Incorporating the Disease phase was the parent's perception of the child's health. The choices that parents had made during Learning to Manage the disease had an influence on the child's well being. If parents were able to see benefits for the child, they were more likely to want to further anticipate triggers and avoid them and to maintain lifestyle choices.

The feedback mechanism of the child's health or illness was a reinforcing factor that meant that parents became comfortable with the effort required and the choices that they had made. If their perception was that a child was functioning at their optimum level of health even though there were still considerable numbers of sick days, then they made no further accommodations about the treatment or environment. If the child required more medication to allow them to sustain the choices that they had made about keeping pets or continuing to smoke, then that would be the decision that they would often uphold.

In summary, the health of the child provided the parents with feedback about the choices that they made to incorporate the asthma into their lives. The choices were reviewed if the parents were not satisfied with the symptoms that their child was displaying. If the parents perceived that their child's health was the best that it could be, they felt justified in any of the choices that they maintained. Needs were also anticipated based on the perception of the effect of the environment on their child's health. Medication regimes were adjusted to continue a certain level of wellness in their child.

**Figure 4**  
**INCORPORATING THE DISEASE**

**PROPERTIES**

Maintaining

Anticipating

**STRATEGIES**

Mobilizing

- 1) teaching
- 2) researching
- 3) negotiating

Sustaining

Adjusting

**CONDITION**

Perception of the child's health

**Outcomes of Incorporating the Disease**

The outcomes of successful passage through the phase of Incorporating the Disease were successfully having the asthma controlled through changing situations. The parents were able to anticipate and judge the requirements of the management of the child's

disease. Parents displayed ongoing information seeking behaviors in their research of asthma and some became proactive advocates for all asthmatic children in their area. They were able to look beyond the immediate environment of their child, to the larger social issues that may impact on their child and others.

In conclusion, the phase of Incorporating the Disease saw parents becoming more proactive in their stance to the asthma and its impacts on their families. They were anticipating the triggers and the effects on their child and able to manage them within their chosen lifestyle to maintain the health of their child at a level that was acceptable to the parents.

## **CHAPTER FIVE**

### **DISCUSSION AND CONCLUSIONS**

#### **Introduction**

The beginning substantive process theory titled: "Integrating the Asthma Experience into Daily Family Life," developed from the qualitative data analysis. This chapter provides a discussion of the findings of the beginning substantive theory. The beginning theory is briefly discussed as a whole and the findings are related to the initial purpose of the study and then discussed in relation to theoretical and substantive literature. The third section contains a discussion about the relationship between the conceptual framework of the study, symbolic interaction theory and family systems theory, and the research findings. Recommendations for nursing are proposed. Finally, limitations of the study are discussed.

#### **The Theory and the Original Purpose**

The theory of Integrating the Asthma Experience into Daily Family Life describes the phases that parents progress through in managing their preschool child's asthma. The parents develop their own definition by Ascribing Meaning to the diagnosis of asthma, based upon their own experience. Then parents progress to learning to manage their child's asthma in the home. Some parents are able to incorporate the management of the asthma into their lives as the family continues to progress through time. The initial purpose of the study is reviewed and related to the beginning substantive theory.

The overall goal of this study was to understand the process of managing a preschool child's asthma from the parents' perspective. The questions that directed the study included:

- 1) What are the experiences of a parent caring for a preschool child with asthma?
- 2) What factors facilitate a parent's management of a preschool child with asthma?
- 3) What factors hinder the parent's management of a preschool child with asthma?

The beginning substantive theory provides explanation for these questions and provides some direction to the overall goal. The first question of the study about experiences of the parents are described in the findings chapter, including excerpts from the data to reveal some of the participant's experiences to the reader. The parents of asthmatic children have quite different experiences. Their perceptions of the care that they receive for their child and the problems that they encounter are individual and interpreted in their own way. When parents are given the diagnosis of asthma, they have a certain reaction. Their reaction is embedded in the previous experience with the disease and their interpretations of that, as well as their perception of the severity of their child's disease.

Factors that facilitated parent management of preschool child's asthma included such factors as the parental definition of the asthma, the amount of support received and their perception of the child's health. As parents begin to learn to manage their child's asthma, they begin with information seeking. The amount of information that they believe is required has been influenced by their perception of the severity of their child's disease. If the parents interpreted the disease as enough of a threat to require action, then they progressed to the next stage of active information seeking. Parents from different

families require distinct kinds of support and have a unique perception of the support that they receive. This support, as defined by parents, is the key factor influencing their ability to learn to manage their child's asthma. Successful incorporation of the disease was influenced by the factor of parental assessment of the child's health. If the parent's perceptions were that their child was as healthy as he or she could be, whether he or she was still exhibiting symptoms of asthma or not, the parents were satisfied with the care that was being provided for their child.

Three main conditions for the three phases are identified from the beginning substantive theory. The first is the parent's perception of the severity of their child's disease. The second is the parent's perception of the support required while learning to manage. The third is the parent's perception of the child's health. The parent's progression through the phases of the integrating process is not linear or related to a specific amount of time and is individualized. These three conditions are examined further in the next section in the discussion of the findings in relation to the existing literature.

### The Three Phases

#### Ascribing Meaning

The Ascribing Meaning phase refers to the meaning attached to the diagnosis of asthma. The Ascribing Meaning phase was based on the parent's ability to acknowledge the diagnosis, recognizing their child's experience and their evaluation of the correctness of the diagnosis. This was facilitated or hindered by the parent's previous experience with the diagnosis and the symptoms that parents believe were attributable to the diagnosis of asthma. These three factors: acknowledging the diagnosis, drawing on prior

experience, and recognizing the impacts of the disease contributed to the Meaning Ascribed to the disease in their child by each family.

Several studies have identified the acknowledgment of the disease as a requirement to stimulate the behavior of parents (Deatrick & Knafl, 1990; Knafl & Deatrick, 1986, Knafl & Deatrick, 1990). Parental behavior was in response to the definition of the chronic illness or the family member's perceptions of the total situation. The family-management behaviors followed the definition of the situation.

Chronic illness literature has previously identified the importance of the meaning given to an illness by individuals and families (Baker & Noerager Stern, 1993; Baron, Veilleux, & Lamarre, 1992; Bauman, Cameron, Zimmerman, & Levanthal, 1989; Gallo, 1991; Knafl, 1985; Leahey & Wright, 1987; MacDonald, 1996; Orem, 1995; Shaw and Halliday, 1992; Stetz, Lewis, & Houck, 1994; Wuest & Stern, 1990; Wycoski, 1989). This research has generally agreed that action by families is based on their definition of the illness. In a study by Wuest and Stern (1990) which explored family interaction when a child has otitis media, the results paralleled results from this study. The process described was Leaning to Manage. They highlighted the importance of symptoms within this disease entity as being important to the response of parents. The parents tended to focus on the presenting symptoms that they thought were important. This finding is similar to findings in work done with self-care in diabetic patients (Wycoski, 1989), where the selection of treatment choices was based on personal beliefs of the patient rather than the blood-glucose results. The perceived symptoms of abnormal blood glucose levels were a better predictor of action to normalize the blood glucose. The difficulty patients have in actually relating the symptoms of asthma with those that they are experiencing is

identified by Tattersell (1993). Only 50% of their respondents were able to recognize that difficulty in talking due to shortness of breath as a severe symptom.

Shaw and Halliday (1992) define the crisis phase of a chronic illness as the symptomatic period before a medical opinion is rendered, when symptoms are present but their meaning is unclear. It is the family's perception of the event that determines whether the crisis is perceived as a threat or a challenge. In this way, Shaw and Halliday (1992) use the evolutionary model to see a crisis as a turning point in which the family has the opportunity to grow and evolve.

The primary condition for the parent's progression through the Ascribing Meaning phase was the parent's perception of the severity of the asthma. Because new definitions of asthma have emerged in the last 20 years, the parent's previous experience with asthmatics has often been with severe asthmatics, as these were often the only patients previously diagnosed (Cookson, 1987). Therefore, if parents had a child with mild asthma, and experience with only severe asthmatics in the past, they were less likely to believe in the diagnosis and therefore less likely to act on learning the management of the disease. Many parents' perceptions underestimated the severity of their child's asthma, based on the severity rating used for this study. The rating of some children's asthmatic severity fit with the parents' estimation.

Deaves (1993) in an exploratory study looking at three groups of asthmatic children over a two year period, found that there was a tendency for parents to categorize their child's asthma as less severe than the physician. One study stated that the over-anxious mother may perceive and report that her child's asthmatic attacks were severe while objective assessments provide little or no evidence of airway obstruction (McNicol &

Williams, 1973 in Khampalikit, 1983). The idea that parents may over estimate the severity of their child's asthma was not supported by this study.

Donnelly (1994) studied family hardiness, family stressors and family functioning in 27 families of children with asthma, aged 1 to 5. Perceptions were found to be reflective of the meaning or interpretation given to the experience as stressful (or not) by the parents. In the stress assessment used in Donnelly's study, it was interesting to note that only four parents of children with a diagnosis of asthma indicated that 'a family member became chronically ill' as a family stressor. Twelve parents indicated that a family member became seriously ill. This could imply that parents do not have an accurate assessment of asthma as a chronic illness and this has an impact on their perceptions and definitions. Clark et. al. (1988) found that being hospitalized and participating in health education were two predictors of subsequent health promoting behavior in children with asthma. This would support the idea that the hospitalization had affected the child and families' perception of the severity of the disease.

In chronic illness literature, several nursing models have been developed that have included the need to assess a family's beliefs or attitudes toward a chronic illness. The Double ABCX Model of Adjustment and Adaptation (McCubbin & Patterson, 1983) includes the need to assess beliefs and attitudes or family definition. Beliefs are defined as cognitive information family members have about the illness. Attitudes or family definition is defined as the meanings family members have given to the total situation or their attitudes about it. The family definition also includes the health condition and the ramifications of living with it. Anderson and Tomlinson (1992) call the shared meaning of the experience, the meaning that family members collectively attribute to experience

as part of the integrity processes. Addressing this area is considered important because a family's values, rituals and history greatly affect its behavior (Austin, 1990; Danielson, Hamel-Bissell & Winstead-Fry, 1993; Friedman, 1986) These studies have not clearly identified the actual assessments that are required for specific chronic illnesses. This study also addresses the importance of the family's definition of the situation in phase one, Ascribing Meaning.

This study identifies the properties of the Ascribing Meaning phase to include acknowledging the diagnosis, drawing on prior experience and recognizing the impact of the disease. This study's beginning substantive theory supports many findings in the literature about the importance of the meaning of the disease to the patient and family.

#### Learning to Manage

The second phase of the beginning substantive theory is Learning to Manage. The primary condition, the parent's perception of support, was a major factor in the parent's successful progress through this phase. Support needs varied between families with different compositions, as well as between families with different disease severity being displayed in the child. The support in the parent's immediate environment was important to the parent's comfort levels in learning to manage the illness.

Many studies have been completed about the support required during chronic illness and hospitalization to facilitate coping or adaptation of families (Burke, Kauffman, Costello, & Dillon, 1991; Clements, Copeland, & Loftus, 1990; Fugate Woods, Yates, & Primomo, 1989; Hodges & Parker, 1987; Kirschbaum, 1990; McCubbin, 1984; McCubbin, 1989; McCubbin, McCubbin, Patterson, Cauble, Wilson, & Warwick, 1993; Simon & Smith, 1993). Most of the studies report the need for social

support or support systems for the family to facilitate coping levels in families with chronically ill members. The issue of repeated hospitalizations is also applicable to the findings of this study, as often asthmatic children have had repeated hospitalizations. The following section provides more detail about some of the studies.

Extended family social supports have been associated with better health of the child. An increase in the child's health problems has been linked to total family stress levels, because families have difficulty in carrying out the prescribed care for the child (McCubbin, 1988). Other supports may be developed which assist families in coping with their child's chronic illness. Support needs may be met through relationships with other parents with chronically ill children, financial supports, respite and child care support and relationships with health care providers (Simon & Smith, 1992). The support needs were unique for each family. The family or immediate environmental support that families feel that they have received has an impact on their ability to manage their child's asthma successfully.

Several studies have examined the relationships of physicians and clients. The importance of this relationship has been illustrated by several studies. Hodges and Parker (1987) studied the concerns of parents with diabetic children. One of the four major categories of concern to parents was working with the health care team. Within this category the most frequently discussed items were the issues of medical management, the support from health care providers and the issues of trust of health care providers. Parents reported insensitivity to their anxieties in the early disease stages. Parents felt that they had received too much information too quickly during the initial period following diagnosis. Parents of asthmatics in this study also reported insensitive health care

providers. They discussed the importance of feeling that specialists or people that were truly experienced in asthma management were consulted for their child. This would contribute to the trust that is required for parents to feel supported.

Thorne and Robinson (1988a & b) have described family's relationships with health care providers as continually fluctuating forward and backward through phases of entrusting, becoming disillusioned, learning the rules, and negotiating. Entrusting in health care professionals implies that the family is willing to follow the advice of the professional. They tend to give control to the professional. Families tend to make the assumption in the case of chronic illness that the professionals will work with the family in the best interests of the sick member. But, there may be limits to this trust, if the parents did not see the expected results. Thorne and Robinson (1988a & b) discuss family members becoming disillusioned when there are conflicting opinions among physicians and inadequate information to parents. This can also be a problem when the real needs, as perceived by the parents, are not attended to by the physician or the health care system. Learning the rules (Thorne & Robinson, 1988a & b) is the learning of both formal and informal rules when dealing with the health care system. Parents in this study did talk about going to emergency to see a different doctor to get the medication that they wanted for their child. Some parents were more knowledgeable about the system than others. Negotiating (Thorne & Robinson, 1988a & b) is described as parents becoming good at using the system to attend to their needs. Negotiating can be in the form of manipulation, assertion or confrontation depending on the situation and on the personalities of the parent and health professional involved. In this study parents were also seen to negotiate the best care that they thought was possible for their child. Parents

of the preschool asthmatic children could also be described as using different strategies to gain the cooperation of the health care professional.

Perceptions of not being supported were intensified by poor relationships with health care professionals. Parents identified many issues around their relationships with health care providers which had an impact on how they learned to manage their child's asthma in this study. Wuest and Stern (1990) also identified similar issues as being important to parents learning to manage a child with otitis media. They concluded that the parent's relationship with the health care system, coupled with the effects of the disease on the child and the family lifestyle, had a powerful influence on how the process of leaning to manage proceeded.

#### Incorporating the Disease

As the family progressed beyond the time period of the initial diagnosis, several changes were made to incorporate the disease into their daily lives. The families made decisions about the amount and type of medications to give their child, how many environmental and lifestyle changes were required, and the symptoms that they thought their child still displayed. Sometimes parents described symptoms that health care professionals would consider part of the asthma, but parents viewed them as normal for their child. It was this perception of the child's health that contributed to decisions that parents made about the need to continue or sustain changes made in the management of their child's asthma.

The importance of the severity of the disease and the family's assessment of the health of the child has also been illustrated by studies with other chronically ill children. In two studies (McCubbin, 1988 and McCubbin & Huang 1989) families of children with

myelomeningocele and families of children with cerebral palsy, were studied.

Differences in relationships between family characteristics were based on the severity of the condition. Family systems variables contributed more to the health status of the child when the child had more impairment. Poor health in the child exacerbated the stress on the family and subsequently the response from the family.

Stetz, Lewis and Houck (1994) determined family goals as indicants of adaptation during chronic illness. The most frequently reported goal was cohesion, the expression of support, unity, and emotional bonding between family members. Maintaining health was viewed as one of the most important goals of the family in trying to adapt to chronic illness in the family. This would support the concept of the child's health as being important to the families in this study.

In another study of parental attitude and adjustment to childhood epilepsy (Austin, McBride & Davis, 1984) perceived seizure control was significantly positively related to parental adjustment. It was the parental perception of the level of control of the epilepsy that was more predictive of adjustment than the actual number of seizure events. This would support the findings of this study that indicate that parental perception of the child's health is the primary condition of the incorporating phase.

Educational programs that have been developed to improve compliance with medical regimes have increased the importance of finding ways for patients to assess their own need for medication (Boulet, Chapman, Green & FitzGerald, 1994). It has been identified that an increase in education and use of peak flow measurement is helpful but does not translate into a change in behavior. Parental and patient cooperation is one of the most important components of asthma treatment and prevention (Becker, et al.,

1994). It is acknowledged by this study that the parental perceptions of the child's health will influence the effectiveness of the teaching provided and the changes that parents are willing to sustain.

Anderson (1981) studied the social construction of the illness experience in families with a chronically ill child. Anderson argues that the semantic definition of the sick child as 'well' is a coping mechanism used by parents to deal with their child's sickness. The parents in this study considered themselves as coping well. They saw themselves as normal families. The regime that the child was asked to comply with, was not in conflict with family lifestyle. The family as a unit changed their lifestyle. This further facilitates the understanding of managing the asthmatic. The family identifies the child's health from their own perspective and the family sustains changes that are acceptable to all. Therefore they do not have to consider their asthmatic child as ill. This may be used as a way of families coping with a chronic illness, but in some cases may interfere with parents paying attention to symptoms of importance in their asthmatic child.

In summary, the beginning substantive theory is supported by previous literature. Looking at the entire model, similarities can be drawn to other models. Needs assessment studies using the health belief model share some commonalities to this model. The predisposing factors include factors such as beliefs and knowledge. This can be compared to the initial Ascribing Meaning phase. Enabling factors could include such factors such as criteria for parents to monitor an asthma attack (Mesters, Meertens, Crebolder, & Parcel, 1993). Reinforcing factors would include the issues of parental perceptions about their child's health, the symptoms that they attribute to the asthma and

the effectiveness of the treatments. The evaluation of the program by Mesters, Meertens, Crebolder and Parcel (1993) identified that checking the parental understanding of information is very important to the tailoring of information to the specific situation of the patient.

The theory of Integrating the Asthma Experience into Daily Family Life is theoretically linked to Lazarus' (Lazarus & Folkman, 1984) coping theory. The core concept of the coping theory is appraisal. There are three levels of appraisal. During primary appraisal a judgment is made as to whether an encounter is irrelevant, benign-positive or stressful. Stressful events can be categorized as harmful, a threat or a challenge. Secondary appraisal is concerned with judgments about what might be done to deal with a stressful event. Reappraisal occurs when there is a change in the appraisal of the situation based on new information from the environment and/or persons around them (Lazarus & Folkman, 1984). This study's beginning theory can be compared to the three appraisals described by Lazarus. The initial diagnosis of asthma is an event that requires appraisal and the Meaning is Ascribed to that event. The secondary appraisal could be compared to the decision made by parents to respond to the initial appraisal to Learn to Manage the asthma. The parents make decisions about how to treat the asthma and how to manage it. The final phase of the model is ongoing secondary appraisal about the way to incorporate the disease into the family life. Reappraisal could represent the continuous nature of the beginning theory. The parents are constantly reappraising the effect of the disease on their child, their ability to adapt and continue to sustain or try new changes to incorporate the disease into their lives. As the parents may see new symptoms or decreasing symptoms they decide what that means to them, and they begin

again leaning how to manage the disease based on the new meaning ascribed. As identified earlier the beginning theory is not linear or time-limited.

### Conceptual Framework Link

The theoretical framework for this study included symbolic interaction and family systems theories. Symbolic interaction theory is a broad general theory with an approach to the study of human behavior that emphasizes human interactions and the way that these interactions shape both the individual and the society. Family systems theory is also related to interactions. Families develop unique meanings related to their own interactions between family members and within their larger social systems. The findings of this research will be related to these two theories.

Symbolic interaction (SI) theory is based on three main premises. Blumer (1969) states that: a) human beings act toward things on the basis of the meanings that the things have for them, b) the meaning of such things is derived from, or arises out of the social interaction that one has with one's fellows, and c) these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters. This theory states that nothing has inherent value in and of itself. The meaning attached is created by experience. Once defined, meaning can be attached to it. Action or behavior is a result of the meaning or value given to it by the individual. As people encounter different situations, they guide themselves by defining the objects, events or situations. Families, society and organizations are based on shared meanings or consensus about relevant phenomenon and people. New meaning may be created through interaction.

Data in this study supported the premises of this theory. The parents in this study were faced with a child with the diagnosis of asthma. Each parent defined this asthma in an individual way, based on their own prior experience and the experience of their child's illness. As parents were faced with a large variety of symptoms, they placed these within their own reality. This supports the second premise of the SI theory.

The definition that parents gave to the asthma in their child, led to their action or behavior, in the second phase Learning to Manage. The parents in this study used strategies to respond to the meaning that they had placed on the diagnosis of the disease asthma, in their child. The parents became more or less active in their learning to manage the asthma, based on the meaning that they had attached to the diagnosis of the disease in their child.

The third premise of the SI theory addresses modifications that people make in their handling of situations based on their ongoing interactions. In the third phase, Incorporating the Disease, the parents have ongoing interactions with society and expanding environmental exposures, which results in a response in their child's health. The changing encounters may lead the parents back to modifying the meaning that they have attached to the diagnosis, or may lead them to continue to sustain the decisions or practices that they adopted during the Learning to Manage phase. This is an ongoing interpretative phase.

Family systems theory views families as a social system in constant interplay with other systems in the community at large. A family is both a part and a whole, the same as other systems. Each individual is best understood within the larger context of the family. A family system is a part of a larger social suprasystem and also has many subsystems.

Boundaries within families filter the flow of inputs and outputs from the environment. A change in one family member affects all family members. The family is able to create a balance between change and stability, once a significant change has occurred to create a disturbance.

In this study, the child with the diagnosis of asthma, creates a disturbance in the family functioning. The parents are the ones who must respond to this illness, as the child is a preschooler and is unable to care for him/her self. The interactions of all family members are affected as well as often the extended family members. The illness often created changes in the family's ability to attend extended family functions, or respond to other individual's needs on any particular day. Other siblings are affected by the family's need to limit exposures of the asthmatic child to allergens in environments such as at animal fairs and restaurants with smoking.

The parents' interactions with larger social systems such as the health care system and their satisfaction with the interactions, influences their future actions and behavior. The parents often made decisions about how to care for their child and what treatment was required for their child based on the perception of support from their immediate social systems. Individual families did not have the same needs for support based on their particular family situation.

In summary, symbolic interaction and the family systems theory were used as the theoretical basis of this study. Consistent with the findings of this study, and the premises of the conceptual frameworks, the parents of the asthmatic child developed a meaning of the asthma, which influenced their actions and behaviors in terms of learning to manage their child's asthma. The interactions were ongoing within their own family's unique

situations and social systems to influence the shared meaning and behaviors. The two theories provided the conceptual framework which assisted in the articulation of the empirical data into an understandable beginning substantive theory. The conceptual framework contributed to the applicability of the theory to clinical situations.

### Recommendations

#### Recommendations for Practice

Recommendations for health care providers in working with families with a preschool child with asthma are highlighted. The findings from this study indicate that previous history of asthma is important beyond predicting the risk of the disease in families. Previous experience and the impressions that parents have of that relative's disease influences how parents perceive their child's disease and symptomatology. The previous history and understanding of asthma requires further evaluation by nurses in their assessment of the family with a preschool child with asthma.

The parent's perception of support needs to be evaluated in the early stages of parental experience of learning to manage their child's asthma. Health care providers need to be aware of the variable responses of parents to help being offered. Parents must perceive the information as applicable and helpful to make use of the information. This has implications for educational programs developed to support self-care in asthma management. Because of the variable pattern of asthma, classes and group learning are often not applicable to many parents. They may find that their own questions are not answered. If parents have been trying to manage the disease for a period of time, they do not want to be told that they have made mistakes or what they are doing and happy with is wrong.

**Education should be provided where it is convenient to parents, on an individual basis. Parents have frequent questions about the management of their specific child, who may also be experiencing complications because of medication use or other diseases. Team work between physician ordering the medication regime and nurses to supply ongoing family assessment and education about how to administer the medications effectively may result in better management of their child's asthma. Medication usage needs to be taught and rechecked regularly for parents to feel supported in their efforts and to provide better compliance with medical regimes.**

**Health care providers should not presume knowledge on the part of parents because they have other children with asthma. The disease has a variable presentation and needs to be managed and observed quite differently for each child. When a family has several children with asthma each child should be managed and education provided based on each unique child's needs.**

**For parents to continue their efforts of managing their child's asthma, they need ongoing information, education and support. The parents' perception of their child's disease and the symptoms that they are displaying needs to be evaluated in an ongoing manner. The parents may or may not be attributing certain symptoms to the asthma and therefore are not administering medications appropriately to control the disease. The asthma may be considered out of control by the health care providers, but the parent's perception is that they are managing fine. The child's development may be affected by the parent's perception of the child's health. As preschool children expand their environmental exposures and encounter different triggers, they may display different symptoms that parents are not aware can be attributed to the same disease process. This**

contributes to the miscommunication between health care providers and parents about the effective management of a child's asthma.

#### Recommendations for Future Research

The following recommendations are presented as areas for future research. More understanding of the management of the preschool child's asthma is required. The parent's perspective sheds some light on the issue of compliance with medical regimes prescribed for the treatment of preschool children's asthma. Further study of the issue of previous experience could include parent's with no previous experience. This study did not find any families without previous history of the disease. This would strengthen the results of this study's implications. Longitudinal research would benefit the medical regime compliance issue.

Additional research also needs to be conducted evaluating some types of intervention by health care providers which may impact on the perception of support. Parent's who felt supported were more likely to follow the recommended medical regime. Can health care providers supply the necessary support early in the learning process which will impact positively on the child's future health? This future work of nurses needs to be implemented and evaluated for effectiveness in improving the health of asthmatic children.

Future research needs to be conducted to evaluate the father's role in the family's management of their child's asthma. In several interviews, the father's role was alluded to but is not clearly understood. Their role appeared to affect the meaning ascribed and may have influenced the mother's action or desire to learn to manage the disease.

## Conclusion

This thesis is the researcher's attempt to understand the process that parents followed in managing their child's asthma. Factors that hindered and facilitated have been suggested by the beginning substantive theory. The grounded theory approach used in this study has been challenging and enlightening. Guidance from the thesis chair in this methodology has contributed to some relevant findings in the explanation of the parental perspective of management of their preschool child's asthma. This beginning substantive theory is the researcher's interpretation of the experience as presented by parents.

The conversational style of the semi-structured interviews provided a large amount of rich data. Parents encounter a large number of challenges in managing a child's asthma. This is a complex process that necessitates many skills on the part of parents. The analysis hopefully provides some explanation about this complex process. It is also hoped that the findings can contribute to health care providers' ability to meet the needs of parents by first making accurate and thorough assessments of the parents and families.

## Limitations of the Study

Limitations of the study are as follows:

1. The group of parents recruited for this study come from one region of the province, and other geographic areas may have other environmental concerns for asthmatic children. Therefore, the findings of this study may not be applicable to all parents in all areas of the province.

2. This study is a snapshot of only one time period. Longitudinal studies would strengthen the beginning theory.
3. Length of time in the field With more time negative cases could possibly have been found to test the theory more thoroughly.

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**APPENDIX A****ASTHMA HISTORY of CHILD**

How long has your child been diagnosed with asthma?(years)\_\_\_\_\_

Do any of you other children also have asthma? If so, which child?\_\_\_\_\_

Is there a family history of asthma in \_\_\_\_\_'s family      Y \_\_\_\_\_ N \_\_\_\_\_  
Who?\_\_\_\_\_

What symptoms does your child display?\_\_\_\_\_

Any symptoms at night?\_\_\_\_\_ How often?\_\_\_\_\_

Any symptoms with activity?\_\_\_\_\_

What medication does your child use?\_\_\_\_\_

How many times did your child use oral steroids in the last year?(# of times)\_\_\_\_\_

How many Dr. office visits did your child have for the treatment of asthma in the last year?\_\_\_\_\_

How many Emergency room visits did your child have for asthma in the last year?\_\_\_\_\_

How many times has your child been admitted to hospital with asthma?\_\_\_\_\_

How many times in the last year?\_\_\_\_\_

What was the average length of stay for each hospitalization?\_\_\_\_\_

How many days of work have you missed to stay home with your child because of asthma?\_\_\_\_\_

Child's FIN number\_\_\_\_\_

**APPENDIX B****Preliminary letter used by physicians with possible participants**

Dear parent,

Dr. Low Ying and Dr. Elves have consented to present you with information about my study as a possible participant, because your child is treated for asthma. No information about you or your child will be released to me without your consent.

My name is Bev Clark. I am a Registered Nurse and a Master's of Nursing student at the University of Manitoba. I am from Brandon and have been nursing in the area for 20 years. Throughout this time I have been interested in the health of families. I have focused in the last few years on families with asthmatic children. This letter is a request for your participation in a research study I am conducting.

For my research as part of my Masters Degree, I wish to interview parents of preschool asthmatic children to describe parent's experiences of managing their child's asthma at home. Parents who wish to participate will be asked to be involved in an interview with myself. The interview would require about one hour of your time and would be kept strictly confidential. Participation in this study is strictly voluntary and your decision to participate will in no way influence the care that your child or your family receives. If you are willing to hear more about my study, your name and phone number will be released to me by the clinic and I will call you. If you do not wish your name released please notify the clinic within one week at 728-4440. If you would like to speak to me sooner, please call me at my work number 726-2269 (Brandon General Hospital). Thank you for your consideration.

Sincerely,

Bev Clark RN  
Masters of Nursing Student

**APPENDIX C****Telephone Explanation of Study**

Hello, my name is Bev Clark. Thank you for your interest in my research study. As I discussed in my letter, I am a Master's of Nursing student and am carrying out a study of how parents manage their child with asthma at home. This study will be supervised by three faculty members from the University of Manitoba.

I would like to describe to you the purpose, method, and risks involved in the research. I hope to learn how parents manage their child's asthma. By identifying the concerns that parents have, we, as health care providers, may be able to help families more. If you are interested, I would like to review the requirements for participating in the study. Parents must have a child who has been diagnosed with asthma by a doctor while a preschool child. This includes ages 1-6 years. The parents must speak and read English. If you have any concerns or questions, please do not hesitate to ask me.

Parents participating in this study will be asked to participate in an interview that will be tape recorded. The interview will take approximately one hour. I may need to contact you a second time to clarify any questions that I may have after reviewing the interview tape. The questions in the interview will include questions such as: when your child was diagnosed with asthma, what that was like; how did you learned to manage the asthma and who gave you support and if that was helpful. Parents will also be asked to fill out a sheet that asks for background information about your family and for permission to obtain information about your child's asthma from your child's clinic record and from the child's pharmacy records, if necessary.

Following our interview, notes will be made from the tape recordings. Your name will not appear on the tapes or on the transcribed notes; a code number will be used to identify the information gathered. The tapes and transcriptions, and name and code number combinations, will be kept in separate locked areas. My research supervisors may read the interview notes but your identity will not be revealed.

This study, or parts of it may be published; however, it will be written in a manner so that your statements could not be linked to you. The physicians caring for you will receive only a summary of the information from all who participated. This study is approved by the University of Manitoba, Faculty of Nursing ethical review committee.

Your involvement in this study is voluntary. You may withdraw at any time without risk to the care your child or your family receives. If you agree to participate, you will be asked to sign a consent. You may also receive a written summary of the research if you like. This research does not involve any direct risk to either you or your family. If you are uncomfortable with any of the questions or topics you may refuse to answer, withdraw from the study or ask to have the tape recorder turned off. There are no known specific benefits from participating in this study. However, hopefully in the future, education and support aimed at parents of preschool children will be more effective with the information gained from this study.

Do you have any questions about the study at this time?

If you are interested in participating, I would like to arrange to meet with you at a time and place that is convenient for you. Thank you for your time and consideration. If you have any questions or concerns, please feel free to ask me. Bev Clark (204) 726-2269

**APPENDIX D****Semi-structured Interview Guide**

**1. Lets go back to when your child was diagnosed with asthma, could you describe that?**

(Probes: What were your feelings at that time?; What did this diagnosis of asthma mean to you?; What were your thoughts about your child's needs at that time?)

**2. How did you learn about managing your child's asthma?**

**How did you handle a change in the child's respiratory state?**

**Who was involved?**

**What influenced the process?**

**Where did the parent get the information they used in their decision making/problem solving process?**

**How did they know when to utilize the Health Care System?**

**3. I wonder if you could share one positive experience and one negative experience related to managing your child's asthma?**

**4. What needs for support do you have, to help you manage your asthmatic child?**

**5. Have your needs changed over time? If so, how have they changed? (General or specific?)**

**6. What do you see as the health care system's role in managing your child's asthma?**

**Where do they think help should be available?**

**7. Have you used Emergency room services for your child? Could you talk about that and whether that was helpful?**

## APPENDIX E

## DEMOGRAPHIC DATA

Code # \_\_\_\_\_

Please answer the following questions.

1. What is the age and sex of the preschool child with asthma? \_\_\_\_\_

2. What is your age? \_\_\_\_\_ What is the age of your partner? \_\_\_\_\_

3. What is your occupation? \_\_\_\_\_

Full Time \_\_\_\_\_ Part Time \_\_\_\_\_

4. What is your partner's occupation? \_\_\_\_\_

Full Time \_\_\_\_\_ Part Time \_\_\_\_\_

5. Number and ages of other children \_\_\_\_\_

6. What is your highest education level achieved?

Less than high school \_\_\_\_\_

High school diploma \_\_\_\_\_

Community College/ Vocational School \_\_\_\_\_

Undergraduate degree \_\_\_\_\_

Graduate degree \_\_\_\_\_

Other (please specify) \_\_\_\_\_

7.. What is the highest education level of your partner?

Less than high school \_\_\_\_\_

High school diploma \_\_\_\_\_

Community College/ Vocational School \_\_\_\_\_

Undergraduate degree \_\_\_\_\_

Graduate degree \_\_\_\_\_

Other (please specify) \_\_\_\_\_

**8. What is your family income?**

<10,000 \_\_\_\_\_  
10,000 - 19,999 \_\_\_\_\_  
20,000 - 29,999 \_\_\_\_\_  
30,000 - 39,999 \_\_\_\_\_  
40,000 - 49,999 \_\_\_\_\_  
50,000 and greater \_\_\_\_\_

**9. Which cultural/ethnic group do you identify with?**

Aboriginal \_\_\_\_\_  
British Isles \_\_\_\_\_  
French \_\_\_\_\_  
European \_\_\_\_\_  
Asian \_\_\_\_\_  
Other \_\_\_\_\_

**Completed by**

Child's mother \_\_\_\_\_  
Child's father \_\_\_\_\_  
Both parents \_\_\_\_\_

**APPENDIX F****List of Categories Developed during open Coding**

**Diagnosis** – Prior Knowledge

**Learning to Mange** – Information Seeking

-- Recognizing symptoms

-- Treatment

-- Success at managing

-- Method of learning to manage

**Work of Managing** -- Environmental changes

– Lifestyle choices

**Impacts** – On children

– On family

– On parent

**Support** – Support received

-- Support needed

-- Anticipated changes

**Relationships** -- With health care providers

– With others

**APPENDIX G****CONSENT FORM**

I \_\_\_\_\_, volunteer to participate in this study, titled **Management of a preschool child's asthma: The parents' perspective**. I have been provided with and have read, a written explanation of the study.

This study is being carried out by Bev Clark, a registered nurse and a Master's of Nursing student at the University of Manitoba, Winnipeg, Manitoba. She is conducting a study in order to describe the process of managing a preschool child's asthma, from the parent's perspective. This study will be supervised by Dr. Karen Chalmers at the University of Manitoba. Her telephone number is (204) 474- 7318. Dr. David Gregory (Faculty of Nursing) and Dr. Wade Watson ( Faculty of Medicine) are also supervising the study. This study is approved by the University of Manitoba Faculty of Nursing ethical review committee.

I understand that I will be interviewed once by Bev Clark for approximately one hour about my experiences of managing my preschool child's asthma. These interviews will take place at a time and location convenient to me and will be tape recorded. I will also be asked to fill out a short form with background information about myself and my family. After the interview, the information will be typed out. Bev Clark may contact me by telephone following the interview in order to clarify any questions she has following her review of the interview. She may take notes during or after the interview about the visit. The total time involved will be about one and one half hours. I understand that Bev Clark may obtain information from my child's chart in the clinic about my child's history (e.g. number of visits to the pediatrician for asthma problems). Also, information may be requested about my child's asthma medication from computerized pharmacy records using my child's Manitoba Health's FIN number. All this information would be kept strictly confidential.

I understand that only the researcher will have access to my name and any identifying information. My name will not be used on the transcribed data, the study report, or any publications or presentations related to the study. The interview tapes and notes will be identified by number only, and no one will have access to the name and number combinations except the researcher. This information and the tapes will be kept in separate areas that are locked and secure. The interview tapes will be transcribed; the researcher and her thesis committee members will have access to this information. Findings from this study will be summarized and may be published, however, my name or my child's name or any identifying information will not appear in writings. I may receive a summary of the results of the study if I so desire. The Brandon Clinic will not be provided with any information regarding the identity of the participants in this study; they will receive a summary report only.

I understand that this study has no direct benefits to me, however, hopefully this information may help health care professionals understand how they can assist parents to manage their preschool children with asthma. There are no known risks involved in participating in this project. However, in discussing a child's asthma management, some people may experience some concerns. I am free to stop the interview at any time; I have the right to refuse to answer specific questions or ask to have the tape recorder turned off.

I may call Bev Clark, by telephone, at (204) 726-2269 or by writing her at N211, Brandon General Hospital, Brandon, Manitoba. R7A 2B3 during the course of the study. I may also contact her supervisor Dr. Karen Chalmers at any time.

I understand that participation in this study is voluntary. I am free to refuse to be in this study or withdraw at any time without any effects on the care of my child or my family.

I have received a copy of this consent form for my records. My signature signifies my agreement to participate in this study under the terms above.

Date	Researcher	Participant
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I would like to receive a summary report of the research:

No \_\_\_\_\_

Yes \_\_\_\_\_

Please mail the summary to:

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_